December 1, 2024

Quality Improvement Project

A Bridge Over Scary Water: Ombudsman Program Strategies and Barriers in Addressing Residents' Fear of Retaliation in Long-Term Care Homes

Prepared by: Eilon Caspi PhD

Image created by Kate Goebel

Funded by: Connecticut Long-Term Care Ombudsman Program

Executive Summary

General Background

Residents' complaints in nursing homes are considered 'the front-line system for addressing their concerns' (U.S. Office of Inspector General, [OIG] 2006) and 'a critical safeguard to protect vulnerable residents' (OIG, 2017). However, research has found that 23% of nursing home residents worry about retaliation when voicing care concerns and that 'worry about potential retaliation was just as fearsome for some individuals as the experience of retaliation itself' (Robison et al. 2007; 2011). A recent study examined the lived experience of fear of retaliation and retaliation in 100 nursing homes in 30 states (Caspi, 2024). These studies suggest that fear of retaliation represents a strong barrier for reporting care concerns, rights violations, and mistreatment.

Quality improvement Project

The primary goal of the project was to identify Ombudsman representatives' strategies and barriers in addressing residents' fear of retaliation and actual retaliation against them when voicing care concerns in long-term care homes. Semi-structures interviews (Zoom recorded) were held with 50 representatives from 32 states. The interviews were transcribed and systematically examined to meet the project's goals.

Main Findings

- Residents' fear of retaliation was reported by numerous representatives to be prevalent.
- Dozens of forms of retaliation against residents were identified (subtle forms of retaliation were reported to be more common and harder to prove than blatant / obvious / evident retaliation).
- Characteristics of residents more and less fearful of retaliation as well as those considered at higher risk of retaliation were identified (preliminary evidence only; research is needed to confirm it).
- A series of contributing factors were identified (e.g., institution-centered culture of care, leadership role ('it starts from the top'), poor staffing levels and staff training, and the way staff are treated).
- A series of challenges and barriers operating inside and outside care homes were identified (e.g., consent requirements, the burden of proof ('it happens in private'), culture of care instilling fear of retaliation and dismissing care concerns, staff compromising Resident Councils, poor staffing levels, and poor documentation). Barriers outside care homes included inadequate federal and state regulatory oversight and enforcement and weak state regulations governing the assisted living sector.
- Dozens of strategies were described as helpful (e.g., resident education and empowerment, staff education, detecting signs of fear of retaliation, breaking the isolation ('there's power in numbers;' finding 'internal advocate),' thorough investigations, Resident Councils, Care Plan meetings, the grievance process, examining discharge notices, and working collaboratively with care homes.
- Over 130 stories and numerous other examples demonstrated representatives' success but also challenges and barriers in addressing residents' fear of retaliation and retaliation against them.
- Educational efforts delivered by representatives to residents and staff were described (though gaps in these efforts were also identified and recommendations for improvement were made).
- Characteristics of Administrators / care homes with low resident fear of retaliation were identified.
- Lessons learned, advice to new representatives, and assistive technology's role were described.
- Areas in need of legislative changes and other important recommendations were identified.

Conclusion. The project enhances understanding of representatives' strategies and barriers in addressing residents' fear of retaliation and actual retaliation when voicing care concerns. The knowledge could be used to improve representatives' educational efforts, resident-driven advocacy, and systems advocacy.

Table of Contents

Appendices

Acronyms

AAA – Area Agency on Aging

ADL – Activities of Daily Living

APS – Adult Protective Agency

BIMS – Brief Interview of Mental Status

CPAP – Continuous Positive Airway Pressure

CMS – Centers for Medicare & Medicaid Services

CNA – Certified Nursing Assistant

FTE – Full Time Equivalent

LTC – Long-Term Care

*For brevity, the term "care home(s)" is often used in the report to represent LTC homes.

LTCOP – Long-Term Care Ombudsman

MFCU – Medicaid Fraud Control Unit

SLTCO – State Long-Term Care Ombudsman

SSA – State Survey Agency

UTI – Urinary Tract Infection

Definitions

*__Fear__ is defined as 'an unpleasant often strong emotion caused by anticipation or awareness of danger.'
**__Fear of retaliation__ is defined as 'a concern or feeling of vulnerability that one's actions may cause retaliation by another.'
**__Retaliation__ is defined as 'an actual or perceived negative reaction of a person as a result of another person's action or behavior.'
***__Retaliation__ is also defined as 'acts of retaliation / revenge by facility staff in response to complaint to the facility, Ombudsman program, or state survey agency.'
* Merriam-Webster Dictionary ** Voices Speak Out Against Retaliation's Instruction Guide *** National Ombudsman Reporting System – Complaint Code D06

“Representative(s)” – Term Used Throughout the Report

‘Under the federal Older Americans Act (OAA) every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long-term care system. Each state has an Office of the State Long-Term Care Ombudsman, headed by a full-time State Long-Term Care Ombudsman who directs the program statewide. Across the nation, staff and thousands of volunteers are designated by State Ombudsmen as representatives to directly serve residents.’

Source: Long-Term Care Ombudsman Program: What You Must Know. Fact Sheet. National Center on Elder Abuse / The National Consumer Voice for Quality Long-Term Care / The National Long-Term Care Resource Center).

For brevity and consistency purposes, instead of using the full term “Representative(s) of the Office of the Long-Term Care Ombudsman” each time, the words “Representative” and “Representatives” will be used throughout the report.

Acknowledgments

Mairead Painter – Connecticut State Long-Term Care Ombudsman

For seeing the need for the project and allocating the funds to do it. I greatly appreciated the ongoing support and guidance you generously provided me during numerous meetings and email communications throughout the project as well as for your ongoing encouragement of Long-Term Care Ombudsman Programs across the country to participate in it. It has been a pleasure working with you on this project.

Amity Overall-Laib, Director, the National Long-Term Care Ombudsman Resource Center

For providing a thorough review of an early draft of the interview guide (two versions: Ombudsman Representative version and State Long-Term Care Ombudsman version) used to collect the data in this project. Your ability to prioritize and better phrase core issues has substantially improved the interview guide and thus the quality and practical usefulness of the data collected in this project. It also saved a tremendous amount of time as it helped shorten the interview guide, the time it took to interview the Ombudsman representatives, and the transcription process. Thanks also for responding to my questions throughout the project and for your ongoing support of this line of work.

Others Who Provided Input for Improvement of the Interview Guide Included:

Professor Julie Robison, UConn Center on Aging, Anthony Chicotel, California Advocates for Nursing Home Reform, and Mairead Painter and Daniel Beem (Connecticut Long-Term Care Ombudsman Program). Thank you for your assistance with this process.

Lori Smetanka, Executive Director, National Consumer Voice for Quality Long-Term Care. For your early advice and ongoing support of this project.

State Long-Term Care Ombudsmen in the 32 States Participating in This Project

I greatly appreciate your willingness to have your programs participate in this project and for your ongoing efforts to recruit Ombudsman representatives from your program to participate in the interviews. Without your openness, generosity, and trust, this project would not have been possible. Thanks also for responding to my questions via email during the project.

Ombudsman Representatives and State Long-Term Care Ombudsmen

For generously willing to take the time from your very busy schedules to share insights from your work and advocacy related to the issue of residents' fear of retaliation. I was often at owe by your wisdom, knowledge, passion, compassion, and dedication to protecting the dignity, well-being, and safety of these individuals. I hope that I've done justice with your words and messages.

Kate Goebel, Kate's Musical Memories LLC, for the creative design of the image on the title page.

Andrea C. Alexander, Grants and Contracts Specialist, Central Contracts Unit, State of Connecticut

Thank you for your ongoing assistance with the project's contract.

Disclaimer

I believe that the majority of direct care staff members are caring and compassionate individuals who want the best for residents. They want to provide dignified and safe care.

As one experienced and professional nurse aide said years ago:

'*We love working with the residents. It gives us joy that we can assist them in the evening of their lives. We truly care for the residents and that honest care shows in the work we do*.'

Source: Certified nursing assistants: The foundation. Presentation delivered on May 14, 2008 at the Annual Meeting of Massachusetts Alzheimer's Association, Marlborough, MA.

Chapter 1

Introduction

Residents' fear of staff retaliation and actual retaliation against them when voicing care concerns or filing mistreatment complaints is a longstanding problem in long-term care (LTC) homes. A study published over half a century ago reported on severe physical retaliation against residents in a nursing home (Stannard, 1973) and a U.S. House of Representatives report (2001) described serious incidents of residents' fear of retaliation in nursing homes. In one case involving an Ohio nursing home, a resident sustained severe lacerations on his ear, skin tears, and bruising on his neck and hands. When asked by two staff members who had hurt him, the resident said, 'He'll bit me again if I tell you.' Later, the resident identified a male aide who confessed to abusing him.

In addition, a UConn study has shown that residents' fear of retaliation when voicing care concerns is common in different types of LTC homes in Connecticut (Robison et al. 2007; 2011). For example, nearly one-quarter (23%) of the nursing home residents surveyed reported being worried about retaliation if they voice care concerns. In-depth interviews with several residents revealed that 'the worry about potential retaliation was just as fearsome for some individuals as the experience of retaliation itself.'

Several years ago, the National Long-Term Care Ombudsman Resource Center stated (2018), 'Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity. Since residents live in a facility and rely on staff for their basic needs, their fear of retaliation cannot be overemphasized.'

Referring to retaliatory discharges, Cheryl Hennen, Minnesota State Long-Term Care Ombudsman (SLTCO), said that fear of retaliation is 'a human rights issue. Vulnerable adults with complex medical issues are being retaliated against for the simple act of speaking up. Someone needs to take the lead here and stop the practice' (Serres, 2017a).

Based on his examination of threats of retaliatory discharges of residents from LTC homes, investigative journalist Chris Serres stated, 'The threat of retaliation not only terrifies residents…, it discourages them and their families from taking steps that would protect their rights or enforce public regulations' (Serres, 2017a).

A recent study examined residents' lived experience of fear of retaliation and retaliation in 100 nursing homes in 30 states (Caspi, 2024). The findings and other insights from this study were described in the report '*They make you pay': How Fear of Retaliation Silences Residents in America's Nursing Homes* (Long Term Care Community Coalition, 2023).

The study demonstrated the gross asymmetry of power that often exists between residents and staff. Physically dependent on staff for meeting their basic care needs, many residents remained silent to avoid retaliation. They continued to suffer while their care was neglected and/or when they were verbally and/or physically abused. Many perpetrators and care providers were not held accountable for their acts. The study also provided detailed accounts of the ways in which residents' fear of retaliation, staff threats of retaliation, and actual retaliation results in serious psychological and physical harm to residents.

To build on this line of work, the next step needed was to examine ways to address and alleviate residents' fear of retaliation and actual retaliation against them. To my knowledge, no prior project or study examined strategies used to address these issues in LTC homes.

Given their critical role as educators and advocates for realizing the rights of people living in LTC settings to receive dignified and safe care, representatives of the Office of the State Long-Term Care Ombudsman [hereinafter "representatives"] are often in a good position to understand and address residents' fear of retaliation when voicing care concerns or filing mistreatment complaints. Through their educational efforts and resident-directed advocacy, representatives are also well positioned to address threats of retaliation and actual retaliation against these individuals.

After discussing this knowledge gap with Mairead Painter, Connecticut SLTCO, she generously agreed to fund a Quality Improvement Project on representatives' strategies and barriers for addressing these issues in LTC homes.

On August 3, 2023, I submitted a proposal to the Connecticut Long-Term Care Ombudsman Program (LTCOP) to conduct the project. While waiting for the proposal to be approved, I developed semi-structured interview guides (the data collection tool) with invaluable input from the individuals mentioned earlier in the Acknowledgment page.

The project contract was approved by the Connecticut Department of Aging and Disability Services on January 4, 2024. As will be described in detail in **Chapter 2** (Methods), the first interview was held in mid-February 2024. A total of 35 interviews (Zoom recorded) were held with 50 Ombudsman representatives (including a few SLTCOs) from 32 states.

The report presented here consists of the methods used to collect and examine the data to meet the project's goals (**Chapter 2**) and the following chapters:

Chapter 3 describes representatives' general thoughts about the issue of fear of retaliation such as whether they think it is a common problem (including how and why urban care homes may differ from rural care homes in this regard), the ways in which fear of retaliation constitutes a barrier for reporting of care concerns, and characteristics of residents who are more and less fearful of retaliation.

Chapter 4 identifies contributing factors to residents' fear of retaliation and actual retaliation against them (e.g., institution-centered care, poor staffing levels, inadequate staff training, and the way Certified Nursing Assistants (CNAs) are treated by LTC homes).

Chapter 5 describes dozens of forms of retaliation against residents. The chapter also addresses the distinction between subtle and blatant / obvious / evident retaliation (including representatives' thoughts about the prevalence of these two sub-types) as well as characteristics of residents considered at higher risk of retaliation.

Chapter 6 identifies a series of challenges and barriers in representatives' efforts to address residents' fear of retaliation and actual retaliation against them. The chapter is organized into challenges and barriers operating inside the care home and those operating outside the care home. Special attention is dedicated to residents living with dementia but also to those living with serious mental illness, among other vulnerable populations.

Chapter 7 describes dozens of strategies used by representatives to address residents' fear of retaliation, threats of retaliation, and actual retaliation against them.

Chapter 8 describes representatives' educational efforts to address residents' fear of retaliation and actual retaliation (e.g., education provided to residents, families, staff, and Administrators). The chapter also reports on care staff who may be unaware that certain things they do or say to residents are perceived by the residents as retaliation. It also identifies representatives' need for a structured education program on fear of retaliation.

Chapter 9 describes areas in need of legislative changes such as the need for stronger federal and state oversight and enforcement related to residents' fear of retaliation and actual retaliation and the need to bridge major regulatory gaps in the assisted living sector.

Chapter 10 addresses the issue of Ombudsman-to-LTC bed ratio (in general and in rural regions) and the need to centralized tracking of residents' *fear of* retaliation in LTC homes nationwide.

Chapter 11 identifies characteristics of care homes with less or no fear of retaliation while **Chapter 12** identifies characteristics of Administrators of care homes with low or no fear of retaliation among residents.

Chapter 13 includes a discussion of the report including practical and policy implications.

In addition, several substantive appendices address the following issues in the context of residents' fear of retaliation: Lessons learned by representatives from working with and advocating for residents over the years (**Appendix 4**), advice for new Ombudsman representatives (**Appendix 5**), issues related to residents from a tribe in a very rural nursing home (**Appendix 6**), and the role of assistive technologies (existing and those needed) in addressing residents' fear of retaliation and actual retaliation against them (**Appendix 7**).

Beyond countless insightful quotes of representatives, helpful resources, and findings from prior research studies, the report is filled with over 130 real-life stories illustrating representatives' success but also challenges in their efforts to resolve residents' fear of retaliation, staff threats of retaliation, and actual retaliation. The stories span across varied situations and circumstances, and they are presented throughout the report based on the issue or message they illustrate (each **story** is highlighted in bold letters).

The spectrum of knowledge shared during the project's interviews was succinctly described by one representative, 'I've given you the good, the bad, and the ugly about it.'

Several representatives expressed their hope that the project will lead to increased awareness about the issues of residents' fear of retaliation and actual retaliation and the ways in which they could be more effectively addressed.

At the end of one interview, one representative said, 'I hope you're bringing more attention.' Her colleague added, 'Yeah, exactly. And bring ways to alleviate it.'

The following chapter describes the methods used to try and meet their expectations.

Chapter 2

Methods

Recruitment Process

A 1-page description of the project (**Appendix 1**) was emailed (February 6, 2024) to all 50 SLTCOs as well as those working in District of Columbia, Puerto Rico, and Guam. The majority (n=32 states; 60%) agreed to have their LTCOPs participate in the project.

The success in recruitment had largely to do with Mairead Painter, Connecticut SLTCO, who encouraged their participation on an ongoing basis. This, in combination with many SLTCOs and representatives who thought that the project's topic is important and that there is a need to improve current knowledge about it and the ways to address it (for illustration, see representatives' words of appreciation of the project in **Appendix 8)**.

The LTCOPs that participated in the project (n=32 states) represented varied geographic areas of the country: Eastern [n=15], Central [n=11.5], Mountain [n=3.5], Pacific [n=2]. They included:

Pennsylvania, Alabama, Illinois, New Mexico, Indiana, Missouri, Georgia, North Carolina, South Dakota, Louisiana, California, Maine, Minnesota, Rhode Island, Oklahoma, Colorado, New Jersey, Iowa, Michigan, Ohio, Vermont, Nevada, North Dakota, Maryland, New York, Connecticut, Florida, Tennessee, Kansas, Kentucky, Arizona, and Texas.

There was a good mix of urban areas and rural areas with the following breakdown:

n=17 rural, n=14 urban and rural, and n=12 urban.

Slightly over half (53%; n=17) of the LTCOPs participating in the project were considered by interviewees as Centralized while 47% (n=15) were considered as De-centralized. For reference, during fiscal year 2022, LTCOPs in the majority of states (n=32) operated under a centralized structure (U.S. Government Accountability Office, 2024).

Several SLTCOs did not respond to email requests and follow-up requests to participate in the project. Others responded but declined to participate. This is completely understandable of course as SLTCOs and their representatives are very busy fulfilling their varied duties under the Older Americans Act, oftentimes with inadequate resources and funding, as described in the recent U.S. Government Accountability Office (2024) report.

One SLTCO declined to have their LTCOP participate in the project because they were new to the position. Another SLTCO wrote, 'I am not sure if this is much of a problem in [de-identified state].' A SLTCO from another state wrote, 'We don't get any complaints of fear of retaliation.' Later, they wrote, 'We have not had anyone file a complaint regarding retaliation

and we only have a few that express fear that it might happen but then talk to us when we reassure them that it is against federal regulations.'

SLTCOs agreeing to have their LTCOP participate in the project reached out to their representatives asking who among them would be willing to participate in a Zoom interview (except for those three SLTCOs who chose to be interviewed themselves). The SLTCOs were asked to try and select experienced representatives with significant experience handling residents' fear of staff retaliation and actual retaliation against them.

Interview Guides

In most cases, the interview guide (i.e., Ombudsman Representative version or SLTCO version) was emailed to the interviewee a couple of weeks prior to the interview with the hope that it will give them enough time to review the questions and prepare for the interview. They were also given the opportunity to choose an interview time that works best with their busy work schedules within the project's data collection phase of over 2.5 months (see dates below).

Appendix 2 displays the semi-structured Interview Guide – Ombudsman Representative version. It includes an Introduction to the project, background questions about the interviewee's role as a representative, the region they serve, and their LTCOP.

The Interview Guide includes the questions that were planned to be asked during the interview. That said, the interview guide allowed for significant flexibility with regards to asking follow-up questions not included in the guide (a separate version was prepared with a series of potential follow-up questions interviewees didn't see prior to the interview).

During the interview itself, representatives were also asked questions not included in the interview guide (such as questions on important issues identified by representatives in prior interviews held for the project as well as issues brought up by interviewees that warranted further exploration with them during the same interview).

A Zoom Workplace Pro account was purchased for the interviews. It is considered secure, not limited by time, and it allows for video recording and easy storage of the video files. A 1-page Zoom User Guide – Troubleshooting Technical Difficulties was prepared and emailed to the interviewees when the interview guide was sent to them. In only a handful of interviews, there were technical difficulties (mostly with logging on and a couple of sound issues) but most were easily resolved. The Zoom platform proved easy to use and very useful in the project, consistent with other researchers' experience (Archibald et al. 2019).

Interviewees

A total of 34 Zoom recorded interviews were held with 49 representatives and SLTCOs from 32 states between February 14 and May 6, 2024. The recruitment goal of 30 states was reached by the planned date (April 30, 2024). Interviews with representatives from two other states were held during the first week of May. An additional preparatory interview was held on March 16, 2023 (prior to the official data collection period) with Mairead Painter, Connecticut SLTCO – bringing the total number of interviews held for the project to 35 and the total number of representatives and SLTCOs interviewed for the project to 50.

Nearly all interviewees were representatives (94%; n=44). The remainder were SLTCOs (6%; n=3; as noted earlier, an additional SLTCO was interviewed in a preparatory interview prior to the official data collection period; another representative used to work as the SLTCO prior to her current position). An additional (informal) interview was held with a representative working in a nursing home serving a tribe. All representatives and SLTCOs interviewed for this project were paid staff – none were Certified Volunteer Ombudsmen.

The project aimed to primarily capture 'hands-on' / 'ground level' representatives' insights pertaining to residents' fear of retaliation and actual retaliation, complemented with perspectives of a few SLTCOs. This goal was achieved.

Gender. 92% (n=46) of the interviewees were women and only 8% (n=4) were men. While this information was not collected in a structured way, a handful of the representatives interviewed were African American (i.e., roughly 10% of the project's 50 interviewees).

The average number of years working as a representative or SLTCO was 12.4 years (range 7.5 months to 39 years). The actual experience providing Ombudsman program services is somewhat higher because several interviewees reported working as Certified Volunteer Ombudsmen prior to taking on the paid representative position (information regarding this prior volunteering experience was not collected in a structured way and thus it is not presented here). A significant number of interviewees worked in health care professions (e.g., social workers, nurses, nurse aides, mental health professionals, and Administrators of LTC homes) prior to their role as representatives or SLTCOs.

In their role, 43 of the 50 interviewees (86%) were overseeing a geographic region (i.e., three representatives held positions (such as Information Specialist) where they did not oversee a particular region; four others were SLTCOs).

Length of Interviews

The average length of the interviews was 77 minutes (with a range of 38 minutes to 1 hour and 59 minutes). This was significantly longer than planned (i.e., 1-hour). Part of the reason had to do with the lengthy interview guide but also the general background questions presented to representatives prior to the substantive questions (See **Appendix 2**). in retrospect, a better approach might have been to ask these questions via email prior to the interview itself. During the interviews, as the 1-hour mark approached, I checked in with the interviewees regarding their time. Nearly all of them were able and generously willing to continue the interview, for which I was grateful.

Transcription process

To improve the quality of the data collected, interviews were transcribed as soon as possible after they were completed (typically within 1-3 working days). This helped in getting a closer, nearly real time, sense of the data collected and refining the quality and focus of subsequent interviews (through ongoing reflection on the data collected as well as ongoing write up of a document aimed to improve my interviewing skills and techniques).

While this was not a research study, a common mistake made by new and inexperienced qualitative researchers is that they tend to start the data analysis only after they complete collecting all the project's data. They often end up with mountains of data where a significant portion of the data are not useful. Doing so also poses significant challenges in data analysis, and it tends to waste a lot of time (Miles and Huberman, & Saldana, 2014).

Approximately 816 pages were transcribed from 33 interviews (average 24.7 pages; range 15 to 35 pages). The total number of transcribed pages is 828 because two additional but informal interviews were held: One with a representative overseeing a nursing home serving people from a tribe i.e., an interview guide was not used during this interview (six transcribed pages). The SLTCO recommended holding an informal interview with this representative given the unique nature of their position and population served. As noted earlier, the second informal and preparatory interview was held with Mairead Painter, Connecticut SLTCO, prior to the official data collection period (six transcribed pages).

Data Examination and Report's Write Up

The transcripts of the 35 interviews with the 50 representatives and SLTCOs were printed and thoroughly reviewed in two separate rounds. The data examination and the write up of the project's report spanned five general phases, including:

In **phase 1**, the transcripts were read and labels representing units of meaning were marked pertaining to the different project's aspects as they are outlined in the questions contained in the Interview Guide (e.g., forms of retaliation, representatives' strategies, barriers faced by representatives, role of the Resident Council, and legislative changes needed). Extensive handwritten notes and color highlights representing distinct units of meaning were made on the text and in the margins in preparation for later retrieval.

During **Phase 2,** marked and highlighted material that could potentially contribute to meeting the project's goals was retrieved into a separate *Word* document where the material was sorted out into the different aspects outlined in the interview guide. Additional labels were created for aspects not included in the interview guide but those that were brought up by interviewees and were contributing to meeting the project's goals.

The chapters (except for the Introduction and Discussion chapters) and appendices of the report were written up during this phase.

During **Phase 3**, numerous compelling quotes were highlighted in the text while helpful resources boxes and findings from prior research were incorporated into the report.

During **Phase 4**, the Introduction and Discussion chapters were written up.

During **Phase 5**, the entire report was reviewed, organized, edited, cleaned up, and de-identified (to protect the privacy and confidentiality of residents, staff, family members, care homes, representatives and SLTCOs, and the state in which their LTCOP operates).

Chapter 3

Ombudsman Representatives' General Thoughts About Residents' Fear of Retaliation

In general, the scope of residents' fear of retaliation and actual retaliation against them was found to be significantly broader than reported in the Long Term Care Community Coalition's report '*They make you pay': How Fear of Retaliation Silences Residents in America's Nursing Homes* and my study titled *Residents' fear of retaliation in America's nursing homes: An exploratory study*.

Many representatives reported that the issue of residents' fear of retaliation is real, valid, challenging, longstanding, multifaceted, harmful, and prevalent. Others said that the issue is underreported and untracked.

One representative said, 'It's normal obviously. It's a normal feeling. They are 100% dependent upon the staff that work there. So my feeling in general is…it's just something that's natural and normal for a resident to feel that way.'

Quote
'*It is real and it is prevalent. It's real, it's prevalent, and it harms residents*' – Ombudsman representative referring to residents' fear of retaliation when voicing care concerns

A representative from another state said, 'I think retaliation is real and that fear of retaliation is valid and should be taken seriously.'

Another representative said, 'I feel like their fear is *very* real. We go in the building, we are working with them to share concerns, to help resolve those issues and then we *leave*. They're there left with staff and so that is fearful for them. They're dependent upon staff to provide the care, provide timely care, and when you're complaining about someone who is responsible to care for you, it really puts them in a vulnerable situation. I have *absolutely* seen retaliation so I know it's real and I know their fear is very real.'

A representative from another state said, 'We know retaliation takes place, we know it's a very real fear for residents and their loved ones and we are *not* in that facility 24/7 so even though we can say to them, 'It's your right. There are laws that protect you,' we're ultimately all leaving that facility and that person is under their care 24/7.'

Representatives spoke about the fact that the issue of residents' fear of retaliation is longstanding. One SLTCO said, 'It has been going on for years where people are afraid to speak up.' Another SLTCO said that they've seen these problems over the years and that 'you would think that at some point you'd be surprised that it's still happening.'

One representative spoke about the multifaceted nature of fear of retaliation, 'I think it's very valid. We hear it often and it's usually not one type of care. It could be related to medication, it could be related to personal care, showering, bathing, toileting. And it could be just the fear of asking for help whether it'll be for whatever. When we talk to residents, when we hear that and we get that feedback, it really is not one aspect of the care. It seems to be multifaceted from our perspective.'

Representatives perceived residents' fear of retaliation as harmful. When asked about her general thoughts about residents' fear of retaliation, one of them said, 'It's a very real concern. We have a lot of residents that that's the barrier for us helping them. They do not want to speak up and [there are] lots of reasons why they fear retaliation. It's a real significant issue. It has very detrimental effects because then residents' issues don't get addressed. They often don't address them because they are often afraid to even bring them up with us. So they sometimes just sit and they sort of suffer in silence, which is really sad and unfortunate.'

Quote
'*I think that it's something that everybody who is working in the industry needs to take the fear of retaliation seriously and see it as a form of psychological abuse as it creates terror among the residents*.' – Ombudsman representative

A very experienced representative said, 'In my mind…in my experience it comes down to the vulnerability. They don't get to leave, they are completely dependent on the staff that they are complaining about. So, of course, that automatically puts people in a scary situation. I get to leave, the staff leave, families leave. *Who is still there?* The resident who is complaining and *totally* vulnerable.'

Power Imbalance – An Underlying Thread

The power imbalance between residents and staff / care homes was identified as an underlying thread in the interviews held for this project. Examples include:

One representative said, 'They're dependent on who comes in. It's their home truly but at the same time they have no control over who is coming there. They are not part of the interview process, they're unable to find out what's their background is…they are not part of that. So they are 100% dependent on these people that are coming in and caring for them. So yeah, there's definitely a power balance. I think in their eyes, 'Well, if I complain, am I am going to get my next meal on time?' or 'Am I going to get up?' if I lived in a home, I would feel the same way.'

Resource Box
Residents Interviewing Staff Candidates
In one care home, residents serve on committees that oversee the hiring process of direct care staff. They actively participate in interviews of candidates for care staff positions. Dr. Allen G. Power (2017) shared this **story**: In one job interview, after all team members have approved the applicant, a resident with dementia said, 'I wouldn't hire her.' The resident explained that it had to do with the applicant's non-verbal signals. The candidate said all the right words, but her posture, tone of voice, lack of eye contact, and other body language belied her answers. The applicant was an expert in interviewing but seemed insincere to the resident. She was not hired.

When asked about the value of empowering residents in the context of the asymmetry of power, one representative said, 'Folks are typically *really, really* hesitant because in large part that imbalance of power. They know they're vulnerable…even folks that are 'vulnerable' by our definition are. That's extremely powerful because it [i.e., empowering residents] is the only thing that we have that most folks are comfortable with.'

When asked for her thoughts about power imbalance in the context residents' fear of retaliation, she said, 'I think it definitely impacts it because the staff are seen by the residents…right or wrong…as *in power* and they [i.e., the residents] need to 'get in line' and not 'buck the system' because they are reliant on those in power. I believe that's a common thing that comes up in conversations, 'Well, they're in charge, they're in charge.''

Another representative said, 'I think we just dismiss it a lot more than we should. There's always going to be a power dynamic that's going on. A lot of the times the residents refer to the bosses of the facility instead of seeing them as the worker that cares for me. They have that boss ideal. I think a big problem that 'That's the boss' and that adds to the retaliation fear. Residents feel that the Administrator, the nurse, and the Director of Nursing…they're all their bosses. They are their bosses so anybody with power within the facility, they feel they have to ask permission, they have to seek out the approval from the boss.'

Residents' Lived Experience of Fear of Retaliation

Quote
"*Fear of retaliation is not something you can look up in a dictionary but if you live in a setting where you depend on others to care for you, you know exactly what it is*" – Ronnie, nursing home resident Source: Voices Speak Out Against Retaliation training video (2010)

Several representatives shared their thoughts about residents' lived experience of fear of staff retaliation when voicing care concerns. When asked about her general thoughts related to residents' fear of retaliation, one representative quoted a resident saying:

'When we think of fear, we think about the opposite; we think about fear of heights, fear of flying, we see different facets of how we feel; fear is within us. To expound on the reference, when combining fear and retaliation together in any situation; it takes on a whole new meaning, especially in a Long-Term Care setting. But fear of retaliation generally for residents is something that has become a fact of life for them. In other words, their fear is their lives are now being controlled by someone else.' The resident added, 'Staff tends to pay attention and focus on residents who they know are fearful.'

Another representative said, 'I wish that we could expand on exactly what the residents are feeling because I would never say I could feel what they are feeling because I am not in their shoes.'

With that important caveat, here are some things representatives said about the ways in which they believe residents experience fear of retaliation:

One representative said, 'When I say, 'fear is retaliation in itself,' what it does is it psychologically affects the resident internally. Because they've lost a spouse, they have no

family, they're dependent on staff in the facility and they feel helpless. So I feel that the fear is retaliation *on oneself* for the simple fact…you're trying to deal with an issue…you [had] no clue when you were placed there that fear is going to be a factor of your life.'

Another representative said, 'Residents are dependent on others for their care and so the fear of retaliation could mean, 'I don't get my breakfast or lunch tray.' It could mean, 'I'm sitting on the toilet for an extra *hour* because I told on the CNA.' That is retaliation. It's more the *unknown* that could happen. It's that actual, 'Oh, if I say something, this could happen.' It's that unknown…that 'What if.'

One representative said, 'Abuse is now verbal abuse, emotional abuse, actual physical abuse. Residents are being really harmed, it's really fearful for a lot of these residents who can't move, can't just get up and walk away. They have to just sit there and take it. So the fear is I think a lot greater than it was. Staff or people in general are not afraid of consequences that there were 20, 30 years ago.'

When asked to reflect on residents' dilemma as to whether they should report their care concerns, the same representative said, 'Well, obviously the fear, dread. It's not wanting to 'rock the boat.' It is not using their call light as much. Trying to be more passive, 'Yeah, okay, I [know] this is done but I am not going to say anything because they may not brush my hair at all.' It's kind of being in the corner. Don't make any waves. Be unseen.'

She added, 'Those are the things that I am talking about and I am seeing more of that, 'I am just going to go with the flow and not exert my rights.' They know what their rights are because that fear is so *deep*, they are not going to call attention to themselves.'

She went on to say, 'It brings anxiety to them. It brings depression that I can't speak up for myself or I don't *dare* speak up for myself. And it might be someone who was very active in the community before and now they don't have that control anymore. It's given to somebody else…and that just goes against the resident.'

For detailed descriptions of the emotional and physical consequences of fear of retaliation, threats of retaliation, and actual retaliation against nursing home residents, see my recent study (Caspi, 2024).

Perception and Reality

Representatives shared their thoughts about residents' perception and reality underlying their experience of fear of retaliation. One of them said, 'Sometimes it's not warranted… Sometimes it's just that person has heard things and they're assuming that if they bring it, that something bad is going to happen.'

Another said, ‘It’s often that fear of…the perception of what might happen…is I think more fears than what actually may happen. Does that make sense? The fear is bigger.’

One representative said, ‘Although there is retaliation, I don't think that it is it is as prevalent as a lot of people maybe lead you to believe. It happens 100% but I don't think it happens as much as people think that it happens.’

She added, ‘I think there's fear that if I go and say something about this person, that automatically I'm going to be retaliated against, and I don't think that really happens. I do think it happens some but not as much as people feel that it is on the outside just as many people on the outside feel, ‘Oh, the nursing home is bad and they abuse people over there and they don't feed them.’ I don't think it's as bad as people feel it is.’

Call for Research
Research is needed to identify the prevalence of staff retaliation against people living in nursing homes and assisted living residences.

A representative from another state said, ‘It is a real fear, it’s a real problem’ and added, ‘There wouldn’t be fear of the retaliation if it wasn’t warranted.’

Quote
‘*Whether it is in their perception or if it’s a real thing, it doesn’t matter. It’s real to them*’ – Ombudsman representative

The National Long-Term Care Ombudsman Resource Center (2022) stated, ‘Retaliation is one of the most common reasons expressed by residents for not seeking resolution to their concern. It may be real or perceived, but in either situation, it is frightening to residents.’

Research Findings
In-depth interviews with residents in long-term care homes found that ‘worry about potential retaliation was just as fearsome for some residents as the experience of retaliation itself.’ Source: A study by Robison et al. (2007; 2011).

Characteristics of Residents More and Less Fearful of Retaliation

A few representatives tried to convey that this issue is complex, not always as straightforward as it may initially seem, and that classification attempts may sometimes be limited in their ability to adequately capture unique circumstances, context, nuance, and variation across individual residents and care homes.

For example, when asked about characteristics of residents who are more or less fearful of retaliation, one experienced representative said, 'It's not a cookie cutter type thing. There is certainly a whole long line of types of people that have fears or how they're going to react to speaking up for themselves.'

With this caveat in mind and with the recognition that the following list is not exhaustive (research is needed to shed light on this issue), representatives shared the following views:

Prior Positive Experience Working with an Ombudsman Representative

One representative said that in general, residents who have experienced an Ombudsman's advocacy or 'worked with an Ombudsman before' are less fearful of retaliation. She explained, 'I think they know who they can turn to. I've had residents living in one community and they transferred to another community and then they'll call me. I just feel like they know that we're here for them and they can call us when they need us.'

It is important to recognize that not all representatives' involvement is necessarily a positive experience for residents and at times it may result in a negative outcome (e.g., retaliation against a resident after speaking with a representative about care concerns). This was also recognized by a few representatives interviewed for this project.

Compliance Culture and Socioeconomic Background

When asked about characteristics of residents who are more or less fearful of retaliation, one representative said, 'I think sometimes at a very topical level it might present as being obvious that some people are just more concerned with it or feel more threatened by it when in reality once you get really to the undercurrents of what's going on, sometimes an individual's social awareness and their ability to continue to live in a particular setting all of a sudden those threads maybe aren't the threads we thought they were because sometimes I think certain environments create almost a compliance culture more so than others. Environmental factors are something that I hope are an element that are really being looked at.'

He added, 'We're getting into the power variables there…when we're talking about a compliant approach and unwillingness to 'rattle the cage' if you will and from one facility to the next and from one resident to the next, it's always very very unique.'

He went on to speak about socioeconomic factors, 'I often will say in long- term care, if you look at the Los Angeles area you have a tale of two populations' socioeconomics. You have people living in the $1,000,000 homes up on the Bluffs and you have people laying in a tent on the sand…you have the who's who and who's not. And we've seen a polarization in regard to just kind of the economics within the last 20 years in particular that I've noticed. I would say that we see that dynamic in long-term care as well where we have providers that are the desirable ones, that have a waiting list, that people want to get into and then we have the rest and the rest are oftentimes marginally performing just kind of clawing along, providing bare minimums or not even providing bare minimums. So when you're looking at this threat of retaliation and the sense of empowerment within those two particular profiles of skilled nursing or assisted livings, you can see where the dynamics of retaliation are very very different from one to the other.'

He explained, 'The who's who, the folks up on the Bluffs, their retaliation oftentimes is sometimes socially imposed…like they just don't want to cause any problems, they would never want to get kicked out of the Taj Mahal…those types of dynamics of the fear of retaliation. They are really kind of more of underneath the radar oftentimes I think whereas the alternative there's variability there and when you're profiling…right that's what I'm doing, I'm kind of profiling in it…so nothing's absolute…but I kind of wanna paint a picture.'

He added, 'You can also look at funding…the who's who is oftentimes private pay and the marginally performing is oftentimes public benefit and so oftentimes you have two different groups of people based upon just their personal characteristics.'

An article by Mor et al. (2004) titled 'driven to tiers' provides support for the classification delineated by this representative. Research is needed to examine residents' fear of retaliation and actual retaliation against them in these two tiers of LTC homes.

The latter representative added, 'We also see a significant higher level of…for example, serious and persistent mental illness prior to chemical dependency or potentially active chemical dependency within the barely surviving types [of care homes]. But what I would say is that with the barely surviving types, the fear of retaliation tends to be a little bit more overt, and I think in the people up on the Bluffs, it's a little bit more covert where [it's] a little bit more difficult to tease out. Kind of breaking it down a little bit and again, nothing's absolute…you might have someone that lives in primarily publicly reimbursed skilled nursing that's underperforming and they're just a very compliant person.'

Ethnicity

One representative identified ethnicity as a factor in residents' fear of retaliation, 'I think that there are certain experiences with people with…depending on where they live that is related to their ethnicity and I think when they are in a facility and they are maybe interacting with people who have different attitudes and thoughts about those particular ethnicities that that becomes another factor within the fear of retaliation.'

A representative from another state said, 'I am going to speak for my area. There are some Hispanic people…I feel like their culture…they are afraid to say anything…maybe because of their status…their immigration status or whatever, they don't speak up for themselves and their families don't either.'

Two representatives overseeing rural regions in another state spoke about fear of retaliation among Hispanics and Mexican citizens. One of them said, 'Here in [de-identified state] we have a lot of Mexican citizens. That perhaps their parents were Mexican and they came across. They don't want to bring any light to themselves and they want to be very respectful and they don't want anybody to look at them and so they won't say anything. They can [get] to the point of being *abused* and they're afraid to speak out for fear of retaliation. They just won't say anything. I think that might happen with the native population as well. Later she said about the native population, 'They are not going to say anything because they are in fear of retaliation. It's a sense of pride.'

She added, 'I think that they don't want anyone to look at them too closely. They kind of want to be separate and being their own closed knit family and they don't want anyone with a spotlight on them. Whether that would be because at one point in time they were undocumented or they have undocumented family members or they were just taught that from their parents or grandparents…they don't say anything. When I say this, I'm not trying to be racist but they're almost afraid of Anglo, the Anglo individuals. They will respect them very much and not tell them much [of] anything. They don't trust them.'

The second representative from the same state spoke about Mexican residents and native Americans' fear of retaliatory discharge to another care home located far away from their families, 'If you look at our area [and] our regions, there's a *lot* of miles in between.' She said that the next available nursing home 'is 100 miles or 200 miles away…so they want to stay as close as…if they have family and let's say the family barely goes once a week to visit, they're not going to do or say anything to mess up them having to move…to be moved out.'

She added, 'A lot of it is visual. They've seen somebody go through something already in the nursing home that they don't want to identify as a "problem" person [said the word problem while making hands' gesture indicating quotation marks], as a "behavior" issue. They want

to stay where they're at.' The first representative then said, 'Being discharged to another place, that takes them away from their support system.'

The second representative went on to speak about fear of retaliation among Native residents living on a reservation, 'A lot of the natives or the majority of the Natives, I think, they live on the reservation so they're surrounded by their own other Natives, their own family because that's how the Natives live…it's grandparents, children, grandchildren and they all live together and so once grandma falls, breaks the hip, they can't take care of her anymore at home, she goes to the nursing facility. Let's say she was being mistreated. If she says anything, then we have the fear of retaliation and then if grandma fusses too much, they're going to give her a discharge and is she going to have to go 100 miles, 200 hundred miles down the road to another facility? because there's no other ones around there. So she's just now been uprooted from her support system, uprooted from her *whole* support system because she was on that reservation and she was surrounded by people of her culture and now she lives with others, other cultures and White people, Hispanic folks, and other ones and she does not know them and she's afraid of them. That all comes back to fear of retaliation. We're not going to say anything, we're gonna sit here and we're gonna deal with it. Maybe Susie Q CNA is not friendly and she's ugly and she might even be racist but we're not going to say anything and we're just going to smile while she's doing this because we don't have any other option and we don't want grandma to go 200 miles away.'

Related to it, a representative from another state identified residents' distrust in the government as a challenge and barrier in addressing their fear of retaliation and actual retaliation, 'People are scared of retaliation and when we try to educate them on their right to be free from retaliation, because they don't know us, there's a trust issue and it takes *time* to build trust and rapport and especially with Appalachia. There's a culture in Appalachia, they don't want 'the *man*,' they don't want the outsider. It's a trust thing.'

She added that she is guessing that 'that resentment from outsiders and trust issues are 'very similar in minority communities…because of historic systemic injustices. I'd think it's very similar, 'I don't know you. I don't necessarily trust you.''

For a summary of an interview on unique issues related to residents from a tribe located in a very rural nursing home, see **Appendix 6.**

Age

A few representatives said that younger residents are generally less fearful of retaliation and more willing to speak up about care concerns.

One of them said, 'People who are younger are going to be less fearful and they're going to be more vocal and stand up for themselves.'

Another said that in comparison to older residents, 'The younger residents that I run into are a little more likely to allow me to identify them or address it directly. [They are] less fearful.'

A representative from another state said, 'There are more residents who are of a young age in nursing homes that are more willing to speak up or support another person when the retaliation is taking place.'

A very experienced representative said, 'Those that are younger and mentally capable are more outspoken.' She went on to qualify her observation, 'I mean, it's different personalities. It is like in all areas of life. Some people that are very bold, [others are] timid. And I think those people that require the most help with basic needs are *very* much fearful and then there's those by nature alone that are more timid…that are meek that are fearful.'

A representative from another state said, 'People that are less afraid of retaliation are the quote unquote younger population. So people from 50s [to] maybe early 70s that are very physically mobile, very mentally there still, they're less afraid because they know what should be going on, they know when something's wrong, they know how to call the state survey agency and talk them through their complaint. They're able to get results from the [State Survey Agency] so they're less afraid of it because they have more confidence in being able to be heard from the facility whether it's directly or from the [State Survey Agency] which is who overseas nursing homes.'

It is important to recognize, however, that age as a factor contributing to residents' fear of retaliation likely varies significantly within the younger resident population in general and across varying circumstances and unique resident characteristics. One should wonder what 'young age' even means in LTC homes. For example, according to one classification, 'younger residents' range from 18 to 64 years of age (Shieu et al. 2021). Caution is therefore needed when making generalizations within the "younger" resident population *and* in comparison to the "older" resident population. Research is needed to shed a more nuanced and context-specific light on this issue.

For example, one representative identified certain subgroup of younger individuals as experiencing *higher* levels of fear of retaliation and actual retaliation. She said, 'The younger resident and when I say younger…younger than 60… That younger resident with maybe an early onset debilitating disease such as Multiple Sclerosis or even some Cerebral Palsy depending on its severity and the retaliation being, 'Well, you can do that. You're young enough. You should be able to do that.' You know, dismissing them because of their age versus attending to them because of a disease process and not looking at their age as a factor. I think that's one demographic that really has a lot of fear of retaliation that

they try to ask for help and get dismissed and get treated like they should be more independent than they are because of their age.'

Gender

Several representatives thought that, in general, women are more likely than men to experience fear of retaliation when voicing care concerns. It must be recognized, however, that male residents certainly are fearful of staff retaliation when voicing care concerns.

One of them said, 'Females are more scared of retaliation. I've had men who don't want retaliation either but it's typically women and typically of course women who are more competent and alert and oriented.' She explained, 'Because they see what goes on.'

Another said, 'We see more females than males who have a fear of retaliation.'

A representative from another state said, 'I think sometimes women…certainly other generations of women were taught not to make waves and play nice kind of stuff. I think that impacts it.'

One representative said, 'Older females. They're not going to say anything either. They're going to keep it to themselves because they don't want to get anybody in trouble for fear of retaliation or because they can't do anything about it. You know, women were made to feel a little powerless during their generation.'

She added, 'Men tend to stand up for themselves a little bit more. Older women are not going to…they are going to be the ones that say, 'I don't want to get so and so in trouble' [or] 'I don't want to say anything' [or] 'Can you take care of it without using my name?''

A representative from another state said, 'Some of the characteristics I see in residents….they already have backgrounds where they don't have a voice, you know, whether in their family life or in their upbringing and then what I see [is] the population of women that is in nursing homes, they didn't have a voice prior to coming in so they don't feel like their voice matters now. So the characteristics of just feeling like I have to take that…like this is my role anyway, this is what was happening to me on the outside so someone talking to me with disrespect [and] with their frustrations is almost normalized when they come into the nursing home…whether they were married or…it's kind of normalized because that's what they saw out in the community.'

The same representative contrasted her observation with her description of a subgroup of strong women who always had a voice, 'They are the ones that are going to 'shout out from the rooftop' that they won't tolerate others mistreating them.'

People from the LGBTQ+ Community

A review of research studies examined the perspectives and experiences of people from the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) community who are living in nursing homes (Skeldon and Jenkins, 2023). It found that these individuals were 'concerned that they will need to conceal their identity and experience abuse.'

The authors also found that 'most staff had a positive attitude toward LGBTQ+ residents, but there were exceptions to this. Despite their positive attitude, staff often lacked awareness of LGBTQ+ issues.' The authors concluded their review by stating, 'Nursing Homes are not welcoming environments for sexual and gender minorities and that staff require more training to support this community.'

In addition, people from the LGBTQ+ community living in senior residential communities have been reported to experience sexual orientation-based harassment (including verbal and physical abuse) from other tenants and their complaints and threats of retaliatory evictions by management were disregarded (Miller, 2016; Harvard Law Review, 2019).

When asked about characteristics of residents who are more fearful of retaliation, one representative interviewed for the current project said, 'Being a person in a marginalized group like LGBTQIA' [Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual].

A very experienced representative from another state also identified residents from the LGBTQ+ community as those who may be vulnerable to experiencing fear of retaliation. She said, 'I might also include right now one class of people that we hear a lot about and it is also impacted within the long-term care community or people from the LGBTQ plus community. I've had cases over the years where there's been some sense that those factors have been involved in how they've been treated and I think now that we have a greater awareness of that particular community, that it enters into our thinking when we are looking at what communities are served by long-term care.'

When asked whether being from the LGBTQ+ community plays a factor in an individual's experience of fear of retaliation, she said, 'Yes. I think that it makes them feel a little bit more vulnerable to it. Not even just from caregivers but I think there's sometimes there's a fear within a facility from other residents…attitudes and experiences connected to that.'

When asked if she had experience with people from the LGBTQ+ community who experienced fear of retaliation or actual retaliation, another experienced representative said, 'Certainly I've seen where co-habitating in facilities where it is okay for a husband and wife to share a room but then you have people of the same sex that would like to share a room…we've had to advocate for that to be able to have the same right as everyone else.'

She added, ‘Or retaliation because there’s a relationship and they’re made to feel guilty for having that particular relationship that staff don’t feel as normal.’

When asked to elaborate, she said, ‘That would be whether it is same sex relationship where staff treat them differently, complain, or just don’t provide the same level of care and support as people with male-female relationship.’

When asked about ways staff retaliates against residents, a representative from another state shared a **story** about discriminatory neglect of a resident who is transgender. She considered these acts as retaliatory in nature. She said, ‘I was on my way to visit with a resident who is transgender and she said that the staff will not change her because she hasn't had reassignment surgery and she feels that she is being neglected because of this. So there can be discrimination on the side of the staff person not wanting to care for a resident based on their ethnic background, nationality, [and] sexual orientation. Yeah, I think that's one of the ways.’

She shared another **story** about a resident who is also transgender, ‘A resident that was admitted to a Residential Healthcare Facility and she did have the reassignment surgery [de-identified number] years ago but when she was admitted, she was admitted with her name in quotations [said with a hand gesture indicating quotation marks] and the staff there referred to her as him right out of the gate and she expressed to me how awful this made her feel and that now she has to be in a shared bathroom. Long and short, our office was able to advocate on her behalf to get her to another Residential Healthcare Facility where she now has a private room, private bathroom, and when she was admitted as [de-identified woman’s name] from day one and she sent me the most lovely text [de-identified time] and that she feels for the first time that she truly is [de-identified woman’s name].’

The latter story ended up with a desirable outcome for the individual. Other representatives also shared stories about people from the LGBTQ+ community who were treated with dignity and respect and had positive experiences in other LTC homes. For example, one of them shared a **story** about one person, ‘He preferred to be referred to as a she, liked to wear women clothing and wigs and things like that. He was given a private room, which was nice, but he did not seem to be afraid to voice concerns or ask questions or make his needs known, which is really good.’

Her colleague shared another **story**, ‘I worked with a facility recently where there was someone who wanted to be referenced as a female and lived her life as a female and had a *perceived* fear of the facility but when I went in to look into some concerns for the individual, the facility had educated their staff, provided handouts, reached out to their corporation, and they really felt like they were doing as much as they could to treat that

person with dignity and to treat them just as they would anyone else. That was really great to see.' The representative said that the person's concerns with regards to issues within the care home have been resolved and they were treated in a dignified way.

At the end of another interview, when asked whether there's anything I didn't ask about, a representative from another state said, 'I do want to recognize…One of the things I am doing now as far as In-Service is…I am doing a [round] of In-Services called Getting Rid of the Taboos. It's an In-Service [on] Diversity and Identity and we're looking at LGBTQ and Aging. This is a group that is out in the forefront now advocating to be recognized. Especially I noticed here in the South…a lot of nursing homes that are not talking about it. There are LGBTQ residents in the facilities that do receive retaliation simply for the fact that they choose to identify however they want to identify. So I am championing that as far as being an advocate and having to educate the staff on making sure they provide an environment that is free from discrimination. That they are also educating themselves about the community and looking at your facility and saying, 'Do you have accommodations to serve this population?' This is a project that I am working on here.'

She added, 'Fortunately, I have not had any complaints or issues from a resident that felt like they were retaliated against because of how they choose to identify themselves. I can say…many of my facilities are open, they are educating their staff and also because you have staff…employees that are part of the community as well…so it's just having the staff…the facilities to talk about this and say, 'Hey, this is a forefront. We can no longer sweep this under the rug. We have to identify [it]…because you're going to have residents who are lesbian couples, transgender, whatever…we're going to have to be able to know how we can accommodate and serve them.'

She went on to say, 'The ability to educate the families whether it would be in Family Council or what not, about that they are mandated to accommodate and foster an environment that is free from discrimination…not only for residents but for staff as well. Let's say, 'I don't want mom to be able to be cared for by a lesbian CNA' or what not. Just education as a whole…not only for staff and residents but also family caregivers…and care providers as well [missing word], and nurses.'

When asked if she believes that a subgroup of nursing homes are in denial about the rights against discrimination and retaliation of people from the LGBTQ+ community, she said, 'I can say this. I'm doing this as general information but just from my experience and my observation. Because you also have staff that are part of the LGBTQ. I have facilities that have Director of Nursing that are part of the LGBTQ [community] so I think that the facilities are aware that, 'Hey, this is a group or people [who] are choosing to identify who they are and it's not just for residents only…staff as well so I don't see where there is a denial simply

because you have staff members that are part of the LGBTQ and so also their ability and their desire that fosters an environment where it's free from discrimination. I've had some very positives where my facilities are *very* open simply because they may be a part of that community as well and so they very much want to make sure that the residents are in an environment where they're free from discrimination where there is no retaliation simply because they identify themselves with however they want identify.'

Level of Independence

Residents' level of independence was identified by many representatives as a key factor in whether a resident may be fearful of staff retaliation when speaking up about care concerns, right violations, and mistreatment.

One representative said, 'We feel the top one is their level of independence. We feel that if a resident is more independent, they're more willing to advocate for themselves and not to be as concerned about retaliation whereas if you have a resident who is pretty much 100% dependent on cares, they have a much higher fear of retaliation because they know if they upset someone, they might not get the cares that they *need* whereas the other residents know that if they upset someone, well, they can probably still do a lot of the cares because they're fairly independent.'

Another representative said, 'Residents who are independent who don't require a lot of assistance' are less fearful of retaliation when speaking up about their care concerns.

A representative from another state said, 'Folks who are higher functioning tend to have more questions about retaliation, what it looks like, what the legalities around it are…'

Referring to residents experiencing more fear of retaliation, one representative said, 'Those that are dependent for care because they feel that they are a little more vulnerable.'

Another representative said, 'I think dependent residents are more fearful of retaliation because they depend on the staff at the facility for their daily cares or their fluids or their food or being changed. I think they are afraid that staff will not respond to their lights as timely or that they might be the last one assisted in the dining room or that they won't be invited to activities if they bring up their concerns.'

When asked about characteristics of residents *less* fearful of retaliation, she said, 'It kind of depends on the personality. I would say someone who isn't totally dependent…maybe more able to take care of themselves or protect themselves if they felt like they ever come to a situation where they came to that. They may feel more secure voicing concerns just knowing that they would be able to protect themselves if it came to that.'

Another representative said that residents with 'major physical disability' and those who are 'bedbound' fear retaliation more than others, 'They can't defend themselves.'

A representative from another state said, 'More fearful residents' include those who are 'totally dependent on a caregiver for their activities of daily living.'

Another representative said, 'The ones who have the fear, these are residents that are totally dependent. When they become widowers, and their healthcare fails them and they seek out healthcare assistance. They were totally dependent on their spouse. If they have no children, if they have no friends, they feel helpless and they feel fear. That is the reason those residents need empowerment. That fear really is retaliation itself.'

Another representative said, 'Residents who are confined to bed' and 'the more vulnerable ones or defenseless maybe' are more fearful of retaliation.

In accordance, a representative from another state said, 'Residents that are more fearful of retaliation, they are a higher acuity either mentally or physically where they need a lot of assistance and help, they might be bed bound.'

Personality and Level of Vulnerability

When asked about characteristics of residents experiencing more or less fear of retaliation, one very experienced representative said, 'I think it comes down to the resident's personality and their level of vulnerability. People are vulnerable just because they are living in a long-term care facility. That *automatically* makes them vulnerable. But then there are different levels of vulnerability within that depending on their care needs, ability to leave, get up on their own. And then personality I think really plays into that.'

When asked to elaborate on her comment about personality, she said, 'You meet residents who are super feisty. You meet these little 90-year-old lady [who is] *totally* dependent on staff but they are going to get them. That's just their personality. And they don't care. But then you get those other residents who are completely fearful, 'No, I would never say a thing. I don't want to put down the staff. They are working so hard. They are doing their best.' You get those. It really comes down to that part of it, I think. And that contributes to that fear and their willingness to move forward.'

When asked if there could be repercussions for 'super feisty' residents who are physically vulnerable, she said, 'Sure and we've seen that but just for that question…determining their willingness to or be more or less fearful of staff retaliation…is that personality component, I think. But then sometimes that personality component leads to some issues. Absolutely.'

A representative from another state said, 'I think residents that are often the most vocal and can be 'determined' maybe as the most difficult have the most fear retaliation.'

Another said, ‘Residents who are probably the most dependent and especially if they have a tendency to be anxious or feel fearful or soft spoken or lacking self-confidence…I would guess would be leaning towards fear of retaliation.’ He added, ‘And maybe those that are more independent and confident and maybe outspoken from their own personalities may tend to not be as fearful about retaliation. It's just my own assumption.’

A representative from another state said, ‘We definitely see residents that are empowered and maybe that's just how they've been all their life or that was their role when they were working…that aren't afraid to say how they feel and say what they mean.’ She added, ‘I'm sure that a lot of it has to do with just their makeup and their personality and their life experiences whether they're comfortable.’

A very experienced representative said that residents who are not fearful of anyone, they are very vocal, they’re outgoing, they are compassionate, very selfless, they are more or less trying to assist other residents, they recognize residents who are very vocal, and those residents are very intelligent, they tend to pay more focus with those residents who are fearful. The residents who are more compassionate and have the drive to assist others, they try to empower a resident who feels fear to act on their own and sometimes it does work for them, but they gravitate to that person all the time and staff knows that the person who is not fearful of them they are going to protect the residents who are.’

Another representative said, ‘Residents who are naturally assertive, residents that are confident, [and] residents that are…let's say have more education are less likely to fear retaliation than those that are just unsure.’

The representative added, ‘Also just thinking from how they were raised…you don’t question the one that’s serving you. Those can be a factor in probably their fear of, ‘Well, if I say something, you know, they’re good to me’ and their concept may be flawed and they don’t understand, ‘Well, this person is really *not* in your best interest’ but they hold back. So those individuals are more likely to receive retaliation or fear retaliation if they speak up and say something.’

One very experienced representative (who earlier identified socioeconomic status and care homes’ tiers as factors in residents’ fear of retaliation) said, ‘I think that there are some individuals that their life experiences have…if they had the opportunity to experience a higher socioeconomic condition, that may be their sense and their expectations in this setting are a little bit different than other people who might have had experienced sort of less opportunities in life and less maybe assurity that their individuality and their circumstances are respected by other people.’ He added, ‘I think there can come with a higher socioeconomic status certain confidence. People who may have not had those

opportunities that higher socioeconomic status can bring, they may have not experienced that or may not have expectations in the same way.'

The same representative said, 'Individuals' personality and how they're coping with their physical and emotional health that has brought them to become needy of long-term care. I think all those factors go into how they see themselves when it comes to dealing with the concern about retaliation.'

Another representative said, 'I think all residents worry about it but maybe the meeker [and] quieter residents that don't feel that they can speak up are more fearful.'

A representative from another state said, 'Every individual is different obviously but individuals who are more timid, not as confrontational. We found that residents who are more empowered…not that they're confrontational but they have more confidence in themselves, and they sometimes speak up for other residents who are not as confident or more timid, you know, maybe some that are more quiet.'

Another representative said, 'Those that are less fearful of retaliation are those that have a strong personality. They really don't care. They speak about everything, anything and they *honestly* don't care. They'll take on anybody. Which that's a good personality to have…sometimes I wish I had that.'

She added, 'And then you have the other residents on the other extreme who are very meek, and mild and timid and they are not used to speaking up and so they won't and they just *take* it. They figure that's the way they're supposed to be talked to. It's just the way it is type of thing or they just try to get through the day until the next shift comes on and that person is nice. I think we really see it on both ends. People who have a *very* strong personality and people who are *very* meek and mild.'

Introverts and Extroverts

Several representatives drew a distinction between residents who are introverts and those who are extroverts. One of them said, 'The one thing that does prevail is personality characteristics in terms of willingness to complain…is a major dynamic. I think if people's personality is more of an extrovert and they're willing to take on a little bit of contention…they're more willing to probably bring things forward than otherwise but when you're looking at that retaliation, it's a unique dynamic that's an undercurrent of it all. And when you're talking about aggravated retaliation, I think, typically, you see that emerge more with that person that's willing to complain.'

Another said, 'Your introverts, the people that just don't like to 'stir the pot,' I think fear retaliation a little bit more. Residents that are more timid have a higher fear of retaliation.'

A representative from another state said, ‘I think that residents who were very active or more of an extrovert have an easier time expressing their needs and their wants and are more not willing to necessary just go with the flow. They'll say, ‘I know what my rights are.’ Some have even said, ‘I'll just wave the ombudsman card.’ We don’t necessarily want them to do that. I want them to certainly speak up.’

The same representative went on to describe residents who she thought are less fearful of retaliation, ‘Those that were very outgoing. Some of them might have been in civic groups where they had to speak up. Obviously, I’ve even met some former Ombudsmen from years back. I think it is that sense of independence. That really helps. From their childhood through their high schools, being on PTAs [i.e., Parent Teacher Associations], more social are more likely to speak up.’

Another representative shared a different view, ‘Introverts and extroverts is what we tend to break it up to. We said that both of them are actually susceptible. Introverts are more susceptible because they are more going to keep to themselves and some staff may feel that they are an easy target for lack of a better term. Extroverts can also be affected because they are the ones who are going to speak up. It’s not necessarily ‘the squeaky wheel gets the oil.’ They’re going to do what they can do to keep them quiet.’ She added, ‘When we got to talk about it, that’s what we said. It’s not that one is more protected than the other because they can both be retaliated against.’

When asked whether she thinks extroverts who are more vocal are more likely to be retaliated against because they speak up, she said, ‘I don't know if they would be more likely to be retaliated against, but I think the retaliation is going to be a little bit more subtle than maybe the introverted portion of it. Meaning, you go from the beginning of the Med pass to now conveniently you're at the end of the Med pass…your dinners or stuff are getting delivered a little later than normal…where it may be more blatant with an introvert, but I still think it happens.’

Past Trauma

When asked about characteristics of residents experiencing more fear of retaliation, one representative said, ‘I think people that have suffered trauma in their life or any sort of PTSD’ [Post Traumatic Stress Disorder].

A representative from another state said, ‘People that have had trauma from their history…maybe abuse in a different facility or a different setting’ such as at ‘home or possibly another nursing home or assisted living that was more prone to have retaliation against them.’ She added, ‘If they are more environmentally aware, hyper vigilant, a lot of times they’re more aware of what feels wrong, and then tolerance, the tolerance for other

people and the tolerance for their own needs.' She went on to give an example, 'In their home setting, if they had a family member that every time they complain, [they heard] over and over, 'Oh, shut up, it's not your problem.' Always, 'Your opinion doesn't matter, your thoughts don't matter. Just deal with it. It's the way life is.''

When asked about root causes of residents' fear of retaliation, an experienced representative spoke about personality as a factor but then they added, 'Their past experiences in life. Some people have domestic abuse.'

A representative from another state also identified 'past trauma' as a characteristic of residents who may be more fearful of retaliation. When asked to elaborate, she said, 'I am more of a listener versus a talker…I can see just even how they're describing situations…I can sense an undertone of maybe domestic abuse…things of that nature.' She added, 'I am thinking about a couple of people in the past that I've dealt with and I've heard or kind of gleaned from…they had some domestic violence. I think they are more scared of retaliation because of their life experiences.'

Another representative said, 'More fearful' residents include those 'who have a history of abuse and neglect.' When asked to elaborate, she said, 'I just think people who seek revenge or retaliation on residents…I guess they're doing it for a number of reasons but I think once you have this aura about yourself…that people know that you were abused or neglected, it's easier for some people to see that and it's just an easier target for them.' She added that staff may 'get away with it because maybe the resident would be experiencing a past memory and when they complain or do say something, it's harder for a staff member to get caught.' She confirmed that this could contribute to residents' fear of retaliation.

Support system

Several representatives thought that a resident's support system serves as a protective factor when it comes to fear of retaliation when voicing care concerns.

One of them said, 'If residents have a good support system with families and friends, we think they're less apt to fear the retaliation because they've got people to kind of back them on their side to help them if need be.'

Another said, 'I do think residents that are truly supported, that they have the support of their family, they have the support of the Ombudsman, facilities that really do put in the time and the effort to make residents feel valued, feel whole, [missed words], I think those residents are definitely going to be less fearful and more likely to speak out about any sort of situation that would make someone else nervous.'

A representative from another state said, ‘I would say that people that are more fearful are people that don't have support as far as family coming in or people coming in checking on them.’ She added that these individuals would be ‘less willing to ‘ruffle the feathers’ because they don’t feel like they have a strong support network.’

Another representative said, ‘Some of them have nobody, you know, they’re very afraid.’

Another said, ‘I think residents that don't have any family or friends really they look to the Ombudsman program as their only voice so when we step out, they really don't have anybody checking in on them.’

One experienced representative saw it differently, ‘I feel as though the ones who have families are fearful of retaliation too because that’s a lot of the family concerns too. I think whether or not they have family, retaliation remains an issue.’

It should be recognized that in certain circumstances family complaints about the care may contribute to their relative’s s fear of retaliation (Caspi, 2024). For example, one state investigation included a **story** about a resident who stated that an aide roughly pulled a mechanical lift harness behind her. The resident didn’t report it due to fear of retaliation. She told the family to stay quiet about it. During a meeting with state surveyors, the resident told her family member, ‘You have to be careful of what you say around here. It will come back to you.’ When asked if she has ever been hurt, the resident wouldn’t answer, turned her head to the door, and said, ‘They are out there. They are listening to everything.’ When her family member spoke, the resident said, ‘You don’t understand. You have to keep your mouth shut.’

In addition, in some cases, family complaints about the care may result in actual retaliation against the resident (such as retaliatory discharges from the care home).

Cognitive Function

Representatives’ views regarding cognitive impairment and dementia as risk factors for residents’ fear of retaliation varied. Some representatives believed that having dementia increases one’s risk of experiencing this fear while others saw it somewhat differently.

One of them said, ‘Dementia probably gives an increased risk just on the fact that people don’t always consider them as believable historians.’ She added, ‘Not everybody that has dementia is in end-stages. There are early stages, there’s moderate, there are all the different stages, and they can still communicate…maybe not specifics but I think that makes them a higher risk because of that.’ Her colleague said, ‘Absolutely. I completely agree with that.’

A representative from another state said that residents in 'early-stage dementia' experience more fear of retaliation when compared to those without dementia. She explained, 'They still have the ability to understand but not 100%. They know enough that they know it *is* retaliation…'

Another representative said, 'Residents who have cognitive deficits and may not understand that they do have a right to express a grievance.' These residents are 'more fearful of retaliation because they do not understand…there's a lack of understanding as far as, 'Is this person's actions are to my best interest?' The representative added, 'It depends on their level of [cognitive] impairment and so fear, anxiety, they don't know how to express that someone is hurting them. But that is just my take on it.'

One representative said, 'The folks with moderate to severe dementia don't necessarily always have the capability and alertness to be scared of retaliation.'

One representative said that residents with dementia with 'paranoid tendencies' may experience higher levels of fear of retaliation.

A representative from another state thought that residents who are cognitively intact are generally less fearful of retaliation, 'Folks who are maybe not cognitively impaired but maybe for whatever other reason aren't as functional, they seem to be more like, 'Well, screw this. I don't care what they say' you know sort of thing.'

When reading the above statements, it is important to take into consideration the fact that every person is different, every dementia has unique manifestations, the same type of dementia can impact different people in different ways, and that different stages of dementia bring about unique cognitive manifestations. Representatives' direct work experience with this population and the quality of their dementia-specific training may play a factor in their views of this issue. Research studies are needed to shed light on the role of unique types of dementia and stages of dementia when it comes to residents' fear of retaliation and actual retaliation against them.

Serious Mental Illness

One representative said that residents living with a mental health diagnosis experience higher levels of fear of retaliation. When asked about characteristics of residents experiencing higher levels of fear of retaliation, another representative said, 'I personally feel that individuals who may have a mental health condition where they are a little more paranoid…that is part of their life.'

An representative from another state said that she sees more retaliation in care homes in inner city, 'With the inner city…because we see a lot of drug addiction, a lot of mental

health issues, a lot of retaliation with that because these people were homeless before [said while making a dismissive hand gesture to illustrate staff attitude towards these individuals], you know, who cares, 'They're lucky to have a warm facility.' That's the attitude that we get a lot of times when we get into the inner city. They get numb to complaints and the concerns that they raise.'

For additional information about people living with serious mental illness in care homes, see **Chapter 6.** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

Increased Fear of Retaliatory Discharges in Assisted Living Residences

A couple of representatives believed that, in general, residents in assisted living residences may experience high levels of fear of retaliatory discharges. This may partially have to do with weak regulatory protections against involuntary wrongful discharges in the assisted living sector in many states (certainly when compared with the requirements in the Federal nursing home regulations).

One of them stated that families of residents who are 'defenseless' 'especially in memory care and assisted living facilities because they are afraid that they are going to be discharged. As you know, in assisted living, there is no discharge rights. It's basically what's in the contract and that's *it*. I think those families especially in memory care units and assisted living facilities have a lot more fear than nursing homes do.'

She added, 'They don't have a right to appeal a discharge. They can't appeal anything. It just basically goes by the contract and in those contacts all it says is, 'You have to give me a 30-day notice. I have to do the same.' She said, 'In memory care especially they have long wait lists for the good ones to get into…so they don't want to 'rock the boat.' So a lot of times they don't speak up because they are afraid of retaliation.'

When asked about the emotional consequences on residents receiving retaliatory discharge notices, this representative said, 'They are *sacred*. It scares them.' The representative went on to share a **story**, 'I had this. My first eviction was in an assisted living facility and the man [who lived with a physical disability] was so scared because he had nowhere to go. He didn't know what he was going to do. And then, there may be stuff documented that would call someone else not to come there. So there they are, they have *nowhere* to go because the facility has documented things…only their side of the story. There's always three sides to the story. Their side, the resident's side, and the truth. So then they're just *stuck* and it's very scary. They feel like they are a step from being homeless. They also feel unwanted and they feel like people don't care about them.'

Another said, 'Residential care and assisted living residents…they don't want to complain to us because they may be at the fine line of level of care…because they can only keep

residents at a certain level and so they would rather stay in their home and accept whatever care or lack of care they're receiving than go on to that next level of nursing home care. But I have personally seen residents moving out of the residential care into a nursing home and they just got *much much* better. But they have in their mind that it's not better and they're much better stay in the circumstances they're in than file a complaint.'

She added, 'I do think staff uses that tactic, 'You really are getting close to a level of care. If you complain, we may have to suggest [a move]' or 'Your rent in assisted living will go up.' They get to the level of care and it really needs to go up according to the contract. Well, they want to save that money so they won't ask for the extra care because they don't want that level of care to go up [because] they have to pay more. They can do that so residents just would not complain. I've had several issues in that situation.'

When asked whether she considers the suggested move as a threat, she said, 'It is a threat. Now, are they saying the words, 'If you complain,…', I can't verify that they actually say those words. But that is something that I look for and after they have talked to me and all of a sudden they are in that next level of care. To me, what is that? That is retaliation because they talked to me.'

Fear of Retaliation is Perceived as Prevalent

Many representatives believed that residents' fear of retaliation is prevalent in LTC homes. A series of brief quotes are presented in this table for illustration:

Quotes Illustrating Prevalence of Residents' Fear of Retaliation
'It is I think probably at the foremost thoughts of many residents and families…truly.'
'We do see it almost every day when we are in the field.'
'It happens all the time.'
'There is fear with a lot of people and facilities.'
'I deal with it almost every visit that I do.'
'It very much exists. We hear it very often when we're in facilities and when we're getting calls in the intake line. I feel like it's prevalent.'
'I know this phenomenon is widespread. It's all over the place.'
'It runs pretty rampant.'
'It's a pervasive problem.'
'…how often we see it…it really is shocking.'
'I think it is an epidemic.'

Research Findings
A study by Robison et al. (2007; 2011) found that 23% of residents surveyed in nursing homes in Connecticut reported worrying about retaliation if they were to report a concern or complaint. A survey by the Atlanta Long-Term Care Ombudsman Program (2000) found that 44% of residents who had seen abuse of other residents did not report it. Half of these individuals did not report it due to fear of retaliation.

When asked about her thoughts related to residents' fear of retaliation, one representative said, 'It's real and it's evident. Every time I knock on the door and walk into a room and I start explaining myself, the process most people are going through [is]…if I share something and what if I don't share something.' She added, 'I respect that because retaliation is a real thing, it's against the law but it's a real thing and so I think it's very hard to quantify. I just think it's *really* there.'

Another representative said, 'It's a very real fear. We hear about this all the time. Sometimes we know it's happening, sometimes we see it happening but so hard to prove.' Her colleague said, 'Sometimes it's the resident who fears the retaliation and sometimes it is their legal representative or a family member who might be reaching out on the resident's behalf feeling like they might be retaliated against for lodging a complaint.'

When asked about her thoughts related to residents' fear of retaliation, a very experienced representative said, 'I think it is an epidemic. I really believe. For so many people just the nature of needing that type of care where you depend on that other person for your very most basic needs…toileting, a drink of water and you are helpless in so many ways and I think that brings fear. And also, COVID brought to attention the *horrible* staffing crisis that we've *known* was brewing. It's difficult to get good staff…staff seems to be more empowered now and the residents much less. They are very afraid to complain. It's an epidemic.' She added, 'I see it everywhere.'

When asked to elaborate on what she meant when she said that staff seems to be more empowered now, she said, 'This is all my opinion…So in every area of long-term care…and I will say as a caveat…with the exception of these very small family mobile homes where it is a family operating this facility and very few people…there is a staffing crisis. It is difficult to hire trained staff, it is difficult to keep trained staff so, in my opinion, it seems as though

people are *bringing in bodied* to meet the *minimum* and not always meeting the minimum staffing requirements in these facilities and it feels as if the corporation, the community would rather have a *body* than someone to provide good care.'

When asked, 'What does it do to the dynamic with the resident in the context of their fear of retaliation,' she said, 'With the resident, you've got these people who say, 'Look, it's me or nobody. I'll walk out of here and you'll have nobody to take care of you.''

When asked what makes her think that residents' fear of retaliation is common, she said, 'Well, it's almost every day. Every day that I am in a facility…there are a few facilities like in any other area of life that are wonderful and it's homelike and people they are much like a family but just that shift of power that I mentioned…it is just visible.'

She went on to share this **story**: 'I had a call [de-identified time] from a family member of a resident that had been placed in a personal care home. And she had some concerns about not being notified about a change in situation…a parent going to the hospital so she called to say, 'This is the second time this happened. Could you please notify me? I'd like to know where my parent is.' And the homeowner replied, 'You don't want to go up against me. You will not win.' Now, that's pretty brazen…don't you think?'

She went on to say, 'That tells me…if someone is that brazen…it's the only word I can think to use…to say that to a family member, what would they say to a resident? In that particular home, I go in…the residents are generally isolated into one area…nobody wants to go into their bedroom to have a private conversation and the look of fear is visible on their face.'

The representative considered what the homeowner said as a threat. She added, 'You don't want to go up against me. You will not win.' I was not present for the conversation. It was shared with me. It appeared to me that the family member was just trying to say, 'Look, if my parent goes out to a hospital or has a change of condition, I would like to be notified. This is twice and I have not.' The sound of this conversation did not appear confrontational.'

Referring to a conversation she held with her colleagues prior to the interview, another representative said, 'When we spoke about this earlier, *we were amazed* at how much we deal with this issue and how important it truly is. It happens more often than we care to admit. This is a real issue that our residents are facing.'

Quote
"*It happens more often than we care to admit*." – Ombudsman representative

Another said, ‘It’s something that happens all the time. It’s something that people fear and are concerned about. It’s also something that is very very hard for us to deal with in terms of supporting people and advocating for them. It’s a real, real tough situation.’

One representative said, ‘It happens far too often and facilities are in denial about it.’

A representative who works in a rural region in another state said, ‘It’s one of the two biggest issues that we face on a daily basis.’ She said that the second issue is that residents and families don’t know that the Ombudsman program exists. She added, ‘Putting those two things together colors almost everything we do.’

Another representative said, ‘Residents themselves, it's a fear for them because they don't want to be labeled as a troublemaker. It really does come up quite often.’

Lower Level of Fear of Retaliation in Rural Care Homes – Preliminary Support

In general, care homes in rural areas were identified as having lower levels of residents’ fear of retaliation when compared with care homes in urban areas (though some variation and exceptions in representatives’ perception on this issue were identified). Of course, not all rural LTC homes are alike. Some provide good care and others provide poor care. The level of fear of retaliation likely varies across these care homes.

One representative said, ‘You can see the difference between the metro and the outstate. There’s more community fabric in outstate. I think statistically, you’re going to see better care in outstate. They get to know the residents more than they do in the metro and even in the outstate I would say it can be a heck of a lot better in most areas.’

When asked whether she sees any differences between rural and urban nursing homes when it comes to fear of retaliation, another representative said, ‘Definitely. For us in [de-identified state] there are nursing homes that are in very small towns so typically when people go to nursing homes they all go to that one, the people know each other, they've grown up there, staff know each other, and it's more of a sense of community rather than in some of the bigger cities that we have in [de-identified state] it's not like that. I feel like it's run like a business. You have staff come in…they do their paperwork. I feel like small towns are definitely more about the care rather than running it like a business.’

She explained why she thinks there’s less fear retaliation in small rural towns, ‘I think people can communicate and I think there's more of a sense of caring there. The facilities there are smaller, the nursing homes are smaller, and in turn, they can provide more attention and more one-on-one care or do activities or the people know each other. It's a place where people don't just go there to die…it's about making their end of life great.’

When asked if she sees scenarios where because ‘everybody knows everybody’ in rural care homes, some residents may be reluctant to talk about issues, she said, ‘Definitely. There’s always the flip side of that. I mean there's definitely positives but yeah, in a small town you don't want to complain about your neighbor that might be caring for your loved one or you know the administrator’s niece that works there or something like that. So yeah, there's definitely the flip side to that…’

When asked what underlies the difference between rural and urban care homes, another representative said (referring to rural care homes), ‘They tend to have more stable staffing and they have more staff. The jobs in rural areas are still good jobs whereas in the city you can make more money in McDonalds than you can make in a facility. In rural areas they tend to have less turnover.’

A representative overseeing a region with a lot of rural care homes in another state said that she believes there’s less fear of retaliation in the rural care homes in her experience. She said, ‘I find that some of my better homes are rural and the reason *why* they are better is because they have the same staff working there for many many years. The smaller towns don’t have a lot of jobs, there’s not a lot of job hopping so those staff that work in those homes, they’re there and they are usually really good and it’s more of a community-like atmosphere. Everybody knows everybody so the quality of *life* seems better because some of them [have] been friends all their life. They all know each other.’

The representative added, ‘It also sets up an atmosphere where sometimes they know too much about each other, you know, they’ll have situations, and you just need to deal with that on the basis that it comes. But as far as the care goes and the quality of life, yes.’

This representative and her colleague recognized the possibility that because ‘everyone knows everyone’ in a small town in a rural community, some residents may be reluctant to speak up and complain about their care. One of them said, ‘That could be a possibility.’ Her colleague added, ‘That’s a really good question by the way. Yeah. I like that one.’

When asked what she sees as the value of these stable consistent staffing in care homes in rural areas, she said, ‘Because they know the residents better and they know what their needs are. They are more attentive to what time this resident is going to need this, this, this. That kind of stuff really does matter. They also tend to know how to do a few things. For instance, if there’s a gentleman who is going to be known to try get up if they don’t get to him in time…if he has a urinal that will keep him from going to the bathroom and falling. It’s little things like that that they can pay attention to. They know about those residents and they are able to care for them in that kind of way.’

She contrasted it with the way she sees things in urban care homes, ‘When you get into the bigger homes like in my bigger cities where I have really big homes, they tend to run through staff like *constantly*…every two weeks, you’ve got new people in there. The other people are *gone* so they don’t know the residents. There’s usually not enough of them. They’ll call in. The rural staff doesn’t call in nearly as much as they do in the bigger cities.’

When asked whether she sees any difference in residents’ fear of retaliation between rural and urban care homes, a representative working in a region with many rural care homes in another state said, ‘I find that the smaller rural facilities tend to have generational caregivers. You might have a mom who is a cook, a daughter who is a social worker, and a granddaughter who works as a CNA in the evenings. I don’t see that so much in the large urban areas. And of course, a lot of these residents grew up in those rural areas and probably *know* staff, etcetera. I think that’s a difference.’ When asked if that generational factor has any potential influence on residents’ fear of retaliation, she said, ‘In my experience, in the larger facilities residents are more fearful.’

She added her views on a recent trend related to traveling staff in urban care homes, ‘I think when the facilities started getting what you call traveling nurses or traveling CNAs, residents may not have had much experience with other races and there was that fear of that and I would have to say that has *really* quite come to be because now the residents are used to people of different colors, of different races etcetera. I think that what I'm hearing from residents is that the Southern states are known for how nice they are and kind and friendly but when it comes to nursing homes, I am hearing especially the larger ones that staff are less involved, they’re more rude and that makes residents more fearful.’

She said that she sees this issue in urban settings ‘because those are the ones that seem to be *employing* more traveling staff. That’s what *I* am seeing. And of course, that all comes with…I mean, when you're out at a facility for six weeks or three months, there is less attachment to the residents and the residents are not as attached to traveling staff. I am not saying that's a color thing…it’s just that when they know that, ‘Hey, I'm going to be here for three months,’ it's hard to have that bond. That’s what I am hearing.’

When asked if she sees more staffing stability in rural care homes, she said, ‘Yeah. I do I do. Not to say that…I know that smaller facilities can get close to closing their doors and there are staffing shortages but they're everywhere also. I think that the smaller [rural] communities…what I have found…have less retaliation because everybody knows everybody. It's a little bit different. There's more *commitment* to the *residents* than say a larger facility that might have more turnover with staff and what not. There's just not that sometimes…that deeper connection.’

A representative from another state said that she sees less fear of retaliation in rural care homes. She explained, 'I live in a very rural community. We have one assisted living and one skilled nursing facility in the whole county…mainly agriculture, mainly pork producing. If you lived in the facility or you need to be in that facility, probably 50% of the workforce live in the same county. These are people that know you from Church or school or some affiliation…probably even family…so you see less retaliation when it's somebody you know, somebody you grew up with, somebody you're familiar with. And again, in a rural environment, gossip spreads like crazy. So if someone is being mean to a resident and they complain, more likely their aunt is going to hear about it…it's just such a weave of people…all connected. In a more urban environment, it's just a revolving door staff, you see higher turnover rate…because they can just go across town and make 50 cents more. There's not as much loyalty or commitment to that facility or the resident there. I also think that they are just not that vested. They don't *know* these people. There is no relationship with these people that you see in a more rural environment.'

That said, this representative also recognized that the flip side of it may also occur where some residents may be reluctant to complain about the care because 'everyone knows everyone' in a rural care home. She said, 'Yeah. I would say that's probably true. I think that there is some of that…yeah, 'I am afraid to confide in that person because then my business will be all over town or be shared even outside the facility' you know, as far as gossip or whatever you want to call that in a small town.'

A representative from another state said, 'I think people in the rural areas of our state…it's a fairly rural state…that they know everybody and that makes it harder. People know everybody in a small town. To make complaints is difficult because of that.'

Her colleague chimed in, 'I agree. Sometimes the person that they might be retaliated against works there. It could be like their brother in-law or a grandchild or something…because the communities are small…that they could possibly and are often employed there.'

Another representative said that fear of retaliation and retaliation are 'far more common in urban' care homes. He added, 'A few are a less stark contrast but where it occurs and how often I see it is urban and maybe suburban areas.'

Another representative overseeing a predominantly rural region said, 'The differences of problems and issues are *night and day*. In the region that I work, we have your typical concerns…call bells, cold meals, not getting showered as much as they would like, things like that. The concerns in the more urban areas are more drastic. It's not only they're not

answering my call bells, but I am waiting in dirty briefs for an entire day. Everything is more *harsh*…I guess is the word I want to use.'

When asked what may underlie the difference, she said, 'It's the amount of people and the amount of staff.' The representative attributed the difference to the lower number of beds in rural care homes when compared to urban care homes. She explained, 'Where there's more residents, there's potential for more concerns, more fears of retaliation, more fears of everything.'

One representative described a unique scenario where residents in rural care homes may experience fear of retaliation. For example, when asked if she sees a difference between urban and rural areas with regards to residents' fear of retaliation, a representative overseeing a rural area in another state said, 'Our rural facilities are suffering for census and so we're seeing closures of facilities because they're not getting the income in or they're not getting the right mix of residents to make up their payer source. They get maybe the more difficult individuals that no one will take or they get more Medicaid recipients…so in the rural areas they were seeing closures. In the urban areas, they can be more selective with their admissions because our urban areas are becoming more populated, so people want to go there versus our rural areas. So the facility staff and the corporations in the urban areas, they are discriminating against in some cases…could be seen as discrimination to even who they're going to let in their door. So that person who may come in as a certain payer source already feels, 'Well, I am just lucky to be here so I shouldn't speak up or I shouldn't complain' when in reality that shouldn't be the case at all.'

She added, 'I think in the rural areas where you may have more hometown local people working, the residents don't have as much fear or retaliation. However, if you're in such a rural area that you're paying agency staff to come in because the pool of staff is just not there, then you have unfamiliarity with the staff, then you have a lot of staff turnover, and I think fear of retaliation increases because their quality of care changes.'

When asked if she sees situations in rural care homes where because 'everyone knows everyone,' some residents would be afraid to speak up about their care concerns, she said, 'I do not see that. I think in those small communities it is more of my aunt works here, my grandma is at this facility, and I think that makes them more open to speaking about it because they feel like there's someone who maybe works there who comes in from their Church and so they're more trusting. It's kind of been my experience.'

Other representatives did not share the view that in rural care homes residents experience less fear of retaliation when compared with care homes in rural areas.

When asked whether she sees a difference in residents' fear of retaliation between rural and urban care homes, a SLTCO said, 'No. When it happens, it can happen anywhere. We see it more in urban areas because I think we have more facilities. So no, I think it's more due to the corporations to be honest with you…the culture of the facilities and then the corporate structure. We tend to see patterns.' She added, 'We see more in urban areas but it is because we have more facilities. So I don't think it is specific to being in a city versus out in the country.'

When asked the same question, another representative said, 'I see the same problems at *every* facility. Unless they are there 100% for the resident only, I see the same problems.' That said, she added later, 'I am just talking about general complaints. I don't know the fear of retaliation complaints…'

When asked the same question, an experienced representative said, 'We're not in the urban areas. Our whole region is a rural area. We often have buildings where staff working where they live in smaller communities and so there's sometimes connections where they know histories of residents.' She shared a **story** illustrating how in small rural communities the fact that 'everybody knows everybody' could sometimes bring about negative consequences, 'I have one resident who…she was an [de-identified name of profession] [whose license was revoked] and staff found that information and shared it with other staff. That has nothing to do with her as a resident. It happened but that was used against her as retaliation. That was a huge issue. The county was involved in that trying to fight and protect her rights. So we can run into those things where that information is shared…somebody knows somebody who knew someone who knew someone who knew the resident.'

I returned to my original question and asked whether she sees a difference in terms of scope and severity between rural and urban areas with regards to residents' fear of retaliation. Her response was, 'I don't think there's much difference. I think the fear is there in every single building in healthcare…with just healthcare in general.' She explained, 'The shortage of staff and needing to fill positions to care for the residents that you have. I think you get a large influx of individuals who are not…it's not a competitive work environment where we're just dying to work in a nursing home. So you have I think a large number of individuals more likely to retaliate against residents.'

A very experienced representative said, 'I find my rural facilities have more blatant abuse. She added, 'And if it's a mixed culture of staff, I don't see facilities having as much abuse or retaliation but if it's an all-Whie facility, there is so much abuse and retaliation. I've just always seen that in my [de-identified number of] years. If it's an all-White facility, those are my biggest abuse facilities.' The representative confirmed that she believes that when there's more diversity among staff, she generally sees less abuse and retaliation.

One representative spoke about care homes in rural areas, ‘In a small town you don’t want to complain about your neighbor that might be caring for your loved one’ and ‘A lot of the problem is that they don’t want to cause trouble for their friend or their neighbor. They don’t want to cause trouble.’ She added, ‘I don’t know if it’s so much fear of retaliation always. Sometimes it's their own perception of, ‘Well, I don't like the way she talks to me, but I don't want to get her in trouble because she'll be mad at me’ so I don’t know how that would really lay in the retaliation, ‘I don’t want her mad at me.’’

Another representative said, ‘I think the big difference between our rural and urban areas is these residents grew up in that area…like you’re talking towns of 1,000 people…so they know every single staff and all the administration, so you have no anonymity. They all know who you are and what you’re like sometimes more than they should know.’

When asked how it plays into fear of retaliation, the representative said, ‘We hear a lot of, ‘That’s just the way they are. They’ve always been complainers,’ things like that…like the gaslighting or that dismissive, ‘She’s just never happy.’’

His colleague shared this **story**: ‘We had a sexual abuse case years ago in one of our facilities. The police came in to investigate. There was a proof, a physical proof but, ‘it just couldn’t have been that guy. He would have never…No, we know him.’ It was a really tough case because no one would believe that it happened because of who the perpetrator was.’ The representative confirmed that there was a proof that the individual was the perpetrator.

Another representative said she has a facility in an urban area from which she never gets complaints even though the building is ‘falling apart.’ She said, ‘When I talk to people, they are all satisfied.’ Then when she asked a state surveyor about it, the surveyor said, ‘I can tell you why…the residents all grew up in [name of town], the staff work in [name of town], their family lives in [name of town]. It is a family facility. These people grew up in this area and they are completely satisfied.’ And I thought, okay, all right, makes sense to me.’

When asked whether she sees a difference between rural and urban care homes when it comes to residents’ fear of retaliation, another representative said, ‘I don’t know if it’s a rural urban thing or if it’s more of a cultural thing that’s bigger than rural versus urban.’

The representative went on to give an example of an area classified as urban but one that is located in Appalachia as well as minority groups in other regions that may resent and distrust outsiders (such as representatives) due to historic systems of injustice.

When a SLTCO from another state was asked whether she sees a difference in residents’ fear of retaliation in rural versus urban areas, she said, ‘I think my concern is…whether it’s urban or rural, when a facility is more isolated and closed off from the outer world and residents do not have family members coming to visit…because maybe they don’t have

them, there is room for instilling fear in residents and that fear of retaliation that that creates for residents because they're isolated, they're alone, they don't have anybody…they may only have us as Ombudsmen…and so when you have those circumstances, I think it's *ripe* for an increase in fear of retaliation, retaliation, threats, and actual abuse.'

A Barrier for Reporting

Representatives spoke about the fact that residents' fear of staff retaliation prevents them from speaking up about right violations, care concerns, and mistreatment.

When asked about her general thoughts related to residents' fear of retaliation, one representative said, 'It's obviously very real and my impression time and time again…the reason that residents do not want to report is that fear of retaliation.'

Quote
"I think it's one of the main reasons that concerns are either brought up but not addressed or just completely not brought up at all because no one wants to be labeled the troublemaker. Residents sometimes live in fear that if I bring it up, it is going to get worse. It is a real thing." – Ombudsman representative

In accordance, one representative said, 'It's a valid concern and sometimes it takes quite a bit of convincing to get them to talk to us because they are truly concerned about it. Most of these conversations will start off with, 'I have a complaint' and we ask them, 'Do you want to open a complaint investigation?' I would say half of the conversation after that is, 'No. Because I don't want retaliation. I am fearful of retaliation.'

Another representative said, 'If I am doing just scope work when I am just talking with residents to get it verified, I have to say to them, 'I am not going to use your name. This is anonymous. It's okay' and then they feel comfortable talking but if you're going to say that you're going to mention their name, they will freeze up and not say anything.'

Family fear of retaliation

This important topic of family fear of retaliation was not the primary focus of this project. The primary focus was on residents' fear of retaliation and how representatives work to address it. A separate project is needed to address family fear of retaliation and research is urgently needed to examine it. Isolated reports in the media provide a glimpse into this common but grossly understudied issue.

With that said, several useful statements and insights were shared by representatives about family fear of retaliation, including:

Referring to fear of retaliation, one of them said, 'I hold Family Councils where this topic comes up a lot for family members.'

Another said, 'It's a real fear. It is natural for a lot of families to bring that up to me whether they want to open a case because they're fearful that with their loved ones will it make the situation worse.' She went on to explain why families have this fear, 'Some family members have had poor experiences with other facilities which just brings an overall feel of, 'Is this going to happen to my mom or my dad?' It was a bad experience at another place. I think also in a small community people talk so they just assume that if something happened at one place, it's gonna happen everywhere and people just don't have any other options. If there is retaliation, where are they gonna go? I think there's a lot of that…a lot of history behind it…why people might feel that way.'

One representative said, 'I have a lot of cases where the families are more scared of retaliation than the residents are.' She added that families will say, 'Well, this is what's going on but I don't want you to do anything.' The representative's reply to the family is, 'Well, I am going to talk to your mom and see what *she* wants done' and I go talk to mom and she's like, 'Yeah, lay down the law' but the family is like, 'No.''

Another representative shared that in two different situations that occurred [within a one month period; time de-identified] two family members 'didn't want me to get involved.' They wanted me to come see them but they wouldn't even let me wear my badge going into their room. They asked me to take my badge off because they didn't want anyone knowing that I was coming in to see them.'

A very experienced representative from another state said, 'The family members fear of complaining because they're afraid their loved ones be retaliated so they're reluctant to complain. They call the Ombudsman program hoping that we could help their loved one…confidential…and try to help all residents without using their name. We find that family members…they want to call and talk to us and we help them but they don't want to give their loved ones name because they are fearful of retaliation.'

When asked how she handles these situations, she said, ‘We open up a case for all residents and we go in and investigate *all*…and visit with as many residents we can and do not use names. We try to go at different times and talk with administration about complaints that we’re hearing…of fearful of retaliation but we may not address it during that original visit because we know facilities have cameras. I explain to residents who might complain or a family member, ‘I may not address that issue today but I will be back’ because we’re here to help you confidential…we cannot use your name without the permission…even when family calls and complains. We have to visit with the resident face-to-face first.’

Another representative described fear of retaliation experienced by families of residents in advanced stages of dementia, ‘Families are afraid they’re going to get their loved ones kicked out or receive poor care…like the care is just going to get worse if I complain…and I know I can’t take them home.’

When asked about her role in addressing family fear of retaliation, a representative from another state said, ‘The families, especially the folks that have dementia that really don’t know that they can’t remember…they are alone with the staff for long periods of time and I’ve had many family members not wanting things addressed because they worry their mother, their father whoever will suffer if they bring the concern up and if they have us involved.’

She added, ‘Sometimes, again, the same thing with the residents…I’ve heard from family members it just got worse because you were involved. And again, most of the times they are not blaming me or the Ombudsmen personally…because they know we’re there to help them. But they’re honest and, ‘This is worse now’ or ‘It’s unchanged, same thing, different day.’ I hear that more now, ‘Same thing, different day, nothing changed. It’s still just as bad and I am still nervous about having you involved in any way or your staff involved in any way.’ She said, ‘It’s really sad.’

She explained, ‘It is a real big concern about folks in the dementia unit because the families really do feel like they have to just trust what they see and they are not there all the time and they worry about what happens when [they’re not there]…or if their mother is different the next day, they worry that something happened to their mother and their mother can’t tell them because their mother can’t communicate or they can’t communicate in a way that we understand.’ She added, ‘Thankfully, there’s still a lot of lovely people out there that if they heard that someone was scared, they would address that head on and do what they could to lessen the anxiety and the fear and do things to make people feel comfortable bring *any* concern forward.’

Note: A description of SLTCO's strategy for addressing family fear of retaliation in the context of a resident who is in mid-to-late stages of dementia was redacted from this part of the report. It will be shared with representatives for internal use.

A representative from another state said, 'They tend to retaliate against family members that are problematic or challenging. Then they want to get rid of the resident because the family members aren't behaving appropriately. We see that quite a bit as well. Obviously, our advocacy is, 'No, that's not one of the six reasons. It's not the resident's fault that the family is behaving in that manner. You can't punish the resident because of the family. It's not how it works.''

One SLTCO spoke about the importance of educating and empowering family members, 'To educate and empower the family member. Let them be *heard*. You want them to feel like there *is* somebody there that is going to listen to them. And if we're going to take action, we need to let them know our rules around that…we need to go and see the resident first…even if they have advanced dementia and bedridden, we got to go do that first. But I think that sometimes what we can do too is not only just empower the family members [but also] give them tools and their toolbox…like on what types of questions to ask, what *should* you expect from staff, what *should* they be doing for your loved one…I think that that is an important piece as well…to empower.'

One representative spoke about her work in educating family members. She said, 'I make a point when I go into a nursing facility…if I see family in a room, I will…except if someone is passing away…you have to use common sense…I might go in, I'll introduce myself to families, I'll give them my card and sometimes families will say, 'We want to bring something up but we're afraid care will get worse.' We talk about things like that. Some techniques that can be used and how to address it appropriately with staff or that they may want to consider starting a Family Council if there isn't one because a lot of them don't. Begin a Family Council so families can address their fear of retaliation and some techniques that can help the resident and themselves speak up as well.'

She added, 'I do say that there is strength in numbers. There is strength in numbers when family members come forward with concerns. The squeaky wheel gets the most traction. It's not traction but you know…and how will it get better if nothing is addressed.'

When asked, the representative clarified that her comment regarding strength in numbers referred to both Family Councils but also to situations where more than one family member can become involved in advocating for their loved one. She said, 'You might have to have three sisters go in and say, 'Here our concerns.''

Another scenario was described by a representative from another state when they shared this **story**: 'A family called and had lots of concerns [i.e. care-related concerns and those related to visitation during COVID-19 pandemic]…lots of things they wanted addressed but the family wasn't willing to share with me even the name of the facility that the resident was in or anything that would help me go to resolve the concern because they were *so* fearful of retaliation. They were like, 'It's already bad. It's going to get worse.' So without even knowing where…and we tried, I tried, the State Ombudsman tried but we just could not get the family member to release any sort of information. She added, 'We felt hopeless because there were a lot of things that we could have potentially done but without any sort of identifying information [didn't complete the sentence].'

Another representative shared a **story** about a resident who was 'overdosed' to the point of being 'not responsive anymore' but due to fear of retaliation, the family didn't give the representative permission to intervene. She said, 'Even the children of the residents that are in there [said], 'I don't want you to say anything. They are overdosing my mom. She is not responsive anymore.' To which she responded, 'Okay, well, can I advocate on her behalf?' The family would say, 'Absolutely not. You cannot do anything.' Okay, well, she is going to call back in a couple of hours, 'Mom is not responsive anymore.' 'Oh, okay, can I do anything? Can I help you? Can I advocate on?' 'No, I don't want them to do anything.' 'Well, how much worse can it get?' We want to do something but they are so *afraid* that they would rather let their loved one become unresponsive and go to the hospital with severe dehydration and a UTI than say anything for fear of retaliation.'

The representative added, 'It is frustrating because they are so anxious and they will call you at all hours of the night and most of the time we don't take calls after five but once in a while you'll take one and you can't do anything because they won't let you do anything and if they won't, then we need to somehow be creative systemically and warm our way in to find out the information we need to know.' Later, this representative said, 'We have our creative ways to work around that and assist them through that fear.'

Note: The description of the creative approach used by this representative was redacted from the report and will be used for representatives' internal use only.

One representative shared a **story** about a resident who she described as 'pretty cognitive' with a significant need for assistance in activities of daily living, 'I had a situation during COVID when we could not go into the building. A family member called and she was worried that if she would say anything…it was her aunt…she said, 'I am afraid that if we say anything, that it'll cause her more problems.' At that time, her aunt was on a COVID hall and there was no staff back there with her so she was not being cared for at all. She was the only one in that unit because at that time they would put COVID positive people in a

unit by themselves. Since there was only one, they said they're not going to do one-on-one staff. So I asked the family member, 'What could happen that could be worse than what's happening?' and she said, 'You know, you're right.' I said, 'We really need to get somebody back there' because at that time she was the only resident back there and she had her cellphone and she would call her niece and say, 'I haven't seen anybody in days.' We ended up doing a Care Plan over the phone where we all talked about it and they did admit that there was nobody there during certain hours and that she had been left there by herself.'

When I asked about the end outcome of the situation, the representative said, 'They finally decided that it was best to have somebody back there with her but they did not want to do one-on-one staff. I said, 'If you're going to put somebody back there, you've got to have staff back there. We argued it out until we won. We won. The [family] put a camera in her room to make sure they were coming in and checking on her.'

She added, 'She had bought a lamp and it had an SD card in it so it didn't take Wi-Fi. She just told them to take it in and let them know she had a camera in there. There was nobody else in there so nobody had to sign off [on] it but her. Anyway, she got it in there and that was part of her Care Plan. And I said, 'Absolutely need to let her have that. She can keep an eye on her…at least call if you'll didn't go check on her.''

It is important to recognize that beyond family members, friends and other members of the community may visit residents and advocate for improvements in their care and safety. It is likely that some of these individuals may experience fear of retaliation when voicing care concerns. To give one example of non-kin supportive visitors, one representative said, 'Especially women in the Black communities, if they are part of a Church, I call it the Church ladies…other Church ladies will be there very often and they are probably the hardest group to deal with on our behalf because they are strong and they're powerful and they are just outraged that some of these things exist.'

Research on the role of non-kin support system and advocates in LTC homes is needed in general and in the context of fear of retaliation.

Retaliation After Private Caregiver Reports Care Concerns to Family

Two representatives participating in the same interview identified another form of retaliation that may occur when private caregivers report care concerns to the family. One of them said, 'What will happen is that those individuals might have private caregivers that don't work for the facility because that facility staff wasn't giving them enough care so they hired private caregivers. And those private caregivers will then feed information to the individual that's giving them the paycheck…the family member who is paying for that resident and then they [the staff] won't speak to those private caregivers anymore. And now

it's made it more difficult for these family hired caregivers to care for those ones in that place because they spoke up.' The staff 'won't talk to them, they won't tell them where certain things are, they will make them do everything for themselves when in fact the facility staff is getting paid also to take care of this person. And now because they've told, they are not going to talk to them anymore or they'll have snarky comments in the corner about that staff person.'

When asked about the impact on the resident, the representative said, 'Whenever that family hired caregiver is not there…because they are not there 24/7, then that resident will not get any care or get very limited amount of care. They might be [without care] until 10 or 11 o'clock in the morning or whenever they get there because they're not going to deal with them.' She added, 'They might not be upset with that resident…they're upset with that private caregiver of the resident so now the resident has to pay.'

Her colleague added that in retaliation to the private caregivers' report on the care concerns to the family, care staff 'would even lock the resident out of their own room. They could not go into their own room. They had to be in the centralized area. So not only retaliation but not allowing them to be in their own room that they pay for.' She added that if the resident wants to go and lay down in their bedroom, they can't.'

Participation of Family Members in Resident Councils

Several representatives spoke about the importance of family members' participation in Family Councils when it comes to addressing care concerns, fear of retaliation, and actual retaliation. At the same time, representatives identified challenges in forming and running Family Councils. For example, one of them said, 'It's like pulling teeth to get a Family Council started.' Another said that 'a lot' of nursing homes don't have a Family Council.'

An experienced representative from another state identified a concerning trend in her state: 'The only thing I would like you to be aware of is I think this too is a detriment…when I first started [over 20 years ago; exact number de-identified] years ago, Family Councils were very very popular. There were many of them particularly in nursing facilities and I think that that was *very* beneficial. As time has gone on, in the [de-identified name of region] we serve [de-identified large number of] counties, there is *one* active Family Council.'

When asked what she thinks underlies that change, she said, 'I do not know. I do feel that the nursing home has some responsibility in that. I think that…well, certainly during COVID, [missed word] were isolated. But even before that it was changing. So I am not sure. I think the nursing home doesn't want to be bothered. The nursing home has a requirement of providing them with a place to visit and social [missing word].'

She added, ‘It is a trend in [de-identified state].’ She confirmed that the trend is concerning because residents are losing an important vehicle for change.

Fear of Family Retaliation

One representative said that fear of retaliation may also occur in the context of residents being afraid of their family members. The representative gave the example of residents’ fear of retaliation when their family members financially exploit them. She said, ‘We’ve had retaliation from family. You know, concerns about family. We have a lot of family members stealing from residents. And not wanting to get their family members in trouble and not to make things worse for themselves.’ She went on to share a **story**, ‘I remember a situation. I did get the resident to agree to bring a Legal Aide Attorney in. It was a long, long time ago. The Legal Aide attorney and I met with the resident privately about the fact that her daughter has been stealing from her for a long, long time and it was starting to affect her Medicaid eligibility and so her ability to stay in the facility. We talked for a long time. She never let us do anything.’ She added, ‘I thought it was a weird sort of success because we at least were able to let this resident know we are here for you if you ever want us, but we educated her about the fact that she wasn’t taking action and what the consequences for her were. And we talked with the facility about supporting her…of course, we had to [missing word] so we told them, ‘You can report it. You’re mandatory reporters.’’

She added, ‘She was also worried about her daughter going to jail, ‘I don’t want my daughter to go to jail.’ This daughter was robbing her mother blind. She had stolen tons of money. Gotten a car, depleted bank accounts and this is not an uncommon thing…it happens quite a bit…sadly. She was afraid that her daughter won’t come see her anymore. She also didn’t want her daughter to go to jail because that’s what would have happened to her. She would have some criminal action because it was clear that this is what was happening. This was not ignorance on the daughter’s part, ‘I am taking Mama’s money.’’

In light of the above and given that previous research reported on family abuse of their relatives who are living in nursing homes (Myhre et al. 2020), research is needed to examine the issue of LTC residents’ fear of retaliation from their family members.

Guardianship-related Retaliation

When asked about main challenges and barriers in addressing residents’ fear of retaliation, one representative said, ‘In our state particularly in [de-identified name of colleague] region and my own we have a number of individuals who are under guardianship. Maybe they have not experienced the retaliation in the form of staff retaliating against them in their particular home but they have written a judge and the judge is sharing their letter and their concerns with their guardian and therefore…maybe their phone was taken away, maybe

their phone privileges were restricted. Guardianship in the state is a *significant* problem. You can do a whole other study on that. Guardianship in the state of [de-identified state] is *disgusting* to say the least.'

Her colleague added, 'They could take all of those things away that you wouldn't think about. They can make any little tiny decision for the resident…what they wear…like [de-identified name of colleague] said whether they have phone privileges, if they have a tablet, what they have access to, what they don't have access to.'

The first representative added, 'Whether that resident even gets mail in the home…things like you wouldn't even consider. So when we think about retaliation, if that is an experience that they have had, even if it is not with the care facility…but going back to the power structure…somebody having authority…that judge or public administrator have authority over them so they are not as inclined to share other concerns because they've seen firsthand when they have shared this concern…the repercussions of their actions.'

Her colleague said, 'Sometimes it seems to the residents that the facility and the guardian are in cahoots so to speak…that they are working together against the resident.' She added, 'I have a facility that if the resident doesn't "follow the rules" [said while making a gesture indicating quotation marks], they threaten to call the guardian and tell them they are not following the rules and then there's repercussion from that guardian.'

Chapter 4

Contributing Factors to Fear of Retaliation and Actual Retaliation

Quote
"Determining the root cause of the problem is essential for finding a lasting solution." Source: National Long-Term Care Ombudsman Resource Center (January 2022). Trainee manual: Initial certification training curriculum for Long-Term Care Ombudsman Programs (Module 8, page 10).

Representatives identified several factors they believe contribute to residents' fear of retaliation and actual retaliation (the list of factors presented below is not exhaustive; other factors are described throughout the report). One experienced representative said, 'I think there are multiple root causes of fear of retribution. It's not a one size fits all type thing.'

The Way Elders Are Treated in this Country

At the society level, one representative tied residents' fear of retaliation to the way older adults are treated in this country. She said, 'I think that…not everyone of course but I think A, I don't think that we treat our elders very well here in the United States at all.'

She added, 'I actually heard a [surveyor] say, 'Well, they do go there to die.' Oh my God, this is part of the problem. If people were reminded, taught…these are people that served their country, their families, they had a life, they had a career…all those wonderful things…and this is their home now and this is how they should be treated. I think that that's part of the whole problem. People treat our elders like they're just…I don't know…even the way I feel staff speak to them at times…calling them 'Honey' or 'Baby,' not knocking before they enter their room. I think that that's part of the whole problem. I think that even with the retaliation, the way that people are treated sometimes…they treat them like they're children. They're punishing them almost.'

'Lack of respect for older adults'

When asked what makes it so that fear has anything to do with care and what are the root causes of resident's fear of retaliation, a SLTCO said, 'There's a lack of respect for older adults and individuals with disabilities. Sometimes it seems to attract people that are just abusive. I've seen aides out in the community with their kids and they treat their kids horribly. They don't know how to treat people. They never learned. How to treat people is not something that's innate, it's a skill that you learn. Sometimes you learn it by experience…because you have nice parents and then you [said while making a hand gesture indicating continuation]. Sometimes that's not true but…I think it's lots of reasons.'

She added, 'I also think that there are some people that this is their opportunity to just not do the right thing. I think it's all of those things…but I think the big thing is…one of the bigger reasons is that this population of residents are not valued and are not treated like human beings and they are treated like commodities. The Private Equity issues, they're money. Residents are money. Therefore, if you think about residents being a task, 'I've got to go take care of this hip down the hall,' that's part of it too. That's one of the root causes…is there is *no* value for these folks.'

She said, 'I'll just give an example. When you're in a restaurant and you're getting a meal, most places band over backwards to make sure your spaghetti is okay. Why isn't that the same in long-term care? And it has an issue with "the value" of the person that you're serving. I think *that's* the issue. There are all these other things too…about the kind of person it attracts, the staff that don't care, that the staff are controlling, the money-driven…but I think that's the main issue.'

She added, 'I think that's why the Ombudsman Program is also underfunded and volunteer-focused…because the population that we serve is…not as sexy as missiles and education…That's what I really think it's about.'

Prior Negative Experience

When asked what makes it so that fear has anything to do with care and what are the root causes of resident's fear of retaliation, a SLTCO from another state said (beyond other factors she identified, which are included in other parts of this report), 'It could be what people have heard before they even come into the building. It could be their own culture, you know, you don't speak about things…so it could be some of that.'

Referring to factors that may increase the likelihood that residents will experience fear of retaliation, another representative said, 'If you have been in multiple settings or if you have been in a facility a long amount of time, I think that you've seen and experienced potentially more retaliation so you have maybe a greater fear of it because of the experience as far as time or that goes.'

When asked about the main challenges and barriers for addressing fear of retaliation, the same representative said, 'Previous poor experience whether it is with our program or telling another staff member or particularly with the hotline to the state [referring to residents who call the state hotline to complain about the care] …they have previously experienced retaliation…so going forward, they don't believe that this time will be different.'

When asked whether 'learned helplessness' is a concept relevant in these situations, her colleague said, 'I don't know if its helplessness as much as it is hopelessness. They're just

hopeless. I think they even use that word, 'I have no hope. It doesn't matter what is done. It doesn't matter.' From my perspective, that is what I see more of than helplessness.'

Another representative said, 'It's a valid fear unfortunately and so my general thoughts of fear of retaliation is due to the resident experiencing it or they may have heard of a situation or experienced a loved one that they've had in a nursing home and their experience of retaliation which brings about the fear naturally of individuals going into a long term care facility because of retaliation if they speak up about their care, if they're unsatisfied with something. So this is a valid fear and I think this is why so many people have that fear of going into a nursing home facility.'

When asked to elaborate on the ways in which previous experiences of a loved one in a nursing home may contribute to fear of retaliation among prospective residents, she said, 'I've heard family members disclosed to me, 'Yes, I really didn't want Mama to be in a nursing home because my father was in a nursing home and had a bad experience' and especially a family member is considered a "chronic complainer."'

She added, 'I hate that term. They have a right to complain and so because of that, I see them as strong advocates and because of that, they've experienced some backlash and that negative experience has just bleed over. You tell others about it so there is with many people having a natural fear in going into a nursing home.'

Quote
"I hate that term. They have a right to complain and so because of that, I see them as strong advocates." – Ombudsman representative referring to the term "chronic complainer"

Later she said, 'More so it's the *fear* of possibly experiencing retaliation. Again, as I mentioned earlier, so many people have negative stereotypes about nursing homes…they see those commercials, 'If your loved one has been abused, bla, bla, bla, please call this attorney.' There's already some negative belief about care in a long-term care facility. And also maybe they may have experienced a friend or a loved one that was in a nursing home and has had negligent care. So that fear alone.' She added, 'So unfortunately, you have some residents who may not have support from families or friends. So, just the possibility of if I say something or if I complain, I want to avoid experiencing that so I will not.' I think the fear of potentially experiencing retaliation more so if they have experienced the actual

act. I get more of that…the potential fear of 'I *might* receive retaliation or they might do this to me if I say something.''

She went on to share a **story** about one of her family members who lives with dementia. She said that this individual often has that fear of 'I don't want to go into a nursing home.' One time I asked her, 'Well, what is it? Why do you fear?' 'Well, because they mistreat you. If you say something, they'll abuse you whether it'll be physical or verbal abuse. You know how these nursing homes are, you know how the staff is, if you say something wrong, you've got to work with them.' That's why I say a lot of individuals come in with that concept…not to say that retaliation doesn't happen because it does. But I think the negative perception a lot of times that family members have and residents have plays a big role in not wanting to say anything. And particularly those residents who don't have family support or support from friends or what not. They have to rely on the care of the staff for their needs and their activities of daily living. Because they have to rely on the staff for care, they'd rather not say anything to [avoid] experiencing that retaliation.'

Institution-Centered Culture

Several representatives spoke about an institution-centered culture of care that fosters residents' fear of retaliation and actual retaliation against them. One of them spoke about being institutionalized and prison-like mentality. She explained, 'In our facilities, they are still very much institutionalized. As much as we try so hard to make sure that those residents have a home and feel like they're at home, they are just very much institutionalized and that alone gives a prison-like mentality and it's very scary for them…always. There are not a whole lot of homes where they feel like at home and everybody feels like family, you know, all those things. It's still very institutionalized and any time they have a complaint because of staffing, they fear retaliation. And because of the institutionalization of it all, it is prison-like and there is that mentality that is going on and it's very very hard on those residents.' The representative added, 'The thing with retaliation is that I think oftentimes it's culturally rooted. It's usually something that is rooted either with a staff member performance or with a leadership culture.'

When asked what makes it so that fear has anything to do with care and what are the root causes of residents' fear of retaliation, one SLTCO said, 'Within the building, I think the people that run these places are the ones that actually foster this awful environment. There's something within them and the way that they deal with people.'

When asked for his thoughts about residents' fear of retaliation, another representative said, 'It is a real thing. It does exist. There are understandable reasons for it to exist. These residents are dependent on others for many and in some cases all things and then these

care providers sometimes feel they are in a position of control or power and that they are sometimes empowered to dominate or treat residents however they feel like treating them which in some cases can be abusive. It is a real thing.'

Poor Staffing Levels and Inadequate Training

Several representatives spoke about poor staffing levels, staffing shortages, staff turnover, reliance on external agency and traveling staff, and inadequate staff training (including, among others, on topics such as knowing the residents and their rights; dementia care; understanding, preventing, and safely de-escalating behavioral expressions, and caring for people living with serious mental illness) as factors contributing to residents' fear of staff retaliation when voicing care concerns and filing mistreatment complaints.

During the last minute of one interview, another representative said, 'I loved it that staffing was a central theme here because I think like with almost every other complaint that we deal with, it all comes back to how many and how well trained are they.'

Earlier in the interview, the same representative said, 'We had the Alzheimer's Association here and one of the things they talked about was the need for patience as dementia progresses. That is an *impossibility* in our world because of the way these corporations choose to staff their facilities or budget their staff in facilities and that's going to be a dynamic that continues and gets worse and lead to retaliatory type behavior because working with folks with dementia is very often really tough and it does require patience if you're going to avoid as much as possible triggering folks.'

Extensive support of a relationship between poor staffing levels and residents' fear of retaliation and actual retaliation is described under the segment titled *Poor Staffing Levels* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

Certain Staff Members Do Not Know the People They Care For

One representative said that many care staff members don't know the people they are caring for. He said, 'In the majority of the cases that I go out on, within 30 minutes to an hour and a half, I already know more about that resident than *any* one person within that setting. That's where there's a huge gap…is that we have people that don't know the people that they're caring of [and] the people that are being cared for don't feel as though they really care about them as people.'

When asked about the extent to which staff lack of knowledge of the residents plays into the phenomenon at the center of this project, he said, 'I think that that's probably the most significant aspect of it all.' He explained, 'When people are working in long-term care, the pace in which they're having to execute tasks has become so aggressive that they're

forgetting about the fact that the task is actually being executed on a person and as a result, they forget to even introduce themselves. It might be the first time they've ever been in that person's room and they never even told them what their name was. You walked into someone's house and you never even told them what your name was. Once you step away from this and look at it from a broader perspective of just social life, some of the things that we observe are critically flawed.'

A representative from another state said, 'As you're visiting with a person, you find out about their culture, you find out about their religion…I've prayed with people before because that has been their comfort and that has been their request. I think it is not only do we provide emotional support but we see outside of their door pictures of their family, pictures of their pets, their past profession. You are always trying to find a way to connect with them. When we go in and visit residents, we can go in and visit with many residents in a facility and in a short time learn a lot about them. Then you're reporting it back to the facility staff and they will say, 'Yes, that is happening. Yes, we are doing this to address that. We didn't know that but we will be happy to.' It's amazing what you can find in a little bit of time. I think that is probably in our demeanor with the social work type background…but they feel comfortable with us even though they may be in a not very good facility.'

Resource Box
For a description of 20 reasons why care staff members need to know the early-life history of people living with dementia, see my blog post on *ChangingAging*.

Staff Stress and Frustration

Referring to retaliatory practices, one representative said that staff 'frustrations have come out on residents.' Another representative spoke about the importance of stress management for staff. They said, 'Residents' fear from retaliation is a real thing and it can happen more so if the staff are stressed, if there are low numbers of staff.'

Later in the interview, when asked about characteristics of care homes with less or no fear of retaliation, the representative said, 'They are already thinking…I think they're thinking to lessen stress and things like that and have more staff to boost up their own mental health as well so there will be less retaliation, other abuse, and things like that and accountability.'

Staff Burnout

One representative said, 'I just want to note about the staff side of it…and I know the focus is usually on residents…but it sat with me for like a year now: Why would the staff do that? Why would the staff ever do this? Why? It's a completely controllable action and reaction. Retaliatory actions are controllable. They are in full control of their body when they are doing these actions. So why are they doing them?'

She went on to say, 'And then it leads me to well, they are burned out, the nurses treat them like *crap*, CNAs aren't respected…it's not a respectable job somehow still. You know, this presentation talked about how do we make these jobs more respected, how do we make these CNAs feel more important in a legitimate way, how do we get them more connected to their workplace because they don't feel like the facility cares about them as people, them as workers, and the only way they show care is when they side in a retaliation attempt basically…they're like, 'No, no, no. This resident did this and the staff has rights' or something. I wish there was like a way to kind of look into staff burnout and things that could be done on the end of CNAs to kind of flip their mentality and their workload so that it is not so unrealistic. I think that really really really leads into a lot of retaliation…not all of it.'

The representative tied her observation to the current unprecedented workforce crisis and poor staffing levels in many nursing homes. She also saw a negative correlation between the way CNAs are being treated, cared for, supported, educated, and being appreciated and residents' fear of retaliation and actual retaliation against residents.

'CNAs are treated like dirt'

One representative said, 'I've often wondered…I think CNAs are treated like dirt by 92% of all nursing homes. I think it's that domino effect. You have the corporate regional or the owners and it keeps going down and down…just treating them that way.'

When asked about the extent to which the way staff are treated contributes to the phenomenon at the center of this project, one representative said, 'I think CNA is a hard job. It's a very hard job. And I see residents especially with dementia or sometimes residents who don't have dementia may feel entitled…and residents aren't nice at all times. But I think that this is the job they chose and their Administrators or corporations should be supporting them properly with a quiet room or a quiet area they should go to to be able to decompress. Because I do feel like they get angry because they work too hard or too much and they tend to take it on the residents.'

Towards the end of another interview, when asked whether there's anything I didn't ask about that she thinks is important to recognize about residents' fear of retaliation, one representative said, 'Treating your staff well correlates to treating your residents well.'

Quote
"Treating your staff well correlates to treating your residents well." – Ombudsman representative

I asked a SLTCO this question: To what extent do you think fear of retaliation has to do with the way staff are being treated? Her response was: 'Oh, I think it's that too but…I don't think staff receive enough training…so that's the other thing…there's lack of training and the fact that they don't understand the population. And they don't understand that the staff have to bend and provide person-centered care, which means that the residents aren't always going to be nice because…they're not able to be because they have dementia or they are not nice people but they still have to be respectful.'

She added, 'They don't get paid well. I mean, it's a hard job taking care of people. But it's not framed the right way. It's [missed word] in the worker and how this is an honorable thing. It's also cultural in our society. We don't value old people anyway. I suspect if you go to a nursing home in a culture where older [adults] are valued, the worker is valued because they are *amazing* to do this type of work…even if they are paid a [little], I think most staff would be pretty nice or at least more civil. In our society, I think it's not that way. So I think there's a lot we can do to support the worker and to help them. I think a lot of people can be trained but I also think there needs to be longer periods [of] training and better screening so that you'll screen out some of those people that treat their children like they're this…and so [said while making a hand gesture indicating that it transfers into the care home] and therefore, we can't teach people how to be good human beings and how to be respectful of people…mostly.'

Resource Box
For a roadmap for supporting direct care workers, consult with the fabulous resources developed by PHI (formerly Paraprofessional Healthcare Institute).

Staff Perception of Working in a Hostile Environment

One representative spoke about staff not appreciating working in a “hostile” environment and how it plays into the phenomenon at the center of this project. She said, ‘Sometimes staff cite the fact that they have a right to not work in a hostile work environment and that's kind of where it starts…is that staff feel this way and they just they don't appreciate that residents are like the vulnerable person in this situation because residents are going into nursing homes especially residents come from a place where they more than likely had complete autonomy before they came into the facility and now they're put into this position where they have to rely on strangers for their basic needs to be met and it's just…it's *so* vulnerable. You go into a room and then you don't know *anything*, you don't know even what to do, if you don't have your call light, you don’t even know how to ask for help if you're bed bound, you don't know how the structure of the facility works…it's different than a hospital…it's not the same thing. Most of us have only ever had exposure to a hospital. You push a button and nurses can tell you how to get wherever you need to get or whomever but that's not how it works in nursing homes. So It's an incredibly overwhelming process.’

When asked to elaborate on what makes it a hostile environment in the eyes of staff, she explained, ‘What they will say is residents that they say are yelling at them or residents that may have mental health issues or dementia or Alzheimer's but that they're allowed to have a safe work environment and when residents have “behaviors” [said “behaviors” with hands gesture of quotation marks] that are allegedly not provoked or caused by the behavior of a staff, they retaliate back by not answering [call] lights, not wanting to work with that resident, they demand not to work with them anymore and then management telling us, ‘Well, they have a right to work in a safe work environment. Just because they're a CNA or a nurse in a nursing home doesn't mean that they should tolerate abuse from a resident.’ So sometimes we have that happening and that excuse happening as to *not* code it as retaliation in a conversation between like myself and a facility. They'll say, ‘Well, you know this resident was doing this. There was no reason for him to say those things. He was saying racial slurs. He was doing this.’ So they will pull the staff and then sometimes it creates like a whole myriad of issues of response time, and staff talk to one another, other staff react to that, treat a resident differently, all of that.’

Chapter 5

Forms of Retaliation

Dozens of forms of retaliation were identified by representatives. In general, retaliatory acts by staff and managers against residents spanned a wide range of circumstances, right violations, neglect of care, verbal, psychological, and physical abuse, wrongful involuntary discharges, and hospital 'dumping.'

Sudden Shift in Staff Behavior

One representative said, 'The way staff treats you…it's like, 'I am going to give you the cold shoulder now because you complained about me.' They have a certain shift in their behavior that identifies you're retaliating at times at residents. It's hard to really have a resident say, 'Well, they are showing me the cold shoulder because they don't want me to talk about what happened with one of their friends.' They kind of gang up on a resident and then they start subtle retaliation that way by really just ignoring, not really paying attention to the resident and then they give them that cold shoulder type attitude when they need them. Their behavior spells it out for the resident and the resident knows that something is wrong. The resident kind of gets back in the corner and not understanding why they're treating you like that. However, they're right on the line…they don't cross it…they're on it when they are retaliating in that way. So it's kind of hard whenever that occurs.'

When asked what she meant by 'right on the line,' she explained, 'When they do it 'right on the line,' it's not noticeable. You're not able to see it. The resident feels it but you can't see it. If their behavior has changed without even saying a word to the resident, they can feel it but you can't actually see it. Now, the person that is committing this kind of retaliation, they know exactly what they're doing when they do this and change their behavior toward a resident without saying anything to the resident. It's just on the tip edge of proving that you are doing it. The resident feels it but you can't see it.'

Silent Treatment

This form of retaliation was described by a very experienced representative as 'ignoring a resident's request for assistance.' She explained, 'If a resident requires your assistance, you are ignoring the resident knowing that he or she needs it. Because the resident had complained about you prior, then your approach is to silently retaliate by ignoring that resident's need.'

When asked about common ways staff retaliates against residents, another representative said, 'I think shunning is probably the easiest…ignoring.'

Quote
"Silence is another way to retaliate when they don't say anything." – Ombudsman representative

A representative from another state gave an example, 'Just ignoring. They do their job and not say, 'Good morning.' To me, that's retaliation, 'I just don't want to deal with you.''

Another said, 'I had one resident who told me that staff would be mad at her after she voiced a complaint and they would give her the silent treatment. They'd come in and give her care but they wouldn't say a word to her.'

When asked about the impact of retaliatory silent treatment on residents, she said that they'd feel 'scared, being unsure of where they're at, 'Should I even be here? Do I feel safe here?' I mean so many questions of just not feeling secure.'

Her colleague chimed in and spoke about the potential lingering effects of silent treatment, 'Given the silent treatment, they're already maybe mistrusting of the facility so even if the facility tried to correct or do things the right way, they may still feel like they're being retaliated against because those mistrusts seem to kind of stack up and add up for the resident…they may be real or they may be perceived.'

Another representative described the following scenario: 'The subtle way of retaliation might be a staff member that comes in every morning and provides a simple 'Hello' to a particular resident that lives there. That has been the routine for months…maybe even years. And all of a sudden there's some feedback and it may have either direct or indirectly have to do with that particular resident…bringing it forward and all of sudden that staff member passively just simply not saying good morning anymore. Almost a quasi-social isolization or silent treatment-type of approach. Those types of things are certainly things that come up and we hear about and they are very very difficult to provide much advocacy in because what's the staff member is going to say or are you going to confront them because we're talking about the soft skills of the work that they do and it is so difficult to really manage, engage or capture those cultural elements of soft skills.'

When asked about subtle ways in which staff retaliate against residents, a representative from another state said, 'Zero interaction with the resident. Granted, they have a job to do when they come in…but let's treat them like a human being as well. I feel that doesn't happen at times because they're like, 'Oh geez, last time I said something to you and, well,

you've made a complaint or whatever about it' so now all of a sudden they treat the resident like a piece of garbage.'

Another representative spoke about certain staff who may be 'ignoring a resident after he or she makes racist comments towards staff.'

'Passive defiance'

One representative said, 'This passive aggressive, you know, passive defiance…waiting to go meet someone's needs because they irritated you…because I am the staff member and they complained about me yesterday. I'll show them kind of thing but very passive.'

Facial Expressions and Body Language

One representative spoke about retaliation through facial expressions and body movements and how 'it's not in black and white' but the residents 'feel it, they *know* it.'

A representative from another state said, 'I think the majority of issues can go on with facial things and the residents are perceiving things as well and they are also experiencing things.'

When asked about common ways in which staff retaliates against residents, another representative said, 'Their attitudes…I think I hear a lot from my residents about facial or intonational or even presence, you know, once they finish something, they are out of there. They are not going to have that connection.'

Distinction Between Subtle and Blatant / Obvious / Evident Retaliation

Many representatives reflected on and drew distinctions between subtle and blatant (i.e., more obvious and evident) forms of retaliation. As can be seen from some of the statements presented below, the demarcation line is not always straightforward and clear. For example, retaliation consisting of a slow response to call lights could be done in a subtle or blatant way depending on the circumstances surrounding it (e.g., prior history of doing it) as well as the nature, severity, duration, and mode of delivery. For instance, the delay may be executed using words directly with the resident (e.g., aggressively telling a resident in the face, 'You think *that* was long? Watch me now') versus doing it quietly by simply ignoring that person's bedroom for hours without saying a single word to them.

In the words of one representative, 'Where is the line between blatant and subtle because that 'good morning' might be what one of my residents *thrives on* every day. They're looking forward to seeing that staff member, they make them feel good about themselves, they feel greeted, they're happy that they're there and all of a sudden it just derailed their whole morning because now they're sitting in bed thinking about it. What's subtle to us, subtle to you, might not be subtle to me so there's just a lot of variability with that.'

Quote
"*What's subtle to us, subtle to you, might not be subtle to me so there's just a lot of variability with that.*" – Ombudsman representative

When asked about the distinction between subtle and blatant retaliation, an experienced representative said, 'I would say the subtle would be…and this is how I explain it to staff and residents when I am doing training…subtle would be, 'We used to talk every day. I would see you in the hall and say 'Hey.' Now that you've complained about me, I ignore you, I walk by you.' To me…I explain that when I train staff…If you're in your home and you and your significant other have an argument and you'll talk for a little while. It's uncomfortable, it's stressful. Even though you're not arguing, it's still stressful. And that's stressful for the resident because at one time they had a relationship with you and now you're acting like they don't exist. Would be more of the subtle.' She added, 'Blatant would be any type of abuse but also slower response times, 'You will be my last person to get the medication,' 'You will be the last person at the end of the hall who receives their meal.' That would be blatant. Or refusing to answer call bells.'

In response to the same question, a very experienced representative said, 'The subtle ways would be not coming for incontinent care, 'I'll be *back* if you ring that again' [said while pointing her finger to a resident's face]. That's pretty in your face. Just not coming at all…that's subtle but there's a *large* message there that is loud and clear, 'You mess with me and I am not going to help you.' These kinds of things. And one I see more of recently is that staff does not appear to hold their tongue anymore. They are, 'Look, I am not coming back and *you* better not tell anybody.' So there are many ways and they all surrounding the care they need and not offering assistance when they need it…and direct threats.'

When asked the same question, a very experienced representative from another state said, 'The blunt is getting a discharge notice…looking for something to get this person discharged for…that's way on this end [said while making a hand gesture to her side] and then the everyday kind of thing…if direct care staff know that there's an issue or this person is complaining all the time about them, they're going to be maybe slow to respond, take them to the dining room last, give them their meal last, 'Oh, I just didn't have time to shower you today.' Those are some of the more subtle things that you see.'

One representative spoke about the challenge of proving subtle retaliation, 'One of the problems…a staff member comes to the resident's room, gives them a look or makes a snide comment and there's literally nothing that can be done because it's a 'he said she said.' The facility management…who are they going to believe? A resident or a staff member? In most cases that I've dealt with, they choose the staff member. I think it goes a lot unreported, untracked, and really unaddressed.'

Ombudsman representatives gave the following examples of subtle retaliation:

Taking a long time to respond to requests for assistance; 'Not responding to the call light.'

'Take a long time to get the snack, take a long time to take them to the bathroom. Things like that can be subtle without words'

'Being late with meals, not giving water, and not showing a person dignity and respect.'

'Putting you last with your food tray' and 'they'll just leave the tray there and walk out and don't even assist with helping with anything. They can't cut things up. They can't open packages.'

'I've seen where a resident may be on a special diet or need help eating but they'll just say they don't have time and they're sort of left there with a tray.'

'Not giving them the water that they need or they've asked for.'

'The staff will "forget" to fill up their water jugs…they won't fill their water…that's another form that we see *all* the time.'

'Leaving their urinals full at the bedside by not emptying the urinals sometimes.' When asked if this is done in retaliation sometimes, the representative said, 'Oh yeah. Some of the residents, when I ask if there's anything I can do for them, they'll say, 'Yes. I would like to have a couple more urinals by my bed.' To me, I could never make sense of it at the beginning. You know, 'Why would you need 2 or 3 urinals?' Because they're not emptying them so they want another one.'

When asked how leaving a urinal full of urine at a person's bedside for a long period of time would make a resident feel, the representative said, 'Horrible. I think it makes them feel embarrassed that somebody comes into their room…like myself, I come in to visit and their urinal is sitting there full of their urine. That makes somebody feel horrible.' Her colleague said, 'it's definitely a dignity issue.' She added, 'It can also cause falls because they will get up and try to go to the bathroom. There's usually a reason why they're using a urinal…they are not safe to be mobile…so you will have falls, hospital trips, the whole nine yards because of stuff like that.'

Subtle Retaliation Without Words

As could be seen earlier, some subtle forms of retaliation may be delivered without words such as through body language and facial expressions. Examples include:

One representative said, 'Just your demeanor. If your arms are crossed, your face looks angry, you're not going to want to ask someone something if they look like just mean and nasty and angry.'

Another representative described how staff can retaliate using body language and facial expressions, 'Just by the way of their body language. If you walk in with your arms crossed or your face scrunched up, it's obvious you're in a bad mood. And the residents are already feeling susceptible to a certain point and they are going to see that and they are going to have fear. It's going to be like, 'I don't need anything. I am good. I'll wait. I'm okay.' Because they don't want to have that interaction with the staff.'

When asked about common ways in which staff retaliate against residents, one representative said, 'I think a lot of common ways that we hear about are *non*-verbal. You know, trays being [didn't complete the sentence] or looks on their faces…maybe they seem angry, they've got an attitude, they don't have to say anything and the residents know…they know I've said something or they feel retaliated against because it was soon after that they said something that now the staff is not talking to me, they're not asking how my day went, they come in and take my trash and leave or they'll put my tray out of reach. There are a lot of *non*-verbal ways which are *very hard* to prove. But the residents know…they know when someone has got an attitude with them…they can tell. To me, it's more common ways that we hear about are non-verbal.' She confirmed that non-verbal retaliation can be as intimidating and scary for residents as verbal retaliation.

Quote
"*There are a lot of non-verbal ways which are very hard to prove. But the residents know…they know when someone has got an attitude with them…they can tell*." – Ombudsman representative

When asked about examples of subtle retaliation without words, a representative from another state said, 'If residents are requesting something and it's a resident that they're just not seeing eye to eye with that shift, if they're asking for a snack, they take a long time to get the snack, take a long time to take them to the bathroom, things like that can be subtle without any words.'

When asked whether there's a way for staff to retaliate without words, another representative said, 'Oh sure, body language. Let's say, somebody goes in to bring a meal tray…slamming it down or if they put it out of reach so the resident can't reach it. I've seen…there are people with vision impairment and they can't see where the tray is, where the drink is or the silverware.'

Other representatives gave the following examples of non-verbal retaliatory acts:

'Sighs' and 'lack of care, which doesn't require words. Not giving them or not assisting them with their bath.'

'Either actions or lack of thereof actions. You have a resident who is in the hallway and needs assistance…I've actually seen staff walk by them.'

'Standing over their bed with their hands on their hips. I see that all the time. I have asked staff, '*What* are you doing? What are you doing? Standing over…actually lunge over someone in a wheelchair, I mean, they are right up to their knees.'

'Just the looks. I have residents that tell me, 'Oh my God. If I bring something up, you should see the looks I get from the staff. It's like the daggers…that term 'If looks could kill' like, 'Don't even think about doing anything' or 'I know what you did last time' and I am just going to give you that look.' Oh yeah, staff do not realize how much residents pick up on that.'

Quote
"*Oh my God. If I bring something up, you should see the looks I get from the staff. It's like the daggers.*" – Ombudsman representative quoting a resident

One representative described an incident from the past week, 'Dirty looks, 'Walking in and giving me dirty looks when I ask a basic question or when I ask for a basic thing.' The representative described it as 'the evil eye as my grandmother used to call it.'

Another representative gave an example of staff 'throwing things around the room' and then shared this **story**: 'I had a recent case where the lady needed assistance so she was on her call light and they were busy so they finally took the call light and just threw it across the room. All they did is just walk in, they threw it across the room, and they left. They do it a *lot*. They will just walk in, turn it off, and place it somewhere else by just not saying a word.'

Another representative shared this **story**: 'A resident was sitting on her bed and she was trying to get her socks off. The CNA wanted her to hurry up without saying anything because the CNA went [illustrated moving her head up and to the side with a sigh of frustration while rolling her eyes] because the residents want to remain independent and they should. The CNA got off the chair that she was sitting on in the resident's room, took the resident's both legs, *slid* her over on the bed, and pushed her down in the bed and then put the covers over her (the resident later said that the CNA 'took both my legs and swung them over and shoved me down on the pillow'). The resident was still wearing her socks. The resident told me, 'That CNA just glared at me. Just *glared* at me. I didn't dare say a word. It was almost like, 'Say something.' That is a good example of nonverbal.' Later during the interview, the representative returned to this incident and added, 'Is that retaliation because the resident was taking too long? Sounds like to me.'

Another form of retaliation that can be done without words consists of isolating residents. One representative said: 'Staff can unnecessarily isolate residents especially someone that's loud and vocal and calling out…that is being disturbing to staff while they're charting or doing something else. Especially a resident that can't undo their own wheelchair's breaks. They can put them in a common room and lock their breaks. They can take them down to their own rooms that could be down the hall and remove the call bell, shut the door so they can't hear them…isolate them. That happens.' The representative said that the retaliatory act of putting a resident's breaks on knowing they can't undo them is a form of physical restraints based on Centers for Medicare & Medicaid Services (CMS) definition.

Similarly, a representative from another state said, 'You can take someone in a wheelchair who has mobility issues and put both breaks on so that they can't move.'

Blatant Retaliation

Examples of more blatant acts of retaliation identified by representatives (beyond those described earlier) included threats of retaliation, verbal and physical abuse, involuntary wrongful discharges, and hospital 'dumping.'

When asked to give an example of blatant retaliation, one representative said, 'I think blatant retaliation is when a staff member actually goes up to the resident and says, 'Stop pressing the call lights or I'm going to unplug your oxygen.''

The representative said that it happened in a nursing home and shared this **story**, 'I had a resident tell me that this is what a staff member said…but it's hard to prove.' She said, 'He used oxygen at night because he didn't want to use the CPAP machine [used for sleep apnea]. He felt like he…because he stopped breathing at night…he was supposed to use the CPAP machine. Staff members were upset they had to check on him every two

hours…and he had a tank…and they had to change his oxygen tank every 4 to 6 hours or something like that…so they were upset that they had to do more work.'

When asked how it made the resident feel, she said, 'He was afraid, he was afraid.' She said, 'He told me he was afraid for his life. He was afraid.' She added, 'The end result was having that staff member removed. We didn't tell him what happened with what she exactly said. We just said that he was uncomfortable with the staff member and so we had her removed from helping him…but I did kind of let the administration know how serious the offense was.' She assisted in the process of reassigning this staff member. She said, 'They have a right…if they have a problem with a staff member, they do *not* have to have that staff member help them at all.'

A representative from another state said, 'I think an example of blatant retaliation would be…we see individuals in long-term care who sometimes have mental health issues or intellectual disabilities. They are placed in a general population nursing home or assisted living, but those blatant ones could be, 'We're only going to let you go outside if you don't act a certain way.' Kind of the punishment-reward when really that should never come into play but we experience that and hear that as Ombudsmen.'

She gave an example, 'If they have outbursts or aggression or behaviors. It might be related to their desire to go smoke, it might be related to their desire to go out on the planned activity that week and the staff may say to them, 'You didn't do what you were supposed to do on Tuesday so you can't go out this week' We view that as retaliation because there should not be a reward-punishment sort of system in any facility. We do sometimes see that in the residential care setting because they can have that as part of their Care Plan, behavior intervention plans but we hear about that in nursing homes sometimes and we always say, 'That's not a reason to take something away' or 'Offer them something more.''

Another representative said, 'Some of the more blatant would be notices of discharge, actual mistreatment and yelling at them or talking to them [in a mean way].'

Subtle Retaliation May be More Prevalent Than Blatant / Obvious / Evident Retaliation

While this issue needs to be examined in rigorous quantitative research, preliminary evidence generated from statements made by several representatives suggests that, in general, subtle forms of retaliation may be more prevalent than blatant retaliation.

One representative said, 'I feel like retaliation that is quite subtle is the most prevalent. For example, call lights ignored, completely ignoring them, not answering them, and not changing them…'

Quote
"*The most common ways are tiny and small. It's the eye roll, it's the hands on the hips, 'What do you want this time?' when they walk in the room. It's the extra 20 minutes they're going to take to answer your call light because they're going to show you who is in charge*." – Ombudsman representative

The representative who said that the most common forms of retaliation are 'tiny and small' thought that some of the subtle forms of retaliation could be particularly harmful 'especially for residents who are primarily bedbound and that's a lot.' She explained, 'These residents…they have nothing to do but to lay in that bed and think *all* day. So your off hand rude comment…because maybe you made a complaint last week, that becomes all you think about this week.'

A representative from another state said, 'I see more of the fear around subtle retaliation, which is a lot harder to prove.'

One very experienced representative said, 'I think my concerns are probably about the very very very subtle ways that it's expressed. Whether it's tone of voice, eye contact or lack of eye contact, whether it may just be how someone touches your shoulder as they assist you walking to the bathroom. It can be something about how they close the door to your room when they leave…it's not necessarily have to be slamming a door but there might be something that's expressed in these smallest subtle gestures of everyday interactions between staff and residents.'

She added, 'I think residents have often told me [that] they're so dependent on these individuals for their every need that these really subtle interactions can be really scary to them when someone is appearing upset with them or frustrated by them or unhappy with something they said or did. For me, it's the subtle kind of difficult to document experiences that residents have with caregivers.'

Another representative said, 'It's the little subtle things that they do that are very harmful because it's very disrespectful to the residents. I think that's the most harmful…is when they do little things like that because it's degrading for them…especially residents that have that minimal dementia…they don't understand it and their fear of retaliation is a lot greater than people that don't have dementia.'

A representative from another state said, 'For those individuals who bring their concerns to your attention, the staff are just more likely in general to be dismissive. I would maybe call that the subtle retaliation…like they are not overtly doing something or aggressively doing it but just not catering to that individual along with the meal trays or the call lights, medication pass. I've had an individual who will say, 'I am the last one to get my pain meds' or 'I am the last one to get my meds' or they choose not to honor my request related to medications or treatments as timely as they should.''

Not Meeting Requests for Assistance or Delaying Assistance

When asked about common ways in which staff retaliate against residents, one representative said, 'People can be left for hours waiting for somebody to come and help them and that might even be getting out of bed in the morning and attending activities.'

Other representatives spoke about being slow to respond to residents' requests for assistance, 'Taking your time getting to the resident's room, taking so much time that you're making them soil themselves versus toileting them.'

When asked about common ways staff retaliate against residents, one representative said, 'I would say probably the most common would be the delay in response to request for assistance whether that be care or medications or just request for assistance to be changed or go to the restroom something like that.'

Another representative said, 'I think one of those things we just assume…I realize there are a lot of variations to care or different aspects to the care of an individual but incontinence really strikes me as one of those, you know, retaliation because they will have to toilet the person anyway so we're just going to leave them in the bed and we'll change them when we can get to it type of thing versus making that extra effort. So I feel like they suffer and I don't know if it is always direct retaliation but obviously a lot of times they don't want to take the time to clean things up either correctly.' She added that that is 'definitely' one of those 'subtle signs' of retaliation.

Another representative said, 'Slow to meet the request, 'I am thirsty. Could you please give me some juice?' 'Yeah, I am not your aide. I am going to get you your aide' or 'I'll be back' and then they don't return.'

In this context, it is worth mentioning that one of the most common types of complaints handled by LTCOPs nationwide during fiscal year 2022 was related to 'response time to resident requests for assistance' (U.S. Government Accountability Office report, 2024).

The importance of this finding also stems from the fact that sometimes staff retaliate against residents simply because they make requests for assistance. In the words of one representative, 'The ways the people who work in facilities retaliate against and instill the fear inside residents for speaking up…for even just asking for assistance.'

Study Findings
"The most common types of complaints handled by the [Ombudsman] program in fiscal year 2022 were related to discharge and eviction, response times to resident requests for assistance, and medications." Source: Study by the U.S. Government Accountability Office (2024)

Not Responding to Call Lights or Delays in Responding to Call Lights

When asked about common ways in which staff retaliate against residents, one representative said, 'Ignoring call bells I think is a really big one that staff retaliate against them.'

When asked the same question, a representative from another state said, 'One of the biggest is not answering their call lights…either they just straight up don't come in the room and don't answer it and let it just beep because some panels like they'll beep after you have it on a certain amount of time. There's a panel in the hallway by the nurses station normally and that'll beep after I think like 20 minutes or 30 minutes and they're immune to hearing it, it doesn't even bother the staff…they're so used to hearing this chirping so they'll just let it go and go and go.'

When asked the same question, another representative said, 'We've noticed intentionally being slow responding to call lights…so a lot of subtle ways and again hard to prove.'

When asked about common ways in which staff retaliates against residents, a representative from another state said, 'I would say slower response time with call lights, attitudes from staff, staff gossiping about the resident complaining and then now you have *several* staff members that dislike that resident. Slower time in receiving medications as well as meals and then threatening to discharge a resident.'

Moving Call Light Out of Reach

Representatives described a practice where staff move the call lights out of a resident's reach or hide it. One of them said, 'They will also hide their call lights. They will make sure their call lights are *not* reachable. A *lot* of times, that would be retaliation if you have

someone who is not mobile that has complained about something or if they hit their call light ‘too much,’ they’ll hide it from them. That’s retaliation too.’

Another representative said, ‘It's more of a passive way like not putting a call light within the reach of the resident whether it be clipped to a shirt or a blanket. If it’s across the room and that resident can’t self-propel themselves to that…to push the button, to call for help that, to me, is retaliation because is somebody is a “frequent pusher” [said with hands’ gesture indicating quotation marks] of the call bell, and the staff is tired of coming down or whatever, then it becomes an issue. Well, if I just put the call bell on the floor and they are in bed and they can’t reach it, now they can’t call for help.’

When asked how this practice would make a resident feel, she said, ‘Horrible. Horrible. There’s a lot of anxiety, fear, there’s concern that they know when they need help or know that they need something and they are not able to get it. Even if they would verbally call out, ‘Help. Help me. I need help,’ if the door is shut and the staff don’t want to deal with it, they can just walk on by.’

She added, ‘A lot of the residents who are alert and oriented know there’s no tracking system for the call light system so if there’s no internal computer program that does what I would call Call Light Audit, you know, you’re looking at a database that says during this hour, we had this many call lights on. If there is nothing like that, then staff know, ‘Well, there’s nothing for me to get in trouble for.’ If the call light is not on, I don’t get in trouble as an employee because I didn’t respond within so many minutes. So if I put the call light on the floor and they can’t reach it, then that makes my job easier.’

She said, ‘So residents have that fear of not being able to get the help I need. And that for them is perceived as retaliation because if the staff even says once to them, and it kind of depends on the person and their temperament, but if they say, ‘Well, what do you need now?’ [said with an irritated tone of voice] or ‘You know what, you pushed your call like three times this hour’ [said in a stern and frustrated tone of voice] or something to that effect, then again it's perceived that, ‘Well, if I press the call light too many times, they won't come so I'll just wait and only do it when I *absolutely* have to.’ And again, that's a form of passiveness and in the sense of I don't know that staff are looking at one resident like ‘I don't want to care for that person today’ or whatever, it's maybe they're overwhelmed, they're dealing with 20 residents and all their needs or whatever their staffing ratio is and it comes out maybe as a flippant answer or flippant statement but maybe not the intention to harm the resident but it puts the fear in them that they can't ask for help and if the call light is not within reach or so that they have to verbalize or call out to someone and they're at the end of the hall…let's say they are the last room on a *long* hallway of let's say 20 rooms, ‘Well ‘they're never gonna get to me so I'm not going to do anything until I *absolutely* have

to' or they're in excruciating pain or they need personal care…maybe going to the bathroom or something of that nature because they're fearful of the verbal response they're going to get for that request.'

Another representative explained why sometimes residents push the call lights multiple times in a short period of time, 'They're pushing that call light four or five times because of their perception of time. It could be 10, 15 minutes but to them it could be an hour, an hour and a half because they're soiled. They want to be changed [or] they want to get up.'

Story
'Please Help Me Lord'
A description of an incident that occurred several years ago (Michael & Lyden, 2021): A 90-year-old resident with Alzheimer's disease was living in a 'memory care' unit of an assisted living residence. One evening, while lying in her bed she called for staff help 99 times over 39 minutes. Nobody came to assist her. Then, around 8:30pm, she fell off her bed. While lying on the floor, she continued to call and cry out for help for 143 times (including multiple loud banging on the bed rail using her small wooden cross). At some point she cried out, 'Please help me Lord.' Nobody came to assist her. In total, she called and cried out for help 242 times over the course of an hour and 38 minutes. Staff came to assist her only after her daughter saw the incident remotely on a hidden camera and alerted them to the fall. An aide asked her, 'Were you calling for help?' When the family showed staff the video of the fall, their response, as reported by another daughter, was, 'This is the assisted living model. If she was at home and had hired another home health group to come in, she would have experienced the same thing.' This daughter reported that a similar incident occurred a month earlier and that the assisted living 'has done nothing to make improvements' to prevent her mother's second fall off her bed and provide a timely response. The daughter wrote that without the hidden camera, the family wouldn't have known what happened to her mother.

Turning Call Light Off and Leaving

Several representatives said that certain staff may come into the resident's bedroom, turn off the call light, and leave without providing care. One of them said, 'The other big one that I hear all the time and saw it as a local Ombudsman as well is a resident ringing the call bell…they obviously need something, staff coming in, turning that call bell off saying, 'I'll be right back' and then not coming back."

Another representative said, ‘A subtle way would be to come in and turn the call light off and say, ‘Oh, I’ll be back’ with no intention of going back to help that resident.’

Another representative said, ‘Some of the things I've seen are if a resident rings their call bell and they may be what staff considered troublesome, they'll walk into the room shut it off and leave because they might not want to deal with them.’

One representative said, ‘A lot of times when they’ll come in and they’ll turn off those lights without even saying, ‘Is there something I can help you really quickly? or if not, ‘I’ll be back. I am caring for another resident’ but they don’t do that, which is so disrespectful, you know, they just turn off the light and they disappear and they don’t ever come back.’

An representative from another state said that some care homes ‘have a system where staff have figured out that they can remotely turn off the [call] light.’

Not Responding to Residents’ Phone Calls

One representative described another way in which staff retaliate against residents, ‘They won't answer phones. If you have a cell phone or a room phone and you call the nurses station, they’ll screen the call, they won't answer, they'll pick it up and hang up.’ She shared this **story**: ‘I have a resident…he has a cell phone….he will call the main number of the nursing home when they’re not answering his [call] light. He will call the main number and then they send him up to the nurse’s station but they have caller ID and they know it’s him. Sometimes he will have a girlfriend call but they’re going to soon learn her numbers, they will screen her too and either let it ring because they’re “not there” [said with hand gesture indicating quotation marks] or they’ll pick it up and put it back down.’ When asked whether this is done in a retaliatory way, she confirmed that it is and added, ‘I can’t prove it but yes, that’s what he tells me.’

She said, ‘A lot of times if residents themselves do not receive a response, they do have family call. They’ll call their family and they’ll say, ‘I can’t get anyone to answer and I need help.’ Then their family will call and usually that gets through to someone.’ She added, ‘We’ve experienced as Ombudsmen that our calls get screened. They know our numbers so they don’t pick up but if we call from a different number, they’ll pick up…so it does happen. It absolutely happens.’

‘*Disrespecting boundaries’*

One representative said, ‘Staff is knocking and opening the door at the same time. They’re not waiting for a response. Is it a matter of training or is it a matter of retaliation? You don’t really know until you get into what’s going on.’

Leaving Bedroom Door Open at Night

One representative described what she called 'very overt' retaliation against a resident who is 'very physically dependent' and 'bedbound' but cognitively intact. She said, 'They'll leave his door open at night and because he can't shut it, he has trouble sleeping.' The representative said that this resident wanted his bedroom door shut at night.

When asked why staff left this resident's bedroom door open, she said, 'A lot of residents want their door shut at night…one, because the hallway lights are always on…they deem them or they are supposed to deem them after a certain time but there's still enough light that, you know, nurses can see and read medications and stuff. There's also the noise at night because some residents kind of yell out, there might be phone calls in the middle of the night…that kind of stuff…shuffling around, residents coming out needing to talk to nurses about stuff…so there's some noise level so a lot of residents want it shut.'

Retaliatory 'Neglect of Care'

Considering the above descriptions of retaliation such as not responding or delays in responding to residents' requests for assistance with basic care needs, it will not come as a surprise that representatives identified 'neglect in care' as a common form of retaliation.

One of them said, 'One of the most common ways is that neglect of care.'

When asked about common ways in which staff retaliate against residents, a very experienced representative said, 'Just refusing to help. Incontinent care…when they don't come for hours and hours and hours. That is retaliation…you know, it's retaliation.'

When asked the same question, another representative said, 'It might be not getting that bath that week.' A representative from another state spoke about being 'purposely targeted' by not providing assistance with showers.'

Another representative said, 'We've seen where you have a resident who wants to be showered every other day or whatever they want to be showered and they're constantly told, 'Oh, we can't get to it today. We don't have enough staff' or 'We don't have time.' We see things like that happen.'

Pretending to Forget Their Food

One representative spoke about how in retaliation, staff members pretend to forget bringing food to residents. She said that they'll say, 'Oh, did I forget your desert?' or being untruthful about food.

Another said, ‘I heard them go back into the kitchen purposely and then come back to the resident and say, ‘Yeah, they didn’t have any more lemon pie. That’s too bad’ The representative said that this was done in retaliation and added, ‘Not for *that* resident.’

Food Tray-related Retaliation

One representative identified a form of subtle retaliation that happens when staff members are ‘not picking up the resident’s tray’ and then ‘saying they forgot.’

Another said, ‘We’ve seen that if you get a room tray, not getting what you’ve ordered on there or if you ask for something else, they’re not going to bring it back or if your food is cold, they are not going to warm it up…they’ll say, ‘This is what you got. You’ve got to eat it.’’

Hearing Aids-related Retaliation

One representative said that another form of retaliation has to do with ‘batteries for their hearing aids. They will purposely say, ‘You don’t have batteries. There’s not enough battery. Those are too expensive. What do you need to hear anyway?’’ When asked about the impact of this form of retaliation on residents, the representative said, ‘It’s just belittling them and it makes it even more isolating, especially with hearing. I think it’s very isolating.’

Medication-related Retaliation

One representative said, ‘I’ve had residents complain of…they feel like their medicine were missed or messed up in some way as retaliation.’

Another said, ‘Medication discrepancy, withholding medication, waiting…being skipped over and then returning to the resident the last person.’

A representative from another state said, ‘It could be somebody asking for their pain medication and the RN or the LPN…the licensed staff that dispensed that being demeaning to them, being degrading to them saying, ‘Well, you can’t have it now. You’ve got to wait two more hours.’ If that’s what it’s prescribed or whatever. When I say retaliating against them, making them feel like or the perception is that they are some drug seeking individual who has an addiction when that is not true. When you have chronic pain, you really need an intervention pretty timely.’

This latter representative went on to describe her role in addressing these situations, ‘Our perspective is if the doctor has ordered the pain medication…say every six hours just as an example, we would go in and help them advocate, ‘Okay, this is not working. We need something for breakthrough pain. We need some other resources whereas the staff is like, ‘Well, we can’t have a pain pill until noon’ or whatever the time is.’

She explained, 'It's kind of flipping, it's dismissive and again, that retaliation comes in the form of that almost passive dismissal of that person. Then the resident gets to the point where they say, 'I am not going to even ask because she won't give it to me' or 'She'll hustle me about it by me asking.' Hustle meaning give me grief….talk to me in a tone that's degrading.' She added, 'The nurse dispensing the medication would give them grief about it. They would treat them in a degrading tone of voice or the word they're choosing would be degrading and this person feels like they're a nuisance or bother for continuing to ask for that pain medication. That is to me part of the retaliation…it seems like staff would just assume that this person is just drug seeking when it may not be the case.'

Administering Antipsychotic Medications

When asked about unique challenges related to residents in mid-to-late stages of dementia, one representative said that certain staff members retaliate against these individuals by giving them antipsychotic medications when they engage in behavioral expressions. She said, 'All the nursing home do to get rid of the behavior is *medicate*. Sometimes there's adverse reaction to the medication so I feel like retaliatory practices is also medicating residents because that's a restraint and I think a lot of our nursing homes they do that. They give medication to residents with dementia to keep them calm or sleep or not being able to speak.' She said that she considers this practice of inappropriate use of antipsychotic medications as a form of chemical restraint. She added, 'Chemical restraining is big with dementia.'

She restated that this practice is done in retaliation against residents with dementia 'to keep them quiet. I've heard, 'We're going to put you to sleep.' Residents could be walking and talking one day and you come the next day and there is slob coming out their mouth, drooling, and they're down. You *know* they are overmedicated. They'll say, 'I am going to give you a medication so you can go to sleep.' They put it in apple sauce, different stuff…even when the resident doesn't want it. But it's for their benefit, not the resident's.'

When asked whether sometimes providers retaliate against residents with dementia by inappropriately giving them antipsychotic medications, another representative said, 'I wouldn't formulate conclusion on that. Is it a question worth asking? Absolutely. I think that's kind of our problem-solving formula in Western medicine right now. It's, 'Just add some pharmacologics on it' rather than look at the root of the issue or help people gain coping mechanisms. I see that in a lot of our healthcare direction.'

To learn about inappropriate and harmful use of antipsychotic medications with nursing home residents living with dementia, see the Human Rights Watch's report titled '*They Want Docile*.'

Resource Box
Fact Sheet
"Difficult" is not a diagnosis. What to do when your loved one is pushed to take antipsychotic medications. Fact Sheet developed by The National Consumer Voice for Quality Long-Term Care

Verbal Retaliation

One representative said, 'Some staff will say disparaging remarks. For instance, if they're upset that a resident did express a grievance or they reported against that particular staff member, it's not uncommon sometimes for them to say some disparaging remarks.'

Other representatives spoke about retaliation in the forms of being rude, demeaning ('So demeaning'), being mean (e.g., 'Saying mean things and saying they're joking'), and making the resident feel awful. Detailed examples are presented here:

Another representative said, 'I don't know if we want to call them verbal assaults but sarcastic comments or belittling of people.'

One representative said, 'They belittle the resident in the hallways or in their rooms. Subtle would be in the hallway and more blatant would be in the rooms where no one else can hear it.'

When asked about common forms of retaliation against residents, another representative said, 'They're pretty good about belittling the residents, like, 'Oh, it's you…always on the call light. I can't go deal with someone else because I've got to deal with you.'

The representative went on to share this **story**, 'I just recently dealt with an issue where the resident put their call lights on and staff came in and said, 'You would make my job so much easier if you pee in your brief.' And the resident was like, 'I still have the functioning. I need assistance to get onto the toilet but I can still go…I don't need to go in my briefs if possible.' So just a lot of being rude, make the residents feel just awful.'

One representative said, 'I think some staff just the language and the tone that they use with residents or just flat out make rude comments or things like that I've seen staff not provide care because it may take a little more time or they may be a little more resistant.'

Another representative said staff retaliates by 'not showing a person dignity and respect.'

'Gaslighting'

One representative identified 'gaslighting' as a form of retaliation. When asked to give an example, she said, 'He refused.' Her colleague added, 'He refused to do that.'

She shared this **story** about one a resident she serves: 'I've actually stood outside [the resident's bedroom]. I will be like, 'Oh, I know it's shower day.' So I'll see a staff member go in and I will run up there to hear and she basically said, 'Your shower will have to be changed to another day and time' and then she came out and I said, 'Oh, I was going to see Joe [pseudonym] but is it shower today?' And the staff said, 'Oh no, he just refused.'' The representative described it as an 'outright lie. And then I will go in there and say, 'Joe, did you want your shower today?' And he'll say, 'Yeah.' And the aide will tell the resident, 'Well, you just told me, '*No*.' I think you have dementia. I think you don't remember things.' That kind of stuff…to really turn it to the resident…turn it on them.' The representative described this practice as, 'It is an abuse of power. Every day.'

The practice of untruthfully documenting that residents refuse care is addressed under the segment titled *Poor Documentation Practices and Unreliable Reporting to State Survey Agency* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

"*Elderspeak*"

'Elderspeak' communication style was identified as another form of verbal retaliation. One representative described staff 'ways to disrespect' residents when calling them 'sweety' and 'honey' and things like that. It's routine with some staff members but I think that it can also be a way to retaliate against a person depending on the inflections you use when you say things.'

Resource Box
“Elderspeak”
Professor Williams et al. (2003, 2009) state that **“Elderspeak” communication style includes** ‘patronizing, baby talk (“Hey baby”), infantilizing, diminutives (inappropriately intimate and childish nominal references (“Honey” “Good girl” “Hey little girl”), controlling, dominating, & bossy speech.’ The researchers state that “Elderspeak” ‘is **perceived** by older adults **as demeaning** and may negatively impact their sense of personhood and self-esteem.’ In contrast, emotional tone of speech includes caring (warmth, support) and respect (polite, respectful, and non-patronizing). The study by Williams et al. (2009) used video recordings of 80 staff-resident interactions during personal care in 3 dementia care homes (52 care staff members and 20 residents were videotaped). The video clips were analyzed frame-by-frame. Results showed that ‘the likelihood of resistance to care was found to be greater following use of elderspeak communication compared to normal talk or silence.’ The study suggests that ‘elderspeak communication may be heard and understood by persons with dementia who may respond with resistance to care to indicate their unmet need for less patronizing, adult communication.’ In addition, an intervention study by Williams et al. (2003) evaluated a Certified Nursing Assistants’ education program. It showed a reduction in elderspeak communication style among these care employees. For a review of studies on the use of “Elderspeak” and its effects on people living with dementia (including how it decreases their self-esteem, produces negative feelings, agitation, aggression and leads to resistiveness to care), see Zhang et al. (2020).

Confronting Residents After Speaking Up

The retaliatory practice of confronting residents (sometimes aggressively and/or with threats) after they speak up about or report their care concerns has been reported in prior research (Caspi, 2024).

A few representatives described this practice in detail. One of them said, ‘I have a facility where if they complain to management…they follow those channels, they complain about a staff, the staff that they complained about will come to them and confront them and say [in a frustrated or angry tone of voice], ‘Why did you complain about me?’ to quote, ‘Why are you spreading lies about me?’ Then, the next time they have to help them, they’re like really huffy and rough…like not talking to them and just moving really fast.’

The representative went on to share a **story** about a recent incident, ‘A CNA got fired for that after the state [State Survey Agency] came in.’ She added that the surveyors ‘went in and verified that there was abuse because of that…like staff coming back and confronting her and then being rough with wheeling her to the bathroom and stuff…so they did fire her.’

Another representative said, ‘There's also verbal and nonverbal bullying that can occur where staff will come right out and say things that aren't nice or condescending or sort of putting a resident in their place and even nonverbal where they just come in and maybe not say anything and just be kind of rude by just being quiet and noncommunicative and not having interpersonal reactions or communications with the resident.’ He said that these actions can be done in retaliation and went on to explain, ‘Because they know that maybe something was said about them and they’ll come back and actually say, ‘Hey, I heard you said something about me.’ They’ll either be direct or indirect and just be not pleasant with them as the reaction to hearing about them.’

A very experienced representative from another state said, ‘They take your call bell away and say, ‘Don’t ring this again.’ She added, ‘Some of them are very brazen and will get directly in your face and tell them, ‘You better not ring that light again.’’

Telling Residents to Expect Retaliation

One representative said that some staff will flat out tell residents that they are going to experience retaliation, ‘I’ve had residents tell me that staff will straight up tell them, ‘Now I am not going to help you. Now you’ll have to sit there and wait’ and they’ll leave. Their call bell will go off and they will not come back for hours.’

Threats of Retaliation

Representatives said that certain staff make threats of retaliation against residents. One very experienced representative spoke about ‘Outright threats’ as a form for retaliation.

A representative from another state said, ‘Saying things like [whispering], ‘You better watch it.’ Staff saying that to a resident, ‘You better watch it.’’

Another representative quoted staff making the following threat, ‘Anybody who complains about their roommate has to move.’

A very experienced representative said, ‘I don’t know if I can actually say I’ve witnessed retaliation but here is one thing…a resident goes and complains to the Administration or say something and their response is, ‘If you don’t like it here, we’ll help you find another place to live.’ Can we prove that happened? *No.* Do I think it has happened? *Yes*. I do.’ When asked if this is something that a resident told her, she said, ‘Yeah, they convey that they’re scared to speak up…afraid they will have to find another place to live.’

A SLTCO shared this **story**: ‘We had a small assisted living where the Administrator was a real jerk. She was telling the residents she was going to throw them out if they didn’t do this…if they didn’t do that. They were afraid. We got a call from an outside agency and we reported them to the Health Department and we went up to the Administrator and said, ‘We

know you're intimidating these residents. We know you're threatening to throw them out if they don't do exactly what you want' so it stopped. It took about three or four visits and a couple of agencies before it really happened.'

When asked what underlies the threats, she said, 'This was complaints about the food, if you're turning around and say you're not getting the care that you're supposed to get, if you complain about how your checks are being distributed…all the aspects an assisted living would have. She wanted a total control of those residents.' She added, 'I knew her from before. She was at another facility and got fired for the same behavior, so it wasn't a surprise to me that she was doing it. And she doesn't like me so when I showed up, she wasn't really happy.'

Another representative said, 'The retaliation and threat. 'If you have bad behaviors, we're going to send you out. We're going to send you out to a behavioral facility.' That is very very scary for our residents whether they have dementia, whether they have schizophrenia or if they have nothing. The fear of being sent out for behaviors is *real*. And when they get to those facilities, they usually use some type of medication to make them 'feel better'…I don't know, whatever they do. It reminds me maybe in the 1950s when you went to an institution and got electric treatments for your behaviors….We're *still* there and that needs to be changed. That's horrible.' She added that sometimes they don't let them back to the care home. Her colleague added, 'They'll just send them out and that was their intention to send them out and not let them come back.'

When asked what these residents are fearful of when they receive those threats, the first representative said, 'That they are going to drug them.' Her colleague added, 'Yeah. The psychotropic drugs. I was just going to say that exact same thing. Yeah, that's what they're afraid of.' She added that they'll give them medications 'that isn't the answer and then they'll bring them back and then there's no other medication. They don't deal with the issue, if there is really an issue.' The first representative said, 'So many times we'll ask them, 'We're Ombudsman, we don't have medical degrees but we will say, 'Did you check them for a UTI?' [And The'll say], 'Uh, no.' Nine times out of ten that'll be what's causing it.'

Race-based Staff-to-Resident Retaliation

While research has shown that racist slurs by residents towards staff in LTC homes is a serious problem (Nerayo et al. 2023), race-based staff-to-resident retaliation also occurs.

One representative shared this **story**: 'I did a Dignity and Respect complaint that was obviously retaliatory as well where my client was called a honky on some [day of week de-identified] night when he was asking for medications in the hallway. This was a White resident and African American staff member.'

Later in the interview he said that this case was ‘successfully resolved. I did a Resident Rights In-Service…I asked for a Resident Rights In-Service with a focus on derogatory racial terms…We did a Resident Rights In-Service and I made sure…not to address it so much in explicit context because the staff at this facility are predominantly Black. The way I approached the issue was more from the other hand and said, ‘Look, I know that there’s a tension point with residents’ right to dignity and respect when you folks are getting called any number of racial slurs and so we addressed it in a roundabout…is not the right way but I tend to choose non-confrontational ways to address things like that. The reason is any facility that is poorly performing for a lack of a better way to put it…is typically also pretty sensitive I found out. So what I do is I come at them in a way that they’ll be able to swallow the information so that one I felt really good about.’

A representative from another state shared a **story** about a White staff member singling out an African American resident, ‘We have a few now…especially when going into the rural areas. You'll see more of that in the rural areas. I had a case where the resident’s trays weren't being picked up but the resident’s roommate tray would get picked up. Then more investigation showed that the staff member is just singling out people by their race.’

She added, ‘I hear that all the time that with the racism that African American residents [experience], they are pretty much the minority in a lot of the places and they feel like they're not being treated equally or their voices aren't heard. I've even had where one assisted living place they do everything…they do every holiday but they didn't put anything up for like Martin Luther King Day…so yeah, and that was the first time I've ever heard that and I went in and we’ve seen it…we looked on the boards and we're like what's going on.’ When asked what she thinks underlies that, she said, ‘Racism.’

When asked for her thoughts regarding race-based staff-to-resident retaliation, another representative said, ‘I live in the South…not that that really is important…and we’ve come a long way but I look at the older generation…I guess the Baby Boomers or those…and how they lived…it was very common for segregation…they lived in a time of segregation…so anger that is expressed and particularly from residents to staff, the staff of course…we learned that we have to accept that…well, this is generationally come from. So a lot of time education and re-direction towards that resident, ‘Well, we don’t do this. We don’t discriminate. This is what we should say.’’

She added, ‘Fortunately, I have not witnessed a lot of racist discrimination from staff to residents and I am very happy to say that. She went on to share a **story**, ‘I think I witnessed one incident and this resident was in assisted living and she was an African American resident. Now, unfortunately, in your assisted living facilities, because they are private pay, you really don’t see a lot of African Americans or people of color in the assisted living

facilities. But in this one case, the resident complained that she was not receiving the same type of care or monitoring of service as the other Caucasian residents. She expressed that to me, she expressed certain staff members that she felt were *targeting* her.' It was White staff who targeted this African American resident.

The representative went on to describe how she handled it, 'I was able to address that with the executive director. A week or two later, her family member made contact with me and stated that I understand that my sister reached out to you with some concerns and I felt that it made the situation worse and she mentioned that the Administrator approached the resident, 'Why would you say something like that?' and so she recognized that the care was *worse*. To make the long story short, I did have the opportunity to educate and to do a one-on-one In-Service with the administration to let him know that it was the resident's right to be able to live in an environment that's free of discrimination and also it is her right to be able to express a grievance without fear or receiving retaliation and if this continues, then, of course, we will take other measures…I will consult with my State Ombudsman and if we have to report it to the Alabama Department of Public health or whatnot regardless. The actions did cease and so I was able to get that point across to the administration.'

When asked about the end outcome of her intervention in terms of the discrimination and the questioning as to why the resident reached out to the representative, she said, 'I can say that the corporate office did get wind of the actions of the Administrator also and there was some disciplinary action with that. I was glad that they came. They also got involved. I believe that the family member of the resident also reached out to the corporate office and so I was happy in their response and they handled the situation. They did provide some disciplinary action to the Administrator and stated, 'This is not going to be tolerated. If we hear one more incident of it, then you know.' It did not. Needless to say, the Administrator I think she stayed for another month and then left her position as Administrator.'

She added, 'But I never forgot that case because I normally…in many of my facilities the administration, staff, I have not seen any type of discrimination and I'm just really proud to say that the staff in most facilities are very open…diversity and they know very well that diversity is something that they accept and they should accept for all individuals.'

A representative from another state shared this **story**: After a White resident called African American care staff members 'blackbirds,' 'they started ignoring her. That was more or less like, 'I don't want to provide services to you because of how you feel about us. Why do you need us to take care of you in you talking to us in that manner?' One CNA decided that she wasn't going to take care of the resident's personal needs because of how the resident felt. 'She was ultimately terminated. They terminated her for the simple fact that she derelict in her duties to take care of him and allowing him to lie there and be soiled for long periods of

time because he didn't want any African Americans to take care of him. She didn't do her job. She was responsible for it even though he didn't want her to do it. She was still charged with doing it. She wouldn't even make an attempt so she was terminated for that.'

When asked whether she sees staff-to-resident racist retaliation, a representative from another state said, 'More of that from resident to staff but I will say…if a resident says something racially charged like offensive, that staff reacts…not all of them but they do react negatively then to that resident. I have seen that. I have not been told. I don't think in my recent memory of it being the other way.'

When asked for her thoughts about race-based staff-to-resident retaliation, another representative said, 'It's more resident-to-aide or provider. We are strongly ethnic community. We have our Italian, our Polish and some of the old girls and guys are still uncomfortable with other ethnicities working with them. So we get calls or complaints from the facilities…they're using [missed word] or derogatory comments' towards staff. So that's more than the other way so far. I don't see much going the other way.'

For a description of a disturbing incident in which a White CNA in a rural care home went into the bedrooms of two African American residents and showed them his hangman noose tattoo (a lynching scene) on his arm, see the segment titled *Lack of Oversight and Enforcement of Harmful Retaliation* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

Physical Retaliation

Representatives identified staff acts they considered to be physical retaliation in response to residents speaking up about care concerns.

One of them said, 'The way they move around all the more heavy with their actions.'

Another said, 'Where a staff member is alleged to be handling somebody roughly or impatiently or being very snide and short…clearly changing their bedside manners.'

A representative from another state said, 'Being rough with transfers. It may not be overt abuse, but they move a little quicker, they are a little harsher with those movements, they may not be friendly when they're doing that…frown on their face…all of those things are things that residents report where they feel like 'they don't like me because they look mean and they're pushing me and rushing me and it hurts.' Those things are a little harder to prove certainly.'

When asked about common ways in which staff retaliate against residents, another representative said, 'The one that stands out to me is rough care. There's something they do and this happened in one of the facilities. They do this almost like grab the skin and burn

it. It's almost like when they're wiping them, they wipe so hard that they harm the resident and that's retaliatory practice.'

When asked what made the staff retaliate against this resident, she shared a **story** about one resident, 'Because she called on how abusive they were in that facility. She was like a whistleblower on all the corruption and the different things that were happening at that facility. And she talked openly. She was very verbal. She was pointing fingers and who it was and so the nurses and aides just ganged in retaliatory practices. She was almost total care. She couldn't clean herself. They had to clean her and when they cleaned her, they would almost scrape her somehow.'

One representative said that residents may also be slapped or dropped on the floor on purpose during transfer. She added that she never had proof that these forms of retaliation occurred.

Another representative said, 'I had a resident where she would be complaining or yelling…I've just seen a lot of it where residents who need more help and some staff get upset with that and there will be a mark that wasn't there a day before and they don't know where it came from or the resident would fall…residents who are fall risk but they would fall and they would come into the restroom when they weren't supposed to [and] the resident would fall…because they get up and try to get there on their own.'

In accordance, a representative from another state said that signs of physical retaliation may include 'bruises and marks on the resident.' In accordance, another representative said that sometimes 'bruises on the residents' could be a sign of retaliation.

One representative shared a **story** where an aide used physically abusive retaliation against a woman in late-stage dementia. Video footage from a camera installed by the family in her bedroom showed how an aide intentionally ran over her foot with a wheelchair after the aide asked her to move and she didn't. The abusive act caused the resident to cry. The representative said, 'I am sure it was very painful.'

The husband 'had capacity but he needed physical help.' The wife 'could physically get around.' The incident took place in their living room. An aide came to help the husband go to the bathroom. The aide was very disrespectful to the wife.

She said, 'I could tell by listening to the video that she had no patience with the wife at all…no patience at all…just very disrespectful, telling her to get out of the room, she needs to back up, she needs to move away, 'I kept telling her to back up' and just very harsh. And when she got the resident up because the spouse did not move, she took the [husband's] wheelchair and ran over her foot.' She added, 'As the aide was taking the husband to the bathroom, the aide kept saying to her, 'I told you to get out, I told you to back up.' It was *so*

disrespectful.' She said that 'the husband had called the family that day…and said, 'This took place. Can you watch the video?''

She added, 'When I went to view the living room, everything was exactly the same as in the video, there was *plenty* of room for her to get around but that was truly a retaliatory situation. She had a good five or six feet between the chair and the TV to get around. It was very much intentional and not apologetic at all. She did not even check on the resident and you can hear the resident just crying in the video. It was absolutely intentional.' She added, 'Thankfully, the staff member was let go but it was absolutely intentional. You could tell just from the start of the video to the end of the video, she had no patience with this resident.'

She went on to say, 'The daughter has reached out to me because of some other situation that was going on and she sent me these videos and I was a little taken back. By the time I saw the video, the staff member has already been terminated. As soon as she saw the video, she immediately went to management about it.' She said that by the time she got involved, 'management thankfully already taken care of the situation.'

She reflected on the incident: 'As Ombudsmen, we first and foremost want to make sure the residents feel safe in their home. By removing that staff member, that was first of all the first way of making them feel safe.'

She added, 'But then also what I did is I went and talked to other residents ('making sure no one else had experienced something like that'), 'Have you ever had a staff member that was disrespectful to you? That was a little rough with you? That you feel like they weren't listening to you?' Just talking to people in that generalized area of where that room was to make sure…and just educating them that this is their home, they should feel safe in their home, they should not feel afraid of other staff members. As an Ombudsman, our role is to advocate and make sure that they understand resident rights, that they have a right to feel safe currently with where they live.'

Abusive physical retaliation can also occur when a resident such as those in advanced stages of dementia do 'literally nothing.' One representative shared a **story** (the incident was caught on a video camera) about a resident living in an assisted living 'memory care' who 'lacked capacity' and was abused in a retaliatory way by an aide.'

She described what happened, 'The resident was in bed. The staff said, 'Hey, Mrs. so and so. I am here to wake you up.' And the resident was just staring at her for a few seconds. The resident 'was not responding, not doing anything, very typical manifestation.' In response, the aide said to the resident, 'Why do you look at me with that damn ass look on your face?' And very quickly from there it escalated. The aide 'started throwing poise pads ['like penny liners for urinary incontinence'] at her face. The woman pulled back and the aide who was

three to four feet away 'gave her three or four more hits with the pads.' When asked whether the woman did anything that triggered this abusive response, he said, 'Literally nothing.'

For detailed examples of physical abuse in the form of "Reflexive" retaliation against residents during provision of personal care, see segment titled *"Reflexive" Retaliation Against Residents Living in Advanced Stages of Dementia* under the heading Challenges Related to Residents with Dementia – Especially Those in Mid-to-late Stages in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

Simultaneous Retaliation by Multiple Staff Members

Representatives spoke about retaliatory practices committed against a resident or residents by several staff members simultaneously. For example, one of them said, 'I've also noticed that they all gang up too. You report one aide, the entire unit or the entire shift will retaliate against you.'

She went on to share a **story**, 'I had a resident who became close with the aide to the point that she was selling the food stamps to the aide.' She said that 'she would take the resident's EBT card and pay her only one-third of what the actual amount was on the card. It wasn't an even exchange or not even half or whatever. No, it was pennies on the dollar.' EBT is an Electronic Benefit Transfer card that allows a Supplemental Nutrition Assistance Program (SNAP) participant to pay for food using SNAP benefits.

When asked if the resident realized that she was financially exploited, the representative said, 'She realized it at the beginning but…in her words, 'I thought we were friends' is what she told me. She said, 'I thought we were friends so I thought I was helping her out because she has kids, she is a single mother, and I just wanted to help her out. I don't need them because I am here in the nursing home. I figured I just need a couple of dollars. She'll give me whatever she can afford and she'll keep my EBT [card].'' The representative confirmed that she thought there was some broken trust there.

She added, 'Something happened that they didn't become friends anymore (they had 'some disagreement on something and it went south from there') and the resident reported her and reported all of it. The resident was not just retaliated by that aide but by the entire *unit*…including the nurse. She had to report all of it because it was retaliation from the other staff…they wouldn't give her ice, they wouldn't give her utensils for her meals, they wouldn't give her juice or water at mealtimes, they wouldn't help her get her sheets so she could change her sheets on her bed, and when she needed her PRN [i.e., as needed medication], they wouldn't give it to her right away.'

She said, 'What I did is I brought it to the Administrator's attention so that they could do a formal investigation on the situation because at that point the aide was exploiting the

resident financially for her food stamps. Then, as far as the other incidents, they removed that aide from the unit, they talked to the staff, and we also had another meeting to make sure that if there are any more incidents going forward, residents would tell the Administrator immediately so they can address it and hold the staff responsible.'

When asked about the end outcome, she said, 'I think that the successful outcome was that before the intervention the aides were retaliating against her and then with my intervention and the Administrator's intervention and just having these meetings and addressing the concerns in real time, the retaliation kind of alleviated. The staff couldn't do it because they knew, 'If I do it now, they're going to catch me right now.''

'*Cares in pairs'*

Two representatives from different states identified another form of retaliation. One of them said, 'This idea that when you complain, the facility…this 'cares in pairs' business where it feels…two things…one, it feels very much like they don't believe you…so now they have that second person in there because they don't believe you and they want a 'witness' to that. [said the word witness with hands' gesture indicating quotation marks]. But it also adds to that not getting the care timely because it is hard enough to find one staff free…finding two at the same time makes it even longer for you to get care.' She added, 'I think it is intimidating to them to feel like that and, again, to feel like they are not being believed…because 'we don't believe your response and we want somebody else in the room to witness that.' That's frequently what's that about.'

The second representative said, 'Double staffing is my "favorite" thing because the excuse always is, 'Well, it's for the safety of the staff and the resident.' Well, often it's because that person is a frequent complainer. And then the resident feels even more uncomfortable because there's two people.'

Staff Members Speaking with Each Other During Care – Ignoring the Resident

When asked about common ways in which staff retaliate against residents, one representative said, 'Talking around the resident when they're receiving care…especially when there's two staff members. A lot of times I hear…I hold the Statewide Resident Council meeting and just the [de-identified time] the two things that they had brought up were, 'Staff talking to each other and not to me during care.'' She added, 'And staff using their cell phone standing in the hallways ignoring call bells on their cell phones and ignoring the residents.'

When asked whether staff standing in the hallway using their cell phone ignoring call bells is done in a retaliatory way or something else, she said, 'I think it's both, I do. I think if a resident has been ringing the call bell a lot during a shift, I do think that it is in a retaliation

way. If a resident voiced a concern or just kind of went against the norm of the night and needs to go to the bathroom more frequently or just anything like that…I do think kind of talking around them…they had an accident and need their brief changed…I do think that it can be done in retaliation.'

Using Cell Phones During Care / Work Shift

One representative said that staff use of cell phones during care could cause residents fear of retaliation. She said, 'All the time. Just having their phone in their hand in the room when they're dealing with the resident…when they're providing care…just having the phone out. I have a few facilities where they do their charting on cell phones…they look similar to what the staff personal cell phones would look like but if they're not explaining that to the residents…that this is a specific cell phone for charting, the residents have no idea…they think that they're talking to somebody while they're providing care or typing something about them while they're providing care and they don't know that it's just for charting purposes.'

When asked what the impact of this practice on residents is, she said, 'Anxiety…major anxiety because you don't know what's going on and you have to think…the residents that we are dealing with are elderly. They are not necessarily tech savvy so they're not sure what's going on and now you have a staff member standing over your bed with already demeaning body language and facial expression…now they have a phone in your face, you're not going to ask what they're doing. You're just going to stay quiet, not say anything and then after the fact, it literally is going to traumatize them.'

A representative from another state described the general problem of staff using cell phones during care, 'This generation that is coming in…you know, when I worked at the nursing home, no cell phones were allowed on the floor. You had two 15-minute breaks and you had your lunch break. And that cell phone sits in your locker the rest of the time. Today when we are going to facilities, they are sitting at the nurses' station…they're giggling, they are laughing with the nurses and they're spending more time with each other or on their cell phone than they are engaging with these residents, changing the residents, doing an activity with the residents. When we bring this up with administration, they're not even being held accountable. They are focused on numbers and getting things done at this level [said while holding her hands high up], they don't even engage with the residents that they have within the facility.'

When asked how staff use cell phones during care impacts residents, she said, 'Fear of retaliation. If the residents see them doing this, they're scared to bring it up because they may get a 'slap on the hand' but guess what? That staff member takes care of them over the

weekend…at night when no administration is there and they might be hitting the call lights to get up to go to the restroom and they let them sit in their urine the next seven hours.'

Recording Residents and Posting It on Social Media

One representative said, 'The facility staff have also been known to record and use that against them. To me, that's retaliation…their behavior…so a dementia resident who might be having a bad day…we're going to record you to make fun of you later and show that to you. And then put it on social media actually.'

Resource Box
Webinar – Mistreatment Using Social Media
Privacy violations and mistreatment of residents through staff misuse of social media in nursing homes: Webinar hosted by Elder Voice Advocates (Caspi, 2023). Newspaper article by Fenster (2023). CT Insider.

Taking Residents' Belongings

One representative described how staff may retaliate by putting away an object a resident wants to have nearby at night, 'They set up someone's bedside table for the night and then pluck a desired item out of it…like something that they would use overnight and want there, they would take it and put it somewhere else.'

Another representative said that some staff members take residents' belongings in retaliation. She shared this **story**: 'The resident was saying that staff were taking her belongings…the housekeeper would take her set of forks, a set of four forks, four knifes, mugs, and cups…they come in sets of four…so one would be missing and she couldn't find it and she'd only have three mugs, she'd only have 2 forks left and it was just her.' The representative said that she couldn't prove it and that 'it's very hard to prove.' She added, 'Taking it intentionally and bringing it back and putting it back like a week later.'

Breaking Residents' Belonging

One representative shared a **story** about staff members in one care home, 'They've also dropped a communication tablet that is also used for video chatting with family. They dropped it on the floor, shuttered it, and then said that he broke it.'

When asked what underlies this act, she said, ‘So he can’t talk to his [family relationship de-identified] who then tells the facility that the staff members are being mean to him.’

The representative said that the incident happened in one of the buildings her colleague covers ‘where it has been *really* bad with retaliation’ and ‘hers is more flagrant like that where they are just dropping it and shuttering it.’ She said that staff broke his tablet ‘because he had talked to his [family member] on the video chat and then the [family member] reported something to the facility Administrator or management and it got back to the staff and they must have talked to them about whatever behavior that they were doing. I think they were ignoring his call lights or leaving the door open. I think this is the guy that they were leaving his door open at night. So after they dropped it, they told him, ‘Now you can’t go crying to your mommy.’ It was very obvious and these people are very overt with their retaliation lately at this building. It’s not necessarily just specific CNAs either, sometimes they have agency CNAs but that do it too there. It’s like it’s a culture there at this building. I don’t know how they can stop it but it has been this culture at this one building for a couple of years.’

Exclusion

When asked about ways in which staff retaliate against residents, one representative said, ‘Sometimes you'll see where they will purposely socially isolate the resident.’ Another representative said, ‘Not including them in some event.’

A representative from another state said ‘Just leaving the resident out of activities’ while another representative said, ‘Not included in community activities. I’ve heard where Activity Director [said], ‘Oh, we forgot to go get them.’ When asked whether this was done intentionally, the representative said, ‘Oh yeah, yeah. How can you forget a resident? They’re on the list.’ Another representative said, ‘Preventing residents from going on outings’ such as saying that there are no buses that can take all residents.

A very experienced representative explained this type of retaliatory exclusion, ‘That one is to keep a complaining resident from participating in activity that he or she enjoys. They are excluded from those activities because they complained about an issue that affected a staff person and so they exclude you from that activity because that activity is important to you. So what I am going to do is exclude you from it because of what you’ve complained about regarding me.’

Pitting a Resident Against Another

When asked about forms of retaliation, one representative said, ‘Losing a resident’s laundry and actually putting a resident’s cloth on another resident.’ She clarified that this was done intentionally and not because staff couldn’t locate the resident’s clothes.

When asked what she thinks may underlie this action, she said, ‘I’ve seen like a lot of staff members cause problems for other residents. They know that resident is going to get upset and they’re going to go and talk to that resident about the issue or be upset with that resident…and blame the other resident for stealing the cloth.’

When asked again what she thinks may underlie that practice of pitting a resident against another, she said, ‘I think like difficult residents…being labeled as a difficult resident…is the only way that they can get back at them, to revenge or retaliate because they’re constantly being called or constantly being complained about so they retaliate against them this way.’

One representative described a version of this form retaliation, ‘Staff basically turning a resident against their roommate.’ The representative said, ‘It happened [de-identified time] but that kind of scenario is happening all the time.’

She went on to share this **story** (names used in this story are pseudonyms): Barbara shares a bedroom with Mary. Mary’s ‘family visits all the time and they stay very late…even up to 11pm at night.’ Barbara asks the roommate and her family ‘if they can have the visit in a common area. The family would say, ‘Oh, we’ll leave now.” Sometimes they’ll leave but other times they’ll stay another 20 minutes.’ Barbara ‘called the Ombudsman and told them that those visits interrupt her ability to sleep.’ Babara ‘will call the Ombudsman or even speak with staff about it.’

The representative went on to say, ‘Then what ends up is that a staff person…maybe a social worker walks into the bedroom and say (in the presence of Barbara), ‘Mary, Barbara says that you’re too loud and keeping her up when she tries to go to bed.’ Then it can go a couple of ways. I see it as retaliation. Staff putting Barbara on the spot and it also creates a divide between the two residents. Maybe they get along during the day. Barbara is then silenced. Barbara says, ‘Why did they do that? Why did staff confront Mary about my concern? I didn’t want that.’ Mary tells Barbara, ‘I don’t like you as a roommate.’

The representative added, ‘We see staff do that all the time whether the roommate is willing to work it out with their roommate or not. They make the roommate with the concern feel bad which often silences the roommate.’ She said the following about what the staff has done when they put Mary on the spot: ‘It is done intentionally.’

She described how the situation should have been addressed, ‘Hey Mary and Barbara, can we talk about the evening family visits? Barbara likes your family. She has no concerns. But after 8pm…would it be possible to have the visits in the common area so Barbara can sleep?’ She said, ‘Discussing these concerns should have been a nice conversation.’

She went on to describe a threat of retaliation against a resident, 'A social worker would go to Barbara and say, 'Since you don't want the family visit at those late hours, you need to move to another room.'' She added, 'Sometimes staff would say, 'Anybody who complains about their roommate has to move.' Over anything.' At a Resident Council, residents would say, 'Why can't we complain about a roommate?' Something that could be discussed and residents could strategize a resolution that is agreeable to both roommates. She went on to give an example, 'A resident would say, '[de-identified representative's name], my roommate…I love her dearly…but her TV is *so* loud…when I go to staff, they say, 'If you don't like it, we're gonna move you to another room."

The representative considered it a threat and added, 'Because the residents could live together nine or ten years happily, but instead of staff working to figure out a solution (providing residents with headphones or have their hearing aids checked – have the batteries run out? Why the TV is so loud? when sometimes using headphones could resolve it as it can allow the resident to listen in a volume high as they'd like it), the staff make it more complicated than it really is.'

Complaining to Other Staff About a Resident's Requests for Assistance

One representative described how retaliation against a resident could result from staff complaints about residents' requests for assistance. The representative gave the example of inconsistent staffing and how shift change report can lay the ground for retaliation during the subsequent shift. The representative said, 'When you have 21 different ones and let's say they do a shift change, okay, and let's say the resident was asking or had a couple incontinency episodes during the typical 8-hour shift on the 1st shift. Then that person makes a report to the 2nd shift employee, 'These are the residents I cared for. This is what's happening blah blah.' Well, they could say to that second shift, 'Well you know what, I had to take this person to the bathroom four times this shift and three of the four times [there] was nothing and they're just doing it for attention…so just be careful about what you do with this person…don't feed into their behaviors.' I have *heard* staff say that at report. They're doing shift change and I have heard CNA A tell CNA B, 'Well, I took them four times but three of the four times nothing happened so I don't know what's going on with them and they just want my attention, they just want somebody in there with them.' Again, that retaliation…and so residents hear that because staff are not clued in that maybe another resident was sitting there within earshot and that person eats at the same dining table as the resident they're referring to and they share that at the meal time, 'Hey, I heard CNA Debbie talking to this CNA and she said that they had to take you four times and three of them were fake or not productive' and so that gets told to the resident or gets back to the resident, 'Well, what makes them think that they should ask for help again?' Sometimes it's

not a direct result retaliation…they kind of hear it…I don't say the back door approach but they hear it from someone else that a CNA was complaining about them and their request for help and I think *that* is probably one of the worst because then it sets up this dynamic of distrust where maybe the CNA comes in and she's like, 'Oh, it's OK, no problem, I can help you' but yet she tells staff and another resident overhears what a *disruption* that was a challenge for her and how she doesn't want to do it anymore, 'I'm not going to do that anymore. Be careful of what she asks for because she is asking for help and she really doesn't *need* it.''

Saying Negative Things About a Resident / Starting Rumors

Telling residents negative things about a resident that staff members don't like. One representative said, 'We've seen in an assisted living here a situation where some of the staff didn't like a resident so they would talk about that resident to the other resident, 'Oh, you don't want to be around her because she is not nice' or 'She is a bully' or 'She smells funny' or whatever it was. We've seen that happen too where staff have actually tried to engage the other resident to disassociate from the resident they didn't like for whatever reason.'

A representative from another state said, 'Talking about them with other residents where staff will start rumors.' When asked if this was done in retaliation, she said, 'Oh yeah, I've seen unintentionally too where people like to gossip…but I've seen where they started rumors just to be mean…because they didn't like that resident…or actually make up lies.'

Another representative said, 'Just gossiping about the residents to other staff and spreading information about them…that they are difficult to care for or that they have whatever issues when that's really retaliation against them speaking up about how they are being treated by anyone caregiver. We've had residents complain that something that they told one staff member and then they went out and told others as a way of shedding bad light on the resident and making themselves look better to other staff members.' He added, 'They hear it. They hear them telling people in the hallways after they leave their room. They overhear them talking to other staff members about them.' When asked if this form of retaliation can also be done by staff in a way that residents are not aware of, he said, 'Yeah. Absolutely. And then they could also hear it from another staff person who heard it in that break room at a later time that that happened.'

Taking Away Smoking Rights

One representative said, 'If they're smokers, they will not allow them to go smoke at the right time. If you take a resident who is supposed to go smoking at 10 o'clock in the morning and you don't show up until 10:30 or 11:00, they are highly affected because they look

forward to that. That's *their* treat.' Her colleague added, 'That's one of the only things they have to look forward to…a lot of these nursing home residents.'

Taking Away Your Green Pass

A representative from another state described what she called 'a kind of covert' form of retaliation, 'I have a facility that when some of the 'younger,' more able-bodied residents have been 'acting up,' facilities will take away their Green Pass.'

She described the pass system, 'A lot of facilities have a pass system where it's red, green, and yellow. Red pass is you can't go out unless staff will go with you…usually it is because of some kind of safety risk if you go out…I am talking about out into the community. If they have like a locked courtyard that they can supervise at all times, you can go out come and go. A lot of places don't have that but Green Pass is you can sign yourself out…there's a certain procedure, you have to let a nurse know…all that. You can sign out and like take a bus and go to the store, if you're capable or just going around in the neighborhood by yourself. Yellow Pass is like staff or a family member or a friend sign you out…just someone has to sign you out to say that they are taking you somewhere.'

She went on to describe the problem for the residents, 'Some of my guys will go from Green Pass to Red and they kind of run us in circles where they say, 'Oh, Social Services handles getting the pass upgraded again' but then we talk to them and they'll say, 'Oh no. I have no control over it. It's the doctor.' So then we try to talk to the doctor, the assistant…the Nurse Practitioner will say, 'No, we don't have a problem with it' and I'm like, 'Can you write an order?' and it's just kind of keeps going.' Meanwhile, the resident 'is stuck inside now and it was during the Summer and it just kept going in this loop.'

She added, 'He was upset because they like messed something up and he yelled…he has temper…he lived there for [several; exact number de-identified] years and never been put on Red Pass…but he got upset and yelled one day and so they put him on Red Pass but they have a procedure for graduating back up, which makes sense. You are in a nursing home, I understand. But then they don't follow it.'

The representative then recalled a key detail, 'They found that he had bought small little wine bottles at the store. He hadn't drank them but they were in his room. So that was 'contraband.' You're not allowed to have alcohol in your room, on the premises. So they put him on Red Pass for violating their Pass Policy.'

The nursing home moved him 'from Green to Red and then you're supposed to have a revision in like 14 days…to have a graduated plan to get back to green if that's still safe but they don't follow that and they just kind of do Red and then stopped. And then he was getting agitated because of it and they used that as more ammo [Ammunition] to keep him

on Red Pass but in reality they were trying to get him to leave because he was younger and bothered them about proper care and they didn't like that.'

She added, 'They eventually gave it back to him but it took me kind of getting into not great conversations with the Administrator several times, calling the State [Survey Agency], which in this building with this Administrator is really not great…he is a very angry person this Administrator but would absolutely retaliate against a resident [missing words] because he does it to us if he knows that we called the state…so they did eventually let him back on green pass. They were citing because he wouldn't take a water pill that he couldn't go out because he was not in compliance with meds but the only medication that he wouldn't take was a water pill that he didn't want to take because it kept him up at night if he took it.'

The representative said that what the nursing home has done to the resident was unfair. She explained, 'They don't follow their process. It's very arbitrary. They were giving other people passes back and not him and it was very *clearly* retaliation to try to either get him to leave or just kind of punish him for yelling at staff when he is getting frustrated because they're running him in a circle and he is irritated.'

When asked to elaborate on what she meant by the nursing home was 'running him in circles' she said, 'The same thing they were doing with me, they were doing with him. He would talk to the Social Worker, the Social Worker would point him to the Doctor, he would talk to the Doctor, and it was just [said while making a hand gesture of circles].'

Collective Punishment

One representative shared this **story**: 'We had one Administrator here in [de-identified state]. It was a smoking facility with a lot of [de-identified information] in that facility and a lot of smokers. When a resident would do something she didn't like, that was always her retaliation…was to change the rules around smoking or take away smoking time or how many cigarettes they were allowed to smoke…things like that.'

Another representative shared this **story**: 'It's not just the aides that are retaliating but it's also the Administration that is retaliating. As soon as I became an Ombudsman, I had to jump into a building and the biggest retaliation was the Administration not allowing residents to go out on leave outside the building.'

When asked what triggered the retaliation, she said, **'**In response to…because they had a history of drug addiction or because they had an overdose in the building. They were punishing the entire building…not allowing residents to leave the building on [name of holiday de-identified] whether to go visit family or to go to events or even to the community. And they also limit where they can order food or goods from.'

When asked whether the administration also punished residents who were not involved in the overdose, she said, 'Yeah. If they had an overdose, the entire building, you couldn't order food anymore. You could only order food from four restaurants…the Administrator's choice. You could only order from [de-identified name of store], you couldn't do like whatever quick delivery system available. It had to be [name of store] and they had to check your packages.' She confirmed that packages coming into the building had to be checked for all residents, 'Yes and all of this is residents' violations but they did not care no matter how much we addressed it. They said they'd rather get a tag for residents' rights than for an overdose or something in that vicinity.'

Retaliatory Bedroom Change or Roommate Reassignment

One representative spoke about bedroom change or move to a different care unit as forms of retaliation, 'Room changes are one of the biggest fears for residents. All they have to do is say, 'You're out of here. We're going to move you down the hall or even put you on the dementia wing. We're going to move you to the crazy side' or what not.' The representative added that these actions 'are one of the biggest fears for residents.'

A very experienced representative described a version of this form of retaliation, 'Giving somebody a terrible roommate.' She explained, 'Like this person is complaining all the time, we're gonna show him. We're going to put Lucy in there and she is going to make it real tough for this resident.' She added, 'I think those things happen more than we realize but yeah, we've seen those things happen. And those things are hard to prove. You know, 'Lucy, she just needed a room and she went to the hospital. She is back and that is the only room available. So that's where we're putting Lucy.' That is just a made-up name.'

Making the Resident Feel Miserable So They'll Want to Leave

Trying to make a resident so miserable that they will want to leave the care home was described as another form of retaliation. One representative #1 shared the following **story**: An Administrator was retaliating against a resident in 'any which way she could.' She gave her an involuntary discharge for using the vape pen ('the vaping was the main trigger' for the retaliation). She couldn't really discharge her for that but she was trying and in the meantime, she was being late getting her out of bed, she moved her to a different room.'

Her colleague #2 said, 'She is trying to intimidate her to want to leave.' Colleague #3 said, 'Trying to break them.' Representative #1 said, 'She did all kinds of things to this person to make her want to leave, including no showers, not getting her out of bed, changing her room, and all of that coming up during the whole discharge process. It was just ridiculous.'

Colleague #2 added, 'We've had this happen too. It's not unusual.' The representatives were able to intervene and prevent the wrongful involuntary discharge ('They could not discharge her') but 'even after they couldn't discharge her, the Administrator continues to nitpick her….just do little things, 'You can't have this many plants in your room' and 'You have too much stuff in your room,' just nitpicky things that she still picks on this lady to this day.' Representative #1 added that the attempt to discharge her was resolved but the resident was left 'with trauma. She does have a lot of trauma.'

Compromising Camera Installed in Bedroom

One representative spoke about a form of retaliation where staff move cameras installed by a family in their loved one's bedroom ('They move them all the time') or 'they turn them off.' Her colleague added that staff 'put them out of view and say they bumped it when housekeeping were cleaning' or they'll say, 'They Wi-Fi isn't working.''

Other representatives reported that certain staff members may do other things to compromise a camera's ability to take footage inside the bedroom. Examples include:

They may cover the camera (e.g. 'I have seen them cover it up'), put an object on it to block its view (e.g., 'I have seen them walk up and put a clothing item over it or something'), physically block it's view (e.g., 'The staff member will stand right against it for the entire time people are in the room'), or they'll disconnect it (e.g., 'Sometimes they get unplugged' and then describe it as an 'accident').

Installing a camera inside a resident's bedroom could sometimes result in retaliation from staff members and managers. One representative shared this **story**, 'I have a situation with a daughter the facility doesn't want to deal with. They were discharging a woman with advanced dementia because her daughter viewed the camera and then called the [de-identified state] [State Survey Agency]. They discharge her to the lowest performing nursing home in the county.' She added, 'They listed reasons on the discharge [notice] but they're not valid.' She wrote, 'The pretext for the discharge in this case was nonpayment and inability to meet level of care. The facility was not meeting the daughter's care expectations leading to her complaint to the [State Survey Agency] (as evidenced by camera footage). The hearing officer immediately clarified that the level of care discharge reason was not valid.' The representative said that nonpayment discharge reason was also not valid and added, 'We won the hearing.'

The situation did not end there. She said, 'A few days later, the resident had to go to the hospital for an infection and the facility refused to readmit stating they did not have an isolation room available. Medicaid consumers get 30 bed hold days per year in this state. The resident had already used about [de-identified proportion] of those days and it was the

daughter's opinion and ours that the facility was trying to run out those bed hold days and not readmit. This triggered another complaint survey by the [State Survey Agency] (called in by the hospital [de-identified name of profession]) and the facility was cited for not readmitting and were able to "find" an isolation room. She concluded, 'The resident still resides at this facility. They are unable to continue use of camera because the roommate in the shared room did not consent.'

Retaliatory Discharges

Two representatives from the same state said that involuntary wrongful discharges are 'very common.' One of them said, 'Very very common and it's something that at least once a day…sometimes more than that…I am dealing with. Now, I am being totally honest with you…it's just kind of crazy.' Her colleague added, 'I would say it's more the assisted living facilities with their using that as retaliation. They're using that to retaliate against a resident that might have left the facility for a little while and they didn't like it or it could be numerous amount of things but at least with the nursing home they still do it but they have to go through more processes and steps to do it.'

One representative said, 'I see residents being discharged out of the facility because they complain or their family complains or they are attempting to do that.'

Another representative said, 'If you have somebody that doesn't want to conform to the expectations…yeah, that happens as well…that they just want to get rid of them…they don't want to solve the problem. We see that all the time. We have residents that have behaviors and they want to ship them to another nursing home and it's like, 'Okay, well, what are they going to do differently that you can't do?' is usually our saying to them…that taking them from one nursing home to another is [not] going to change the behaviors per se.'

A representative from another state described situations where a care home will retaliate against a resident with a discharge after the State Survey Agency (SSA) cited the care home for a deficiency related to the care provided to this resident. She said that care homes 'are surveyed by the [de-identified state] Department of Health to make sure they're meeting the minimum guidance and requirements as defined by law. If a facility has a bad or negative survey and they were cited for various efficiencies, if that is connected to a particular resident or maybe a couple residents, it is not uncommon for them to try to discharge that resident to another facility and that's a form of retaliation.' She added, 'Their way of remediating that is just to get rid of the resident so it's no longer a problem, 'We won't get cited for things in the future, blah blah blah.' We see that pattern when facilities have a poor performing survey and then they will try to discharge X resident who may have been a big focus of the survey team and the care of that resident during that survey.'

When asked what underlies these attempts to involuntary discharge residents after being issued a deficiency citation, she said, 'Because when they're issued a citation, the facility has to submit a plan of correction. And then the [surveyors] will come back out and review that plan of correction to determine…are you really doing what you said you're going to do. If that resident that they were cited for various reasons is no longer there, then they don't have to prove or show or document that those things are being done correctly or efficiently.'

Another representative shared a **story** about retaliation in the form of privacy violation subsequent to a resident winning an appeal on involuntary discharge: 'The facilities have installed what's called surveillance cameras. The surveillance cameras are placed in a hallway should be away from residents.' In one care home, a resident received an involuntary transfer discharge but he won the appeal 'because the facility failed to provide the burden of proof.' Alleging safety violations on this resident, the care home then installed a surveillance camera pointing directly in his bedroom. The resident 'thought they were retaliating against him because he won his appeal. After it was investigated, it was poor management, but I couldn't prove it. I felt that they were watching him thinking that he was going to violate a safety rule. The camera had to be removed. It was a violation of privacy not only for him. It was a violation of privacy for folks across from him…that entire hallway…their privacy was invaded. It had to be removed and placed in an area that did *not* interfere with the home settings of the residents.'

She added, 'And they do have surveillance cameras but the only reason they install these surveillance cameras is for the simple fact…if they had a breach and a resident eloped out of the door, they can have a way of verifying when and how the resident left. They do have surveillance cameras already installed in these facilities.'

Resource Box
Wrongful Involuntary Discharges
For a series of resources on this issue, visit the webpage of The National Long-Term Care Resource Center.

'A hospital dumping job'

The practice of sending a resident from a LTC home to the hospital (such as for treatment of an acute condition) and then when they recover, inappropriately refusing to let them return to the care home is sometimes described as hospital 'dumping' (Curtin, 2016). The refusal is a violation of federal nursing home regulations, and it can cause tremendous distress, frustration, fear, and trauma to the individual who is not allowed to return to the care home, which is their home.

One very experienced representative spoke about 'hospital readmissions where facilities use hospitals as their dumping grounds.' She said, 'It can be real hard to get that resident back in. We call it 'a hospital dump job.' There are lots of protections in federal law about that particular issue but facilities tend to get away with it. It is scary for residents who have a history of complaining or who are raising questions and now all of a sudden the facility isn't letting them back. And the hospital on the flip side is really pushing them to get out of the hospital, 'Oh, well, there is no bed for you anymore' and then sometimes we don't hear about it until after the fact and now they are in a facility down the street.'

When asked to briefly describe how she approaches these situations, she said, 'If we know about it and the resident wants us involved, we can reach out to the facility and say, 'These are the federal rules on this. You have to let that person come back to the first available bed' if there wasn't a bed hold or 'You need to be giving a discharge notice, which I will appeal.' I've done that and we've won and it took moving heaven and earth to get that person back into the facility…but then it is a year later, it's six month later…these things don't happen quickly.'

She said that during this time period the person would be 'at another facility. They are supposed to be able to go back to that facility during the appeal process…but who is making that happen? The Health Department when they investigate it a year from now?' She confirmed that the retaliatory practice of hospital 'dumping' can result in long-term negative effects on residents who are 'dumped' in hospitals and added, 'It's huge.'

A representative from another state spoke about unsafe retaliatory hospital 'dumping.' She said, 'During COVID, there were so many facilities that would send residents out and not allow them to come back because they were COVID positive…this was in the beginning when there were not that many cases. We had to deal with all of these…we wanted to…of course because they can't just dump. We call it dumping and it happens all the time. It is still happening….drop them off at home or a homeless shelter. That's not an appropriate safe discharge either.' She added, 'In those homeless shelters, you can't be indoors 8 to 10 hours a day. You have to be outside. You can't be inside. Who is managing their meds? They don't have the ability to walk to use the restroom…things of that nature. It isn't a safe and appropriate discharge. I still have Administrators to this day that say, 'Of course we can discharge to homeless shelters.' No, that is not a safe discharge.'

Retaliatory Transfer to Psychiatric Hospital

Representatives described another form of retaliation where care homes commit residents with dementia to a psychiatric hospital. One of them said, 'It's where they feel they're mentally unstable and they could potentially harm themselves and/or others.'

Another representative said that staff may tell residents, 'Oh, you're not going to behave? Oh, we're going to send you to the hospital to [de-identified state law] Act you' and making the threat, 'You're going to be put on a 72-hour mental health hold.''

A representative from another state said that a resident will be committed to a psychiatric hospital and then won't be allowed to return to the care home, 'Sometimes they'll send a resident for a [de-identified state law] Act and they'll leave them there. They won't accept them back…especially in our assisted living facilities…sometimes nursing homes but again, the residents in the nursing homes have a few more rights to protect them than the assisted living facilities.'

Retaliation After Contacting the Ombudsman Program

One representative spoke about situations where staff retaliate against residents for involving the representative. She said, 'I've had residents I've advocated for in the last couple of years call me and say, 'Because you and I did such and such together, life is really hell for me now.' And they're like, 'I don't want you to do this for me anymore.' Yeah. They were retaliated against from their perception, they didn't get care the way they wanted, they were not given care for longer periods of time. They had the staff be rude and give them the cold shoulder and in fact, staff have come out and told me and other Ombudsmen that…told the resident like, 'This is what you get for bringing outside people in…calling the Ombudsman' or some version of that. Some staff just don't care what they say to the residents. It completely blows my mind when I hear that…but I heard it from enough people to know that some staff…they just don't care. I don't know why they want to take care for residents but [said while shrugging her shoulders] like, 'Go do something else.''

Quote
"*This is what you get for bringing outside people in…calling the Ombudsman*." – Ombudsman representative quoting staff

Retaliation After Contacting the State Survey Agency

One representative spoke about an Administrator who questioned a resident why she called the Health Department on them. The representative said, 'We always treat that as dignity and respect issue and retaliatory' and that it was intimidating for the resident. He added that when 'they were *in the room* to ask him about it,' he said, 'I called the Department of Health,' and they said, 'Why are you harassing us?''

The representative went on to describe how they handled the situation, 'The resolution was simply having a conversation with the Administrator and saying, 'Look man, you can't go badger them about why they're calling [de-identified state] Department of Health. You can say, 'I want you to come to me before you do that' but you have to acknowledge that that's their right. It's just a direct conversation. He admitted not approaching it the best way. So that was successful.' He confirmed that what the Administrator said to the resident was intimidating to her and added, 'It was also obfuscating in their response. What was told to me was that he brought it up that he had called the Department of Health. But the context was that they were *in the room* to ask him about it and he said, 'I called the Department of Health' and they told him, 'Why are you harassing us?''

Characteristics of Residents at Higher Risk of Retaliation

A series of resident characteristics were identified by representatives as potentially placing an individual at higher risk of experiencing retaliation from staff or managers. The following reports should be considered preliminary. Generalizations about each of the following groups should be avoided as there are many exceptions:

Younger residents

One representative (#1) said, 'Younger residents are retaliated against most in nursing homes.' When asked what makes it so, her colleague (#2) said, 'Because they shouldn't even be there.' Representative #1 agreed and added, 'Because the staff think they don't need to be there.' Their colleague (#3) explained, 'The staff kind of look at them as, 'You're lazy' or 'You must have some substance abuse.' They're pretty cruel to younger residents.' Representative #1 agreed with her.

Serious Mental Illness and Substance Abuse

Several representatives believed that residents living with a serious mental illness (such as Schizophrenia and Bi-Polar disorder) and substance abuse disorders are at an increased risk of experiencing retaliation. When asked about characteristics of residents that place them at higher risk of experiencing retaliation for speaking up about care concerns, one of them said, 'People with mental health untreated or sometimes not properly treated.'

A very experienced representative from another state said, 'I think what I see is a larger population with different types of mental illness tend to be retaliated more often.' She explained, 'Because they have a tendency to complain more and then those concerns are ignored and retaliated against. That's my most frequent concern when it comes to fear of retaliation and actual retaliation.'

Quote
"Just because someone might have past traumas or mental health diagnosis doesn't mean retaliation is not happening." – Ombudsman representative

When asked what forms of mental illness she was referring to, she said, 'I think it would be Bi-Polar [disorder] and Schizophrenia are the top ones that we see in the facilities and assisted living particularly. In our area, we have a difference with some of our long-term care assisted living facilities or 55 and older or 60 and older and then we'll a have a population of assisted living facility that have younger residents and those are high population with mental health diagnoses.'

When asked if this issue comes up more in these groups with these conditions in assisted living, she said, 'Yes. Yeah, in assisted living because they are more high functioning. They are there for, you know, medication administration. So in our nursing homes, we don't see it quite as much because you're dealing with a lot of healthcare issues. But assisted living, we have a high population at least in our area with mental illness in our assisted living…'

I went on to ask her, 'Do you think that in general, as a sector, in your region assisted livings are well prepared to care for individuals with Schizophrenia and Bi-Polar disorder?' Her reply was, 'No. No, not at all because they tend to be…they just Medicaid only, staffing is kind of the lower end, care lower end, services, quality lower end. Unfortunately, we see that they get the bare minimum and that's sad to see.' When asked whether this situation in assisted living contributes to residents' fear of retaliation, she said, 'Absolutely.'

When asked about challenges in addressing fear of retaliation and actual retaliation, another representative said, 'My real concern is if I had one problem all along…I have many issues…it's mental health is really the problem.' When asked what she means by 'metal illness,' she said, 'Schizophrenia, paranoia, behavioral. The facilities are not educated at all about how to manage any of that. We don't have services in place for them. They may have a social worker that has specialty in…but they don't even bring in psychiatrists, psychologists, medications all of that.'

She added, 'We talk about people who *do* experience retaliation whether these are things they tried to do to people to manage their behaviors, you know, all of that. I think they are very much vulnerable.'

When asked about main challenges and barriers in addressing the phenomenon at the center of this project, a representative from another state said, 'Some of the barriers…it's definitely our [State Survey Agency]. I think that they lack…the limited staff and they also have their own biases that come into play because of the change in the population in nursing homes. These are people walking, talking younger adults that are in nursing homes. There is a bias and a lot of them come with mental health and substance abuse issues and so they address them as 'those people' so there's that. I believe that's a systems issue because again there is a lack of support for our residents with mental health issues.'

She added, 'Do they need to be in nursing homes and need that level of care? No. But they are being put in nursing homes so you have that tension of people who don't actually need that care in nursing homes but they have these rights and you have the lack of education on the staff to even handle some of the behaviors or nuances with mental health and substance abuse that's coming in the buildings. They don't have the education or the understanding on how to deliver services.'

She added, 'They are definitely being retaliated more' and said that residents with mental health issues and substance abuse are retaliated against more, 'Yes. They are probably more so than residents with just ADL needs. But the mental health I believe and substance abuse population…the retaliation is at a much higher rate because they look at them already with this bias like, 'You did this to yourself. You caused yourself this harm so why are you in here? We shouldn't even be taking care of you' so a lot of the retaliatory practices are against this population in nursing homes.'

Her colleague said, 'A lot of the staff don't understand mental health, they don't understand the disease of addiction and they would be like, 'Well, you did it to yourself. You're just being lazy. You just don't want to work. I am not helping you.'' When asked how they handle these situations, she said, 'It depends on the case. And honestly, from my experience as an Ombudsman last year, it depends on what the issue is. It might be not getting services, not getting help like making the bed or ADLs because they're like, 'Oh, you can do it yourself.' Honestly, it's education and Care Planning.'

Her colleague added, 'Yeah, and I think education with nursing homes because our nursing homes get to choose who they take…so they're taking residents with a history of mental health and substance abuse so they have to be held accountable to have services in place. I think we have one nursing home body that has like a substance abuse counselor *in* the nursing home. If you're going to take residents with substance abuse and mental health, you have to have partners or collaborations in the community so they can get the care they *need*. Some of them are on meth services…meaning methadone and maintenance programs. Some of them need meetings and different staff like that. They should be

charged to ensure that they are meeting the needs of the entire person, not just ADLs but mental health and wellness and all of that. And if they're not, and this is where the [State Survey Agency] comes, tagged on it until those services are put in place. There has to be an enforcement on all sides to hold these buildings accountable because they know…there is a clear history of it. They know the documentation they're getting. There are some nursing homes that don't do it because they don't have the capacity to take on residents like that but some of them, they know what they're getting and they don't have the services in place.'

Residents Perceived as Abusive to Staff

One representative said that residents perceived as abusive to staff may be at risk of retaliation. She shared this **story**: 'Something that was said to me once that I think makes really good sense is that…for example, I've had a resident who was very difficult…very, very difficult resident, very abusive to staff…in a motorized wheelchair would run into staff on purpose…was the kind of resident who would be difficult to provide care for…but would complain about staff retaliation, would complain about abuse and care but was never really believed because he had multiple layers in his personality that made it seem as though he was not telling the truth. This was brought up in a meeting once and the Director of Nursing said, 'This is the kind of resident that is retaliated against, that is abused because nobody is believing what he is saying because he treats everybody so terribly.''

Residents Disliked by Staff

One representative said that residents not liked by staff may be at risk of retaliation, 'If a resident isn't favored by a staff person, they'll find small ways to not allow them to go to bingo or forget to tell them that the general store is open and they can go use their ticket to get the candy or they'll be looked over to go out on a on a trip. The favorite ones get to go on the same trip every single time and that's not something that is very visible.'

Not Wanting to Be in the Nursing Home

One representative said, 'Nobody really wants to be in a nursing home. When they come there, they don't wanna be there but I feel that the more you're outward about you not wanting to be there, the more retaliation you are probably going to get. I think people who voice the fact that they don't want to be there, they kind of are retaliated against.'

Another representative said, 'I am seeing that…I tend to have the residents that are more difficult…I feel that in my complaint basis, I get more of the complaints…the residents are stating that to me that they are getting some retaliation.'

Chapter 6

Challenges and Barriers in Addressing Residents' Fear of Retaliation

Representatives identified a series of challenges and barriers to their ability to address residents' fear of retaliation and actual staff retaliation against them. These challenges and barriers span various domains and levels – both inside and outside care homes.

Barriers and Challenges Inside the Care Home:

The Very Nature of Fear of Retaliation

Representatives spoke about the fact that the very nature of residents' fear of retaliation represents an inherent barrier and challenge in their ability to address it.

When one representative shared his thoughts about this phenomenon, he explained what makes it inherently challenging, 'It's a very real issue. When you look at the issue itself…looking at the vulnerabilities with regards to those that we serve, I think it's really critically important. They're both categorically vulnerable as well as functionally vulnerable quite often. With that being said, it's a real challenging dynamic in long-term care because the underlying concerns of retaliation are predicated on the very people that are those we serve are dependent on. They are highly dependent on other people, which is why they are in some kind of a long-term care setting. So it becomes a bit of a conflict of…an emotional conflict for people within the settings.'

When asked about the main challenges and barriers in addressing residents' fear of retaliation and actual retaliation, an experienced representative from another state said, 'The main challenge is that it's real. It is real. It actually happens. So how do you support someone when they've seen it happen in the building? And residents talk. It is like a playground…so if something happens to someone else, it just makes it keep going.'

Referring to the inherent nature of fear of retaliation being a barrier for addressing it, she explained, 'Because it's real. We can't sit here and say, 'Well, residents have all these protections and those protections actually protect them' when we wouldn't be having this conversation if it was all happy and lovely and we could all sing kumbaya…cause it's not.'

When asked if there are other challenges and barriers in addressing this issue, she said, 'I think that's the main one…is that residents know it happens so it just keeps it going."

Residents and Families Not Knowing About the Ombudsman Program

Not knowing about the Ombudsman program was described by representatives as a barrier. One representative working in a very rural area said that one of the two biggest issues they face as representatives (the other is residents' fear of retaliation) is, 'They don't know we exist as Ombudsmen. Their families don't know, they don't know.'

When asked what underlies it, she said, 'I am just going to be blunt if that's okay. We don't get money for marketing.' She said, 'It's more of an issue with the rural areas' and added, 'We don't get any kind of marketing. We don't get any kind of budget. We've got a radio station that will give us a little free airtime a couple of times a month, maybe they'll interview us for the morning show, things like that. We used to try to put out public service announcements in our local newspapers and I'm sure at this point everybody has kind of read articles on the death of local news. That affects even us because our little local newspapers and these small rural towns used to put an article in there free of charge for us, 'This month we're going to talk about retaliation or care planning' and now you're talking about these conglomerate type things that aren't necessarily even located in these towns and I get messages back like, 'Well, we might print this as a letter to the editor if we're able to print it at all.''

When asked how she tries to bridge this gap with the limited resources she has, she said, 'I go into facilities. You just have to meet every person you can' and 'Gotta go out there and do the work yourself. You gotta be in the facility meeting people.'

She added that they give out Welcome Packets and Holiday Cards. She gave an example, 'We do a huge thing at Christmas. My district…we print a holiday card for every single resident in in my [de-identified number of] counties…and they have my name and my phone number in them and [missing word]. That's a big outreach for us because people keep those cards and they keep my name and number.'

When asked about things that do not currently exist that if existed would have helped her in better addressing residents' fear of retaliation and actual retaliation, a representative from another state said, 'Just overall general knowledge of our program.' She added, 'There was a brief shining moment where they were going to put posters of our program into each of the rooms. Can you imagine? You wake up in the middle of the night and you see our phone number. They were gonna do it in multiple languages and it passed and everything, but they compromised it away so now all the residents get a piece of paper in their admissions paperwork about our program, which I don't think is enough.'

She explained, 'They passed it but when it went into implementation phase, somebody got cold feet and now all they are doing is sending a piece of paper in the admissions documents. So we made the progress, but we never got the implementation.'

Residents Unaware of the Grievance Process

Another barrier identified by one representative consists of the fact that some residents don't know about the grievance process / filing formal grievances. The representative said, 'They don't always know about them.'

This issue is discussed in the segment titled *Empowerment Though the Grievance Process* in **Chapter 7** Strategies for Addressing Fear of Retaliation or Actual Retaliation.

The Need for Resident's Consent

A major challenge identified by many representatives has to do with the need to receive consent from the resident to intervene. This issue lies at the heart of the Ombudsman Program and several representatives consistently stated that they do not suggest this should change. One of them said, 'We have to have resident permission before we can actually do anything. I think that is a big one.' She added, 'It's what the program is about and that's what it needs to be. But to answer the question, it puts some limits on it.'

Quote
"*We can't go back on consent because that's just like what our makeup is. We can't have trust without that*." – Ombudsman representative

When asked about the main challenges and barriers in addressing residents' fear of retaliation and actual retaliation, one SLTCO said, 'Well, the obvious thing is if the resident won't let us but I am not going to blame the resident.'

When asked whether lack of consent from a resident is a barrier to her ability to bring change, a very experienced representative said, 'Right but it is not about me because I get to leave. The resident needs to feel safe. I am not going to do anything that violates their trust because it is going to come back and bite you later. And you know, residents talk. It is like a big playground in a facility. They are all there, they are all talking, they have relationships, they fight…so the word would spread, 'Don't talk to that chick because.' You know, it is a huge part of our job. The feds got it right when they designed this program back in the day…I don't know how that happened, but they did' [laughs]. She added, 'They don't

get a lot of things right [laughs]. That's just my opinion…like they got it right with this one. It is the only thing of its kind…really.'

An experienced representative said, 'I think a lot of times we've been successful when residents let us address the concerns…because of fear and also the fear goes away. Putting something in place to address the retaliation with the facility so the retaliation doesn't happen, and we have been successful in doing that.'

Another representative said, 'It's one of the greatest things we have to overcome when working with a resident. Actual solutions sometimes are easier than encouraging them and getting them to share. Because Ombudsmen cannot go forward without the approval of the resident. And we've seen some pretty bad things that we either witnessed ourselves or know about and if the resident or their proxy doesn't allow us to move forward, we have to stop right there.'

A representative from another state said, 'The challenge is the residents giving us consent to move forward…I think is our biggest challenge.' Her colleague added, 'Yeah, that would be it. Consent.'

Another representative said, 'As an Ombudsman, it's hard to hear their stories about the issues that they're going through and as much as you plead them to come forward whether it's anonymous or not, they just absolutely won't because like one lady told me, 'It's nice that you want to help me but you get to go and be peaceful. I have to stay here and accept the consequences of my filing a complaint.''

Quote
"*It's nice that you want to help me but you get to go and be peaceful. I have to stay here and accept the consequences of my filing a complaint*." – Ombudsman representative quoting a resident

When asked about the main challenges and barriers in addressing residents' fear of retaliation, a representative from another state said, 'Just residents who do not provide consent to advocate when the issue is very personal and it hasn't happened to any other residents.' She explained, 'If I can't say what exactly happened to you, how do I fight that for you? How do I advocate for you?'

She confirmed that in these situations of very personal care concerns she is unable to expand it to a General Complaint through questions to other residents. She added, 'I

always find it hard to resolve the cases where it's very personal and I go to talk to the other residents and it hasn't happened to them…so when it's very personal to that resident.'

When asked if it's a dead end for her, she said, 'Well, not just after that one visit. I'll keep going back to see if…and then I'll even let the other Ombudsmen know what's going on with this resident if they're going to do routine visits there.'

Another representative said, 'Residents tell us a lot of stuff' but 'without the resident's consent to repeat it, it's hard to prove. Because we can't say anything.'

One representative said, 'It's really, really hard to address an issue if you don't have consent for it. It's really hard. It gets kind of tricky because they're really afraid.'

An experienced representative shared a **story** illustrating how powerful residents' fear of retaliation can be and how it may cause them not to give representatives consent to intervene and advocate to address their care concerns. She said, 'The residents…in some cases…they are resistant to, you know, somebody has been on the floor for 3 hours, then I go to see them [and they'll say], 'I don't want to complain' and I am like, 'So what would make you complain? Being on the floor for 4 hours, 5 hours? What is your threshold here? Nothing can improve unless we address it.'' She added, 'But I understand their fear. Many of them have no control over their lives. Many of them have no outside assistance from anyone other than the Ombudsman. Many people have no family or friends visiting them. So they're very vulnerable and I can understand not wanting to complain but it is my job to try to move them along to see if we can get something good for them to happen.'

When asked if there's a law or regulation that limits her ability to address the issue of fear of retaliation, another representative said, 'Well, of course…and this can never be changed…of course, the Ombudsmen, we always have to have the resident's permission and that could be a hold back but it is *absolutely* necessary to gain the trust of the resident when you say, 'I cannot share anything you tell me without your permission.' We have to withhold that.'

When asked whether securing resident's consent lies at the heart of the program, this representative said, 'It is. It *has* to be there and residents have to have somebody that they can 100% trust and rely on that it's not going to get shared but on the other hand, it does put us at a disadvantage because we know something is going on and we can't share it.'

A very experienced representative said that fear of retaliation is 'one of the many barriers we deal with in getting residents good quality of care and quality of life.' When asked what makes it so, she said, 'Because if a resident is telling me that they have a concern but they are so fearful that they can't move forward with it, then I am restricted as to what I can or cannot do with the problem and I think we'll get into some details about how we might

strategize around it or try to work with it but in general it could end just there like a resident could state that they're fearful and they don't want me to act and I have to respect that within my client-directed role as the ombudsman.'

Another representative said, 'Getting permission from the resident to advocate when they are living in fear. It probably is the number one challenge…if we can't take action…and like I said, 'We'll cast a net wide and we'll start weaving in some of those questioning with other residents like, 'How's it going with your caregivers? Are they treating you with respect?' So sometimes we can elicit more information that way and get somebody who will give us permission to act.'

Another representative said, 'From our program standpoint, we can't address that retaliation without the resident's consent. So that would be a limit for us if you will because we have to have that and if they're fearful of retaliation, to be able to get the consent from them to speak on their behalf…it's very difficult.'

A representative from another state said, 'One of the most important things about our program is resident consent…being resident-directed. That's a huge barrier to pretty much everything that we do. If we don't have it, we can't do anything. We try to come up with creative ways to kind of spread out and get consent elsewhere from another resident about a similar thing. But yeah, not having resident consent…being resident-directed honestly does kind of hurt us in being able to address some issues like retaliation in facilities.'

Another representative said, 'I think a challenge is if a resident has a fear of retaliation and they don't want to bring up their name…like if they want to be anonymous. It becomes a big challenge because when we're addressing an issue anonymously, we really have to watch our wording and how we bring up the issue because if we say too much, the facility is going to catch on as to, 'Oh, we know exactly what this is about. We know exactly what resident this is about' so that's a challenge. We have to remain anonymous if the resident asks us to do that and sometimes it's tougher to get a 'resolve' based on that because I can't get more specific on what the issue actually is…'

When asked if there's something that helps in this situation, she said, 'Until there is no fear of retaliation, I don't think that we would ever get the resident to say, 'Yeah, you can use my name all the time.' And if you can't come up with an example when you're telling the facility…staff that are being rude, they can't pinpoint which staff or where to take it.'

One representative said, 'A lot of times they will say, 'Hey, I want to share something with you but I don't want you to use my name or say anything because I know what will happen if they'll know it was me who said anything.' Sometimes I will [say], 'What do you think is going to happen? What could possibly happen to make you not want to say?' Sometimes

they'll say, 'They'll hold my smoke breaks' or 'They won't answer my call lights' or 'When they'll come in, they'll be short with me' or 'I won't have anybody to talk to.' Those are very mentally effective when they come in and they won't talk to them…because a lot of these people don't have family that's coming in so their communication is with the staff and if the staff won't talk to them, it psychologically *messes* with them because they *need* that interaction.'

After listing several causes of residents' fear of retaliation (such as resident's personality, past experiences in life, domestic abuse, and cultural factors), a representative from another state explained why some residents decline to give representatives consent to intervene, 'They want to keep things private to themselves. We have people that have been…not harmed I would say but disappointed when they have complained but nothing happened…so why put themselves out again for a possible retribution?'

One representative shared a **story** about a devastating incident that has taken place early on in her career as an Ombudsman ('I was pretty young and green'). She said, 'I knocked on a resident's door. I hadn't met him before. He welcomed me in. Established rapport. I'd asked detailed questions. Not vague because if you ask vague, you're not going to get very much. I said, 'Tell me about this' rather than, 'How's the food?' or 'Tell me about the food or whatever.' So this resident was telling me that he was humiliated by a CNA. He had a bowl accident…he was in the bathroom on his own and it had run down the back of his legs and onto his shoes. He asked for staff assistance…it was a call light and the CNA came in and said, 'Oh, that's so shitty, shitty, shitty. Shame on you. Shitty.' And he said he was absolutely *devastated*. Just *humiliating*. He said, 'I couldn't help it. I had diarrhea. I tried to get to the bathroom…I could not make it.' He was just made to feel ashamed. He had tears in his eyes.'

She added, 'So we talked about some things to try to address it. I went through whatever and he was so fearful of retaliation that I left there feeling just mortified about what happened and I didn't not have his permission to share it ('He would not let me report it'). And I tried so hard but sometimes you don't get that permission. At this point, I don't know what happened because I went back two months later and he was no longer there. I don't know if he moved, if he died. I don't know what happened. And that was probably a small one compared to others but to this resident it was *everything*. It was just humiliating to him and that he felt shame, shame because of it.' The representative considered what the staff has done to the resident as, 'Abuse. Verbal abuse. Absolutely.' She added, 'I would consider it also retaliation because she cleaned it up and she kept saying, 'Shitty' and retaliation is also demeaning a resident…and so that is both. It's verbal abuse and it's retaliation.'

A representative from another state identified a couple of reasons why residents won't speak up about their care concerns and retaliation. These included their relationship with the staff and staff working short staffed. She said, 'Residents form relationships with some of these staff members and because of relationships, residents won't speak up when staff will come in frustrated or not provide care. So I think some of it is relationships or they feel bad for the person because they know something about their family life. I think staff are able to get away with some of the retaliatory practices because residents don't even look at it as retaliatory…it's like, 'They're stressed out' or 'They're not having a good day.' I feel like residents take on more concern about the staff than they should. I think it's more so like they hear something…because, again, I always say, 'Residents know more about what's going on in the building than anybody else' and so then residents take on that and say, 'Well, they're just having a bad day. Yes, they did this to me but they just had a bad day' and they won't report it.'

Her colleague added that short staffing contributes to residents' reluctance to file a complaint about lack of care. She said, 'I feel like the new phenomenon is…at least that I've seen in my buildings…are short staff. All the buildings are short staffed. So to them it's like, 'Oh, it's just another day. Short staff is nothing' and the neglect that we're seeing in some of these buildings, the residents are like, 'Well, she did everything that she could. She was just so busy. She was just so busy with other residents and because of that, I didn't get a shower or I didn't get to go to bingo or I didn't get changed right away, I had to wait an hour because she was so busy. They're so short staffed.' Even though they try to get them to make the complaint, they're like, 'No, she'd really tried her hardest.''

Another representative said, 'Not the whole protocol but you know we need consent to act. That is the very basis of our work so without consent and this is what I share, 'My role is to help you, empower you, not to make your life worse. I understand that I am not here at midnight and I cannot offer you protection but I can say to you that this may not get better if [missing word] don't get help. So just know that whatever you tell me is confidential.' I think that piece is important. You have to make them understand that [if] they can't tell you and it will go no further if they don't wish you to do that.'

Quote
"*My role is to help you, empower you, not to make your life worse*." – Ombudsman representative

She added, ‘Then I ask them, ‘What else can we do?’ Because you want to empower the resident…you want them to be involved…you’re *their* advocate. I always ask, ‘What else could we do that may help without directly bringing this to light?’ Sometimes people are so fearful that they say nothing, ‘I don’t want you to mention it. I just want you to know about it.’ She added that this happens ‘so many times.’

When asked how it makes her feel when she hears that, she said, ‘It is, and you feel *helpless*…ineffective…really. I think that every person that enters the role of the Ombudsman representative has a true desire to make a change, to make a difference and bring quality to these people’s lives…so it is a *huge* burden but we don’t stop there.’

She elaborated, ‘What I might do is go to others in that area that that person lives in…the distinctive area and I may begin to have conversations with them. And those who might be a little bit more bold, I’d ask, ‘Do you ever have problems with staff not wanting to help you? To be cruel to you? To threaten you? Do you feel like you can’t call for help?’ These kinds of things. I begin to ask questions. I try to find another person that will allow me to take some action…keeping that individual who is afraid out of the mix. Is it always effective? No but it lets me know that I am laying the groundwork for others. And I am also keeping the confidence of that resident. And then I come frequently…I try to build rapport. If we have a volunteer, we might place him in the building to build some additional rapport…just be extra eyes and ears. We don’t walk away but without consent, we’re basically helpless.’

She elaborated about the second resident, ‘If they have a concern and give permission, then I take action. I go to whomever we decide together…the resident and I go and take action with that person. I am constantly providing ‘mini’ educational moments where when I exit the building and speak to the Administrator, I might say, ‘We’re available to come and do all-staff in-services and we do. Our role is to do some of that and we do Residents’ Rights, we also include abuse and neglect and emotional and verbal abuse.’ She confirmed that the in-services also address the issue of residents’ fear of retaliation, ‘and the neglect and the emotional abuse when you feel you’re not getting what you need and you’re afraid.’

When asked in what way she finds it helpful to speak with that second resident, she said, ‘Because if it’s a ‘bad apple,’ we’ll say…a particular staff member that is doing this or a particular shift as a whole. So then maybe I can identify through someone else that this is a more systemic problem and address it from that light.’ She added that she then addresses it as a General Complaint ‘or if the other resident tells me, ‘You can say this…it came from me.’ I am looking for permission.’

When asked about the potential consequences of residents' reluctance to speak up about their care concerns due to residents' relationship with staff and the appreciation of them working so hard due to being short staffed, the first representative said, 'Neglect.' Her colleague added, 'I think they are being neglected. I feel like they are being *conditioned* to be okay to be neglected…all the way from the Administrator to the nurses to the aides. They are being *conditioned* by staff to say, 'We're short. You're going to have to accept it.' And the consequences is the amount of neglect that they face every day.'

'It happens in private'

One representative said that the main challenge and barrier in her ability to address residents' fear of retaliation is, 'It happens in private. I think that's an issue.'

A substantial portion if not most personal care interactions (such as assistance with dressing, showers and toileting) are done one-on-one inside a resident's bedroom or bathroom, that is, when one care staff member provides care to one resident. Short of having a roommate witnessing the care interaction, another staff member assisting a roommate or walking into the bedroom at the same time, a family member entering the bedroom for a visit, another resident entering the bedroom at the same time, a resident requiring a 'two-staff assist' with personal care and/or having a camera installed in the bedroom, many of these care interactions take place in private. One can see how a significant portion of verbal and physical abuse, threats of retaliation, and actual retaliation against residents may occur in private 'behind closed doors.'

The Burden of Proof

A big challenge identified by many representatives consists of the burden of proof. That is, the representative's ability to gather evidence that proves that retaliation has taken place.

One of them said, 'Proving that it actually happened. That's our biggest hurdle. We can talk to the residents, we can talk to the families, *we know it has happened* but now we have to prove that it actually happened. And that's where it gets difficult.' Her colleague added, 'And how to document that proof so that if we need to refer it to other agencies…for them to say, 'Yes, that resident was definitely retaliated against' is a challenge in itself.'

When asked about the main challenges and barriers in addressing residents' fear of retaliation, an experienced representative said, 'When it is a 'he said she said' where you don't have actual evidence…you just have one person saying one thing and one person saying the other and it really kind of ties your hand. That's one of the most difficult.'

Another representative said, 'It's very difficult if you don't have the burden of proof. It's difficult. It's very difficult to determine what has happened. That's a barrier that really

puzzles me. Then it's the difficulty to corroborate solely because the person is fearful to talk to you. You can't really corroborate it because they don't want to talk about it out of fear. You can't engage to do it. When they are trying to tell you something, you know there's something there. They say it happened…it evidently did if they opened a grievance on it. If there is a grievance that was filed on behalf of that resident, *something happened*. That grievance identifies a problem that occurred. That's my problem.'

Quote
"It's very difficult if you don't have the burden of proof." – Ombudsman representative

The representative added, 'Subtle instances…they pose a barrier because it's difficult to identify as retaliation. However, there is a correlation that it could have been retaliation. But how do we know? Because it was that little sneaky way of doing it. It's very subtle…you can't really identify it that way. And then residents become fearful because of the consequences from staff if they speak about what they may have witnessed or what they may have seen. That's a barrier because they *shut down*. They won't talk about it. It's very difficult to navigate it because of the burden of proof.'

One representative described the issue of residents' fear of retaliation as 'very, very hard for us to deal with in terms of supporting people and advocating for them.' They explained, 'Because first of all, retaliation can be so subtle. It could be a look, it could be somebody moving the call light out of the resident's way or 'Oh, we don't have the favorite sandwich that you want for lunch today' and then you see it being served to somebody. All those things that can be really subtle and it's really hard to…for a lack of a better word…prove and get somebody to listen to you that can make a difference and then act on it.'

A representative from another state said, 'You can whisper something in their ear so that nobody hears them.' Staff threats of retaliation made while whispering in residents' ears were previously identified in the report '*They make you pay*.'

One representative shared that early in her career as an Ombudsman she became discouraged when one of her past supervisors (who is no longer with the program) told her, 'Well, it's really, really hard to prove retaliation.''

She reflected on his exchange, 'I felt that I could have the strongest case and that it was next to impossible to prove it so at that point in time I felt *hopeless* that this could be going

on and there was nothing that I could do or no one was going to do anything about it so what was my purpose?' She added, 'I was so frustrated because I remember I worked hard on that case. I had so much information and to me it was clear as day but to them…I felt like I was shut down…I felt like there was nothing else I could do.'

Poor Documentation Practices and Unreliable Reporting to State Survey Agency

Representatives spoke about the barrier and challenge created when staff document issues in poor quality such as inaccurate, incomplete, or untruthful account of events, care concerns, and provision of care. At times, this documentation was perceived by representatives as retaliatory in nature.

One representative shared a **story** about a male resident living in a 'memory care' assisted living residence who entered the bedroom of a female resident 'three different times' and fondled her. The daughters were kind of involved and the provider was involved. The care home reported the incident to the state, 'but they underreported it severely. What ended up happening is that the daughter was very appreciative of the fact that I was able to come out and help ensure that her mom's voice was the loudest. Because her mom was requesting to lock her door at night. She didn't want the resident removed from the facility. She knows this resident…she knows he has a disability…they live in a small rural community. She was protecting that other resident a little bit too. All she wanted was her door locked at night and the provider was telling her that they can't lock her door at night because that would be restraint seclusion. I go into assisted livings every day. A lot of them are locked. It's not restraint seclusion. 'Well, [de-identified name of the State Survey Agency] would,' she is telling the daughter this. Once I got involved, of course the tune changed really quickly. What it was is that they like to leave their doors open for the convenience of services and observations within their operation.' The representative added, 'This resident is not ambulatory so they were not going to get up and walk out anyways and the staff need to source the key to get into her room. That's the way it is.'

When asked how the situation was resolved, he said, 'They started locking her door. That eliminated the ongoing pursuits of intrusion for this resident. I subsequently talked to the assisted living because the resident just started going into other rooms. They worked with that resident's family and I think they found him a male-only assisted living.' He added, 'The person I was advocating for…the locks solved the problem. The only reason I learned about that was because once [State Survey Agency] got there and everyone started digging into it a little more, they realized that they had only reported that the resident came into her room one time and that they were hugging at the bed at the time…not that the other male resident was fondling her and that she felt *violated* and that it happened three times because they have a camera in the room.' He added, 'Where I grew up, that's called lying.'

Quote
"*Where I grew up, that's called lying*." – Ombudsman representative

The same representative said that the challenge of poor documentation is particularly severe in assisted living residences. He said, 'Here's the challenge that we're really encountering.' He went on to share a **story** about a male resident, 'I've known him for about 5 years…he's been at a couple of my different assisted livings. He is a little bit abrasive…uses some colorful language…that's him…love it or hate it, that's him, that's the way he has been. [De-identified sensitive information about this person's past]. So this is an individual with some red flags I guess if you will. He's got early-stage dementia and now he's starting to have some symptoms and lashing out at staff members and stuff like that. But the barrier for me to truly advocate and help this individual is squarely rooted in the complete and utter lack of documentation from the staff. Their answer is, 'Hey, he swung at another staff member. We need to up his meds' That's the natural reaction…is, 'We just need to do this. Just throw some more meds at it. He's on [de-identified type of specialized care], let's just put some more meds in him.''

He added, 'But as I'm sitting here working through this case, the daughter…I got notified on [de-identified date] that three other residents were complaining about him calling out for help and disrupting their sleep and stuff like that. He's in a traditional assisted living with dementia, he doesn't wander so there is no reason to move him across the street basically. What ends up happening is that the daughter went in [de-identified time] after work like at 3:00 o'clock to check his behavior because they're doing a Behavioral Log in his room and there was nothing written down the entire weekend. I got an Executive Director calling me saying, 'Hey, I've got three other residents complaining. We've had multiple incidents.' But then there's nothing that substantiated facts and history of what's going on.'

When asked what he thinks underlies the lack of documentation, he said, 'It's the staff simply not being held accountable to a performance standard. They're not being trained to a performance standard. The supervision…the leadership is not there to ensure the quality standards of their performance standards. I don't know but it doesn't happen in most of these places.' He added, 'Assisted livings and documentation, it's a night and day compared to skilled nursing homes. It's a huge barrier because I have no absolute understanding of historical fact.' He said, 'That's absolutely convenient for the industry. Absolutely.'

Quote
"*Assisted livings and documentation, it's a night and day compared to skilled nursing homes*." – Ombudsman representative

He added, 'Then I think what ends up happening is that then they turn around and use the most convenient intervention which is pharmacological onboarding. We just dismiss this as being "behavioral" rather than, you know. What happened in this case, as I was talking to the family…and they invited me to the care conference and I said, 'I won't be able to get over there but before the care conference, before we just jump to medications, I think it's important that you try to theme what's going on. Is this happening at a certain time of the day? Is it happening with the same staff member? Are there other environmental factors that are playing a part in this? We need to kind of look at the big picture before we just look at this pharmacological intervention.' I'm not necessarily suggesting that pharmacological interventions aren't necessary in long-term care in particular for people with dementia but it shouldn't be our first go to, it should be our last.'

Before going into the Care Plan meeting, the family 'collected a bunch of documentation' and then during the meeting, 'they started to talk about what they observed in terms of the trends. And the Hospice provider…the third-party provider jumped in and said that the notes provided by the care home 'aren't accurate. They're not accurately reflecting what's actually been going on.' The care home 'completely dismissed the fact that they're [not] doing any charting in regard to the context of what we're after. So now we've been going back and forth with this provider. The daughter is saying, 'I am not going to just throw more meds at dad. It's not how we're going to handle it. It's not what he wanted for himself.' They had put him on psychotropic med in the past…and that zonked him out…so the family is reluctant to do it because the significant negative implications it had the first time.'

He added that after he received the complaints, he told the care home, 'Hey, this is concerning. I want to let you know this could escalate things. Give me a call. Let's talk.' She goes over there and checks the charts for the course of the weekend…Friday to Monday, which is when these three other residents apparently had concerns…I haven't talked to them yet. I haven't gotten over there. But she said, 'There is nothing documented. There is no progress notes noted.' Then, I am looking at this and I am going, 'Okay, if they continue to push this, they may end up filing an APS report…APS could get involved…could result in rearrangement of legal decision making but from my vantage point, I have to align myself

with the daughter in her position in that they're not preparing her to make good decisions even though they're getting *paid* to do it. So you can see where this just gets all convoluted and one thing implicates the other.' He added that the care provider ended up using a different medication 'at a much lower dose.'

"Refused"

Representatives spoke about how certain staff members will say and/or document in a resident's clinical records the word 'refused' (e.g., 'refused showers' / 'refused medications') in a way that does not accurately reflect what had happened. Some of them considered staff use of the word 'refused' as a form of retaliation.

When asked whether there are things staff do to get away with their retaliation or hide it, one representative said, 'I think the documentation piece is huge because I often ask for documentation on things like if a resident is saying, 'I'm not getting showered because they don't want to deal with me' and oftentimes the way staff document as 'refused' when a resident didn't. It's an easy way to not have to deal with that person.'

Another reflected on the practice where certain staff inaccurately document that a resident 'refused' staff offer to assist them with a care task. She said, 'It's an easy way…especially for nurses…they'll just put that somebody refused and then the resident who is alert and oriented said, 'I didn't get my meds. I didn't get them because they told me they weren't available and I know they're available.' You go to the record and you see they put 'Refused.' Sometimes this happens with showers. 'They refused a shower.' She added, 'Or they weren't even approached for a shower. They were just 'forgotten' [said the word forgotten with hands gesture indicating quotation marks] per se but they keep putting 'refused.''

When asked about ways staff retaliate against residents, a representative from another state said, 'They will say a resident "refused" care or just in general, documenting or verbally telling management things that a resident did that aren't true. Like if they refuse care, medications, wound care. I had an allegation that a resident was yelling at a staff member and cursing at her without allegedly any provocation from the staff first. It is a hearsay situation until you get another staff member that backs up the original staff member that in that situation. So a lot of times the staff members team up against them and corroborate the staff side of the altercation. So that will happen and then it's in their record that they refused care.'

She shared her thoughts about this practice, 'If I were able to definitively prove it, it would be falsifying records. It's falsifying documentation, which at this particular facility…the [State Survey Agency] all but said, 'You're falsifying shower sheets. You're saying that people are getting them and they're not. You're saying they're refusing but you're not even

offering them.' Because they were interviewing very alert and cognitively intact residents who said, '*No*, I didn't get a shower.' Paramount of finding and having a citation was floor staff had had enough of a staffing issue and they corroborated what the resident was saying. They said, 'No, we can't give showers when there's only that many people.' They do falsify records, I mean, for non-retaliatory issues but they do falsify records. Very very hard to prove further than 'hearsay' where I have a resident say that he just asked them to come back later and then they got all rude with him and he kicked them out of the room at the end and then they say, 'He refused.''

When asked whether she considers staff practice of saying or documenting that a resident 'refused' care as a form of retaliation, she said, 'It depends on the resident because sometimes they don't have time but if they mark that no one is getting showers, then that's bad…so the records have to show that people are getting showers.'

She added, 'In the case of specific residents, yes. If they're difficult residents, sometimes yes. If they mark "refused" and in actuality they didn't…an altercation happened and they threw the staff out of the room or they said, 'Can you come back later?' and then it got all rude conversation, that's retaliation…yes, I would call it and that's how the resident feels. He's like, 'I didn't refuse that. I didn't swear at her. I didn't do this,' but his reputation precedes him. It is sometimes flat-out retaliation. Other times, it is staffing issues and wanting the documentation to reflect well.'

When asked what she meant when she used the word 'reputation,' she said, 'A resident that has been in the facility for a while and has a reputation of being quote and quote 'difficult.''

A representative from another state said, 'I think that electronic monitoring devices go a long way in proving what care is being given or not, but it only helps if the laws allow the video to be viewed by surveyors when citing a facility. The evidence being in the scenario to have something to do with citing the facility.' Her colleague said that that happens 'sometimes' and added, 'If it's the family and if they have a particular thing that they want to turn in. I've had many of them go unsubstantiated with film…'

She went on to share this **story**: 'I have a prime example. I have a resident…she has [de-identified condition that prevents her from moving] so she can't speak real clear. There is a video camera in her room. There was a complaint called in due to pretty much neglect. The gentleman walks in her room and she says, 'Are you going to feed me?' Her food is sitting on a bedside table and she can't move. She has [de-identified condition] so it has already affected all of her limbs. All she has left is her brain and a little bit of speech. And she is smart, very smart. [De-identified info] so she is not lacking in the area at all. She says, 'Are

you going to feed me?' And he says, 'I am pretty sure someone has already been in here and you probably refused.' He turns her call light off and walks out.'

She added, 'Now you do realize that is how they get out of every thing [said each one of the last nine words slowly]. They go and they put in their chart that they 'refused.''

This representative considered this practice as falsification of records. She said, 'Every single day, every single minute. It happens in those facilities. Yes Sir. And he tells her, 'I am pretty sure someone has already been in here and tried to feed you and you refused.' He turns her call light off and walks out.'

She added, 'That was at 5 [pm] that that happened and at 7 o'clock someone finally came in her room and fed her. Now that food is cold and it's pureed…so I just can't even imagine. She did ask them to re-heat the food so they re-heated the food. It does take her a long time to eat. Another one of those examples where this resident takes a lot of time to take care of but they accepted her as a resident in their facility and they knew she had [de-identified condition] and anybody who knows about that disease knows that they are total care…always.'

She went on to say, 'So regulatory comes in [and] all of the videos were shown but she [the surveyor] says, 'I am not able to substantiate the complaint.'' When asked what they make of it, she said, 'I don't know.' Her colleague said, 'We can't answer that.' The first representative said, 'That's where our frustrations really are.' The representative who originally brought up the issue of cameras sometimes not being viewed by state surveyors when investigating allegations in a nursing home said, 'That's why I made the statement. We don't understand it. That's the only way that it's going to be helpful…these cameras…to continue to have them.'

She went on to qualify her statement when she identified a problem when cameras are used inside bedrooms, 'Residents' care is cut short and not interacted and not nice when they have cameras. I've seen that. They just want to get in there and it's normally two people…a lot of them will have two-people assist for those residents that have cameras and they get in there and they get out because the camera is on them. Because they're afraid…whatever they say, it could be held against them.'

'There is no internal memory'

When asked about the root cause of care homes' lack of responsiveness to addressing residents' care concerns, one representative said, 'I think it's so many people involved. I can talk to a unit nurse and get her on board with the new answer or have a group of CNAs or a CNA know that this is an issue for the resident but within a week the unit nurse could be in another wing or that CNA could be gone. There is no internal memory. I don't think it's

being evil. It just falls by the wayside. Of course, we always say, 'Well, [write] it in the Care Plan' but there's only so much that the facility staff can hold in their brains about everybody's Care Plan. They're going to pick the really big stuff…that she needs her medications by this time, and again, a lot of the stuff that we're dealing with…and particularly in the first big wins are relatively little. We're saying, 'Can we please have coffee in the morning?' or 'Can she have a water pitcher filled regularly?' Or whatever. Usually, not big asks at the beginning. You think that you can just tick that off but those are the ones that slide away because the facility is looking at the *big* issue and staff is just moving around…so one person really knows about it and they may not be there all the time…and there's just no way to share that information.'

Privacy-related Challenges

Lack of Ability to Have Private Conversations with the Ombudsman Representative

Several representatives identified the lack of ability to have private conversations with residents as a challenge and barrier in their ability to address residents' fear of retaliation.

One of them said that some residents 'don't want us to go meet with them in person because 'they're going to know that I made a complaint. If you come in, then things are just going to get worse or they're going to be mad at me.' The representative shared her wish, 'If there was another way for them to talk to us and see us without that concern.'

When asked about a situation where staff hover by bedroom doors listening to residents' conversations, two representatives from the same state said, 'It happens all the time.'

One of them added, 'You have to remind the staff member that the resident has that right to the privacy…to be able to speak to us. Sometimes it's not done intentionally…there are a few times when it's not done intentionally…but I would say the majority of the time they are trying to get the information in regard to the conversation.'

Her colleague shared this **story**, 'When we walk into the buildings, we don't necessarily tell the Administrator or the higher ups who are we going to speak to. We can be walking down the hallway and all of a sudden the maintenance guy is changing light bulbs in the hallway that we're walking in. And I turn around and I look at him and I personally will call him out every single time. I'll say, 'Please go somewhere else. I am well aware.' And they're like [said in an apologetic tone of voice], 'Oh, it's okay, it's okay. We didn't mean to offend you.' The representative said, 'It's definitely not random. It's not random. If you say something to them about it and they're, 'Oh, I am sorry, I am sorry,' then you know it's not random.' She added, 'You'll have housekeeping [staff] following you…same thing.'

One representative described situations where care homes use surveillance cameras to monitor representatives' visits. She said, 'I've had some residents say, 'Well, I'm not gonna talk to you today because you said something' and I said, 'I promise you I didn't say anything but I know there are cameras here.' She added, 'From there on…I knew I was being watched at that point…so whenever I'm there for a complaint…for any reason, I will go to as many doors as possible and talk to as many people as possible because, that kind of showed me, hey, even though I am keeping this confidential, the administration knows that I've been in here talking with them and that there was a complaint made. So yes, that's just how I have to approach certain facilities differently because of that.'

When asked about how it makes her feel when care homes use their surveillance cameras to monitor her visits with residents, she said, 'Invasive. I feel it's invasive. I feel like that resident should have privacy and regardless of who they're visiting, it doesn't need to be monitored…I understand why they have cameras…I think it's a good idea but the fact that they are going in after, 'What did you complain to the Ombudsman about?' It's not right, it's disrespectful, it's rude, it should not happen, it's invasive.'

Quote
"We've had administration that go in and literally tell the resident, 'We know you're talking to the Ombudsman. Do not be talking to the Ombudsman.'" – Ombudsman representative

The first representative said, 'I think that is a threat. Telling a resident that they can't talk with anyone that they wish to, you know, they have the freedom to do so. They are in charge of that home. Yes, to me, that would be a threat just for the simple fact that they're saying, 'You can't talk to this person' or 'Do not talk to this person' like they don't have the right to do so. They do have that right and they should have privacy, they should be encouraged to talk to the Ombudsman.'

When asked if she is aware of situations where she was watched through surveillance cameras and that it triggered a threatening response towards a resident she visited, she said, 'Yes. Absolutely. I'll see a particular staff who isn't a care aide but I'll see a particular staff actually go behind me into rooms in order to see what I have discussed with them. Yes, there has been at least one home where there is a staff member that will go behind me and will ask residents what they've talked with me about.'

When asked how it makes residents feel when an Administrator confronts them and threatens them not to speak with the Ombudsman representative, her colleague said, 'It makes them feel like they don't know what will happen if they talk to the Ombudsman. Again, 'Am I going to be discharged? Are they going to answer my call lights if I talk to the Ombudsman? It's just the feeling of what they feel because we have residents that they *do* talk to us and they depend on us speaking up and not using their name.'

Her colleague added, 'They depend on us so when an Administrator says, 'Don't talk to your Ombudsman,' I would feel like they are taking away, 'That's *my advocate*. Who am I going to turn to? Who can I turn to?' That's another reason if an Administrator says, 'Don't talk to the Ombudsman,' it's basically taking away their freedom in that sense.'

At a later point in the interview, her colleague said, 'I know the frustration that she [referring to her colleague] has made referrals to the [state survey agency] and they go out and interview and then they don't have problems or they won't speak to the agency. And it's due to the Administration. I feel…we're pretty sure…can we verify it? No but we're pretty sure it's because the Administration has told them, 'You've talked to the Ombudsman. Do not be talking to the other agency.''

Ombudsman Representatives Being Monitored While in the Care Home

When asked about things that do not currently exist that if existed would have helped the Ombudsman program better address residents' fear of retaliation or actual retaliation, a very experienced representative said, 'I wish we had a stronger requirement that we could put in place that would allow us to elude the sense of the homes monitoring our comings and goings. We kind of think step back in time when COVID came and they wanted to monitor people's temperature and get your name and the time you visited and some of them even had facial recognition scanning at the front doors. We were caught in this difficult position wanting to come and go without a monitor…without monitoring but then we had the COVID concerns confronting us so to some degree since we were caught off guard by this whole thing, we participated in that for the interest of safety for residents and ourselves but then I think that created a certain culture of monitoring that we haven't been able to step away from. So I would like to see something that is clearer that we are exempt from signing in, from any kind of documentation of our visits and our comings and goings in facilities. That would be something I feel like we need stronger.'

When asked what she sees as the potential problem with Ombudsman representatives being monitored while in buildings and visiting with residents, she said, 'Because they might see what residents or family members or staff I interact with and then there might be a follow up with the resident or the staff person. They might inquire about why I was there,

what I was asking them about, what did they tell me, and I don't want residents to have to experience that and I'm worried that that kind of thing might happen.'

Residents Unaware of Right to Hold Private Resident Council

Many representatives said that many nursing home residents are not informed about Resident Councils and their right to have a private Resident Council meeting if they choose to hold it privately (prior to Ombudsman representatives educating them about it).

One of them said, 'Most of them are not aware.' When asked how many residents know that they have a right to have a private Resident Council meeting, a SLTCO from another state said, 'I don't think they know. We try to educate them and inform on that…'

When two representatives from another state were asked about the extent to which they believe residents are aware that they have a right to hold a private Resident Council, one of them said, 'They don't know.' Her colleague said, 'Probably more often than not they are not even aware of that.'

When asked the same question, a representative from another state said, 'I would say that about 25% of the [Resident] Councils know that they can do that.'

In response to the same question, a representative from another state said, 'They don't know. They are not aware of their rights in most areas…in particular this one as well…of their right to be running by and for them.'

Another representative said that most residents are not aware that they have a right to have a private Resident Council meeting. She added, 'A lot of times they're surprised because they are always thinking that staff has to be in there. For whatever reason, it's always the Activity Director. When I walk into a Resident Council meeting that I am invited to, I see the Activity Director and I'll say to the Resident Council President, 'You are aware that you don't need a staff member at these meetings?' And they're like, 'No, we were told that the Activity Director has to be here,' [And I'll tell them], 'No, the Activity Director does not have to be here.' She added, 'Now, we as a program, we have a Resident Council Handbook that we normally will pass out at these Resident Council meetings…so they are aware and they can see it in print that it states that the staff members do not have to be in attendance.'

Other representatives said that residents *are* aware of their right to have a private Resident Council meeting. When asked, 'To what extent they are aware of that right?' one of them said, 'They are because we educate them. We educate them. They're very aware. Sometimes I have to remind them, 'This is your meeting.' We have a big role in that in making sure that they understand that that's their meeting.'

One representative spoke about how many Activity Directors can be helpful in attending and taking minutes during Resident Council meetings in certain care home. Another explained, 'They need somebody because they have disabilities…they need somebody to take those minutes…they need somebody to do that for them. My Activity Directors are great.'

This representative described how she guides Activity Directors in ensuring that the minutes they take during Resident Council meetings remain confidential, 'I'll have that conversation…I'll tell them, 'You know that anything talked about in this meeting doesn't go anywhere.' In other words, if a resident has something to say…they don't want their name involved or something, then that grievance needs to be created in a different way.' She said that she tells Activity Directors, 'Your confidential level is the same as mine.''

Lack of Secure and Private Way to Communicate with the Outside World

Several representatives spoke about residents' lack of access to a secure and private way to communicate with the outside world including with the Ombudsman representative. This issue is addressed in detail in **Appendix 7** titled Assistive Technology.

Lack of 'Person-Centered' Culture of Care

Several representatives spoke about the culture in the building as a major challenge and barrier. When asked about the main challenges and barriers in addressing the issue of residents' fear of retaliation, a SLTCO said, 'The culture of the place. That's really the thing.' She added, 'It's when there is no desire in the facility to change either because of a specific person that is the problem or if it's the whole building and especially if the person running the building is the problem or in our case also corporate…if the corporation is the problem too. So that's it…when there's a bigger systems barrier. *That's* the biggest frustration.'

When asked the same question, another representative said, 'In the nursing home environment, it's the nursing home culture that is the limiting factor. It's the environment.' He explained, 'I don't know how are things back there but back here we're still very much in a facility-centered business operations in our nursing homes. All decisions in the whole environment are based mainly on the needs of the facility to complete tasks and not the residents' needs for really quality care and quality of life. So still having that antiquated business model here, it's very difficult to have someone not be fearful of retaliation in an environment where they have very little control and decision making.' He added, 'Compounding that would be workforce shortages which don't create pools of potential staff members that are really person-centered versus task-centered…and so the combination of that. Then thirdly, there's the lack of training I would say but it's hard to incorporate good training into a culture that is not set up to really receive it and work with it.

My big thing that I preach all the time is staff are not well trained enough in the difference between task-centered and person-centered care.'

He went on to say, 'I feel like my observations, my personal experience, my knowledge of [de-identified name of form] Reports, which we receive here in [de-identified state]...we the Ombudsman program are one of five states where we are the agency that receives allegations of abuse in licensed long-term care.'

Note: The form this representative referred to is a mandated reporting form for mandated reporters if there's an allegation of abuse and there was a requirement for mandated reporters to complete the form. That form then needs to be sent to certain agencies in certain situations including the Ombudsman program, local police, and licensing.

He added, 'We see a lot of [de-identified name of form] that are really the root cause of the allegation is task-centered caregiving versus person-centered and things go array and then allegations are made and it could have been avoided, which is staff being better informed of how their interactions both verbal and non-verbal with residents end up being a negative outcome for the resident, if it's task-centered. Those are the biggest barriers I see for ever creating an environment that would either minimize or eliminate or create an environment where there would be no fear of retaliation. It's just not resident-centered enough environment.'

A representative from another state identified the following as her main challenge and barrier in addressing residents' fear of retaliation, 'Poor attitudes with administration. Those are the people that we have to go to as kind of our first plan of attack and if they are always like, 'Oh, that person complains all the time' and just kind of dismissive of the concerns, I can already tell right away, this probably isn't going to go anywhere because they're not willing to work with me, they've already labeled this person as a problem and they're not willing to hear them out or do the right thing or even just care about the problems and making them better for this individual.' She added, 'I feel like that just trickles down throughout the whole staff.'

It's Not a Priority in Many Care Homes

A very experienced representative spoke about a challenge stemming from the fact that the issue of residents' fear of retaliation is not a priority in many care homes. She said, 'I think that because of the poor staffing, because of the decrease in the quality of care in the nursing homes at the moment, that really they're dealing with bigger issues like cubitus ulcers and infections and medication errors and a *lot* of really very concerning quality of care problems that have evolved and because of those, the focus is on trying to *repair* or improve the quality of care and I think it just makes any kind of sense that if they were to choose to focus on how are we going to make the home more comfortable for residents so

they can speak up about their concerns, the focus is just not there. They're dealing with these bigger concerning infection control and wound care and their focus is on *that* and it's not really on [fear of retaliation].'

She added, 'We used to say that one of the core principles to our jobs was helping with quality of care and quality of life. We can't even get to quality of life right now because we can't assure that quality of care is happening…so all our focus and attention. We're in a pretty concerning place in long-term care because we're not getting the quality of care that we *have* experienced in nursing homes. It's just gone more downhill because of the staffing, because of corporate priorities in a lot of homes so the idea of fear retaliation is so far down on the list that any home would begin to focus on. I think that's unfortunate.'

Quote
"The idea of fear of retaliation is so far down on the list." *– Ombudsman* representative *referring to care homes' priorities*

Towards the end of the interview, she went back to this issue and said, 'I think right now the quality of care in nursing homes at least in our state is so *bad* that they are so worried about the infective decubitus ulcers that are now putting a person in Hospice care and how that whole series of events take place within the nursing home setting. They're looking at that severe situation. They can't even dust off the concept of thinking about fear of retaliation and how they would address that because, again, we have such *severe* quality care issues and to some agree this is more like a quality of life [issue].'

When asked about it, this representative agreed that there's an inherent paradox. That is, the post COVID-19 exacerbation of workforce crisis and worsening staffing levels in many care homes pushes many care providers away from focusing on residents' fear of retaliation and protecting their rights – including their rights related to fear of retaliation and actual retaliation – exactly at a time when greater attention to these issues is needed.

Characteristics of Administrators of Care Homes with High Levels of Fear of Retaliation

When asked about what she sees as the main challenges and barriers in addressing the issue of residents' fear of retaliation, a very experienced representative said, 'It can be the leadership within the home. I think the culture of the home starts from the top down.'

When the same question was presented to a representative from another state, she said, 'The mindset. When you have an Administrator set in his ways and 'the residents are the problem. They don't know what they're saying. They don't know what they're accusing, their fears that they are not real,' those are very very hard challenges because if you have an Administrator that's, you know, 'You can't teach an old dog new tricks,' he is set in his way, it's *very* frustrating because you know you're not going to get anywhere.'

When asked about the main challenge and barriers in addressing residents' fear of retaliation, one representative spoke about Administrators' denial of the issues, 'Sometimes an attitude from the administration, 'My staff wouldn't do that'…'Oh, that never happens, my staff would never do that.' It is just frustrating to hear that because you don't know what you don't know.'

When asked about the characteristics of Administrators of care homes with high levels of residents' fear of retaliation, a representative from another state said, 'They just don't care and they don't take it seriously and they don't believe. They foster the environment. They're often the ones that are retaliating. Like, 'If you keep having that happen to you, this will happen to *you*.' 'If you do this, then that,' 'If you're going to tell the Ombudsman this, we're going to make sure you don't get care at all.' We have some that threaten and then we have some that are passive about it, manipulative, and some that neglect. And they tell the staff not to follow up or not to follow up timely.' She added, 'We've had some really *nasty* Administrators and nasty staff.'

Representatives spoke about the ways in which the care culture fosters residents' fear of retaliation and actual retaliation against them. One of them shared a **story** about an incident that has taken place in an assisted living residence, 'Staff were quite awful.' While meeting with another representative, a resident 'made a comment that they didn't like getting yelled at and the second they got done saying that the Administrator was on the other side of the door listening, opened the door, and came in yelling, 'We don't yell at anyone here. We don't yell at anyone here' so, of course, right there the resident was all struck…like what is going on.' The assisted living was surveyed by the state survey agency. 'They had so many tags [including a tag issued for this situation] and they just gave up and quit. That facility did eventually shut down.'

The representative interviewed added, ‘I know the Ombudsman took the staff into a private area where there were no other residents, sat down, and calmly explained the role of the Ombudsman, spoke of the resident rights and the other agency staff was reiterating the same thing they had expressed that the residents have the right to express their opinions without fear of retaliation. The representative then had to go back to visit the resident before leaving and explained that what had happened should not have occurred. They explained to both the owners and the residents that the residents can express concerns without fear of retaliation. They ‘gave the resident their business card and contacted the State Ombudsman right away just to make her know of the situation. So that was a really challenging situation.’

Another representative identified another problematic characteristic, ‘Administrators that don’t want us in the building and don’t cooperate with Ombudsmen.’

One representative spoke about Administrators who don’t hold their staff accountable, ‘Having difficult managers who just don’t want to deal with us, they don’t want to deal with residents, they are not going to discipline staff, they’re just going to let them run amok. That has been some of the biggest barriers.’

When asked about the main challenges and barriers in addressing residents’ fear of retaliation and actual retaliation, a representative from another state said, ‘I think the lack of responsiveness. You work hard and you meet the resident regularly and you bring them along and they finally make their complaint that we can take to somebody and we get *nowhere* or it doesn’t stick very long.’

When asked who she referred to when she spoke about lack of responsiveness, she said, ‘Lack of responsiveness by the administration or the facility employees to the complaint that I have extracted so difficultly from the resident. You work and you work and you work and finally she says the problem and you walk out of there and you’re so proud that she is willing to share for the first time and nothing could be better that she actually sees improvement in whatever it is and when that doesn’t happen, it’s like a domino because she will tell everybody that we were ineffective, ‘I talked to the Ombudsman and it didn’t work.’ She’ll tell in a dining room or she’ll tell her roommate. It not only hurts her issue, but it hurts our program too.’

A SLTCO said, ‘A lot of times you'll see the Administrator just kind of hiding behind closed doors and they're just in meetings all day and they don't take the time to get to *know* the residents.’ She added, ‘The Administrators who are not successful at that are those that are defensive, have something to hide, maybe they have compassion fatigue, maybe they have

vicarious trauma and it's not being addressed. They're not taking care of them[selves] or their staff and they don't have good leadership skills.'

Another representative said, 'You walk into a building and you ask residents, 'Where's your administrator?' [and the residents say], 'I don't even know who that is.' They're in their room…behind the door…the door is closed.' She explained, "Arm's length administration' is what I always refer to it because they're just content staying behind the closed door and then when we bring issues to them, they're always, 'I don't know what the problem is' and I have said multiple times, 'You want to know what the problem is? The door needs to go off the hinge.' It's kind of simple because if you have an open-door policy, then you're going to see it firsthand.' She added, 'The ones that hide in their office, they're not seeing those staff interactions with the residents and how the residents might be approached by those staff members.'

Quote
"*You want to know what the problem is? The door needs to go off the hinge.*" – Ombudsman representative encouraging Administrators who rarely leave their office to visit with residents

One representative said that 'new Administrators that can't run the home and staff are not afraid of them' represents a barrier for Ombudsman representatives' ability to address residents' fear of retaliation and staff retaliation against residents.

When asked about the characteristics of Administrators of care homes with high levels of residents' fear of retaliation, a SLTCO said, 'The 'green ones' or 'the recycled awful ones.' She added that they 'don't even know how to run a nursing home and deal with problems because a lot of them just got out of school or a lot of them have been fired from 85 different facilities and now they've ended up here. But I know them all.'

Another representative identified a concerning trend in Administrators' background, 'This is something we're seeing even more and more…we see lesser qualified professionals in the industry. Our problem solvers used to be Health and Human Services directors at assisted livings and those problem solvers have subsequently become business degree graduates….so if you're talking about people in there that have a business degree, are they going to problem solve with a *soft* skill of customer service that is customer-driven? Because in today's world of consumerism, the customer is no longer always right…'

He added, ‘You’re seeing a transition within the culture through the leadership driving a more business centric culture.’ When asked whether this trend could contribute to residents’ fear of retaliation and actual retaliation against residents, he said, ‘Absolutely.’

In one of the interviews, I asked two representatives this question: Is there something in your experience that works with Administrators that run a place with a culture that is dismissive of this issue or not cooperative with you? One of these representatives said, ‘I think it depends on the situation. Sometimes in those homes it is not really the administration that is the issue, it’s the ownership. It is the people that they report to. That’s a different scenario than if it is the administrators themselves. I’d say, more often it is the culture of the corporation than it is that particular person.’

Her colleague said, ‘I would say definitely that makes a difference. Often, I told people in the past, ‘Look, I’d be your bad guy…tell your corporate…the Ombudsman wants’…not that I want it…but ‘tell them that is what needs to happen’ I’d be that person. Feeling empowered…I’m empowering them to go against corporate people.’

For-profit versus Not-for-Profit Ownership Status

Several representatives stated that for-profit ownership status represents a barrier in their ability to address residents’ fear of retaliation and actual retaliation against them.

When asked about characteristics of care homes with less or no residents’ fear of retaliation, one representative said, ‘I divide it into two: Not-for-profit and for-profit. Not-for-profit in our area tend to be religious-based…the Methodists, the Catholics, Presbyterians. They’re there to do a mission and most of the time the people that they actually hire are from their congregations or from their belief system. They have to keep the doors open but they don’t have stockholders or partners or shareholders to make more money. I think the bad apples or the bad actors are the for-profits. Unfortunately, there’s just so few that I have faith in anymore. I would like to go back to the days where not-for-profits had a much bigger role in this word.’ She went on to say, ‘When I get asked…and I am not supposed to answer that question…if I get asked, ‘Where should I send Mom?’ It was always a not-for-profit.’

She added a positive observation about hospital-based nursing homes, ‘Because they can pull staff from the hospital if they are short, they can pull expertise from the hospital if they are short. They tend to be more institutional looking, not soft and fuzzy and comfy chairs but residents are clean, they’re happy, they’re not fearful. I’ll take the difference in aesthetics over, you know.’

Another representative suggested, ‘Really looking at the larger picture of for-profit models and the incentive to cut corners for equity owned facilities and really looking at creating a system that guarantees transparency of finances.’

A representative from another state spoke about the problem of corporate conglomeration, ‘One of the biggest challenges is that it used to be [that] we were dealing with people that were allowed with the autonomy and authority to make decisions at a typically a facility level. Your nursing home administrator or your assisted living director had the authority to be a change agent and we could get solutions at a very local level. And what's happened is that because of the corporate conglomeration that's been unfolding within the industry, it's become not so sourcing solutions to issues. It has become corporate politics. And it's been creative corporate politics have really gotten in the way of our ability as advocates at a local level to support residents in their environments.’

A SLTCO spoke about the problem of private equity firms, ‘One differentiation I can make is equity owned…both equity owned nursing homes and assisted living…the bottom line is money. When that’s the bottom line, then from the top down leadership may…and I am not saying always…I am not trying to make a huge generalization…but may not prioritize good quality of care, paying staff well so that they can have a livable wage…they are the working poor…and provide the support that they need to feel confident and competent in their job and have some level of pride and satisfaction.’

Another representative spoke about the problem of out of state companies, ‘Unfortunately, here in [de-identified state] we have a lot of out of state corporations that are buying up facilities. They are not necessarily familiar with [de-identified state] rules and regulations. They may come from an area that doesn’t have a strong Ombudsman program. I know we’re all 50 states but some states are a little less than other states are and if they come from one of those states where they’ve either had a bad experience with the Ombudsman program or they come from a state where the Ombudsman program is not very face forwarding, they don’t want to hear about what’s going on. I think that would be a key point for us in trying to correct the issue industry-wide.’ She explained, ‘Because you cannot really find who owns each [care home] and it’s this ghost paper trail that you’re going through and Google searching for hours to figure out who the owners are.’

One representative said, ‘I feel that my best cared for residents reside in not-for-profit homes. I have multiple not-for-profit homes and there’s a distinct level of care that these residents receive versus your for-profit large corporation.’

When asked whether there are exceptions to her observation, her colleague said, ‘I would say so…and I will tell you, it is not as an Ombudsman but before this role I worked in skilled nursing and for [de-identified number of] years I worked for a for-profit…it had one owner…it was a couple and they owned the building the entire time. Even though they were for-profit, I will tell you it was a very short jaunt to the top sort of speak and they did empower the Administrator for the most part. There were things she definitely needed to

get cleared by either their owners or their CEO but again, they were all local, they were there, they came on site, they were involved, so like what [de-identified name of her colleague] said…that shorter distance, being present makes a difference too. And there's another [for-profit] facility… similar…that I go to they have consistent staff too and I've worked there for years.'

Staffing Crisis

The current staffing crisis in LTC homes – which was brewing years prior to COVID-19 pandemic – was perceived by several representatives as a major challenge and barrier in their ability to address residents' fear of retaliation and actual retaliation against them.

Research Findings
A review of research studies conducted by Harrington et al. (2016) several years prior to the COVID-19 pandemic found that half of nursing homes had 'low' staffing levels and at least a quarter had 'dangerously low' staffing levels.

One representative said, 'The staffing crisis…exacerbation of that since COVID has made that worse that I think they are willing to accept less in their staff because they are so desperate to have them.'

Her colleague added that, 'Administration probably knows what's going on and doesn't do anything about it. That kind of a culture…like a culture in the building [said while shrugging her shoulders] that, 'We need staff and it doesn't matter what goes on.''

A representative from another state said that staff retaliation against residents has become more blatant in recent years. She said, 'I would tell you in the [many; number de-identified] years that I've been doing this…retaliation has always been real. I believe though in the more recent years it is more blatant. What I mean by that is we've never been able to prove retaliation. It's always been there. It has always been a fear for family members and for residents. It didn't seem to be that we ever had *enough* information to verify it happened. In today's society post COVID, it seems as though not only is the retaliation real, but staff are very open about retaliating like it's blatantly there.'

Her colleague explained, 'because the demand for staff in long-term care is so great, there is no fear of losing your job…that you can bounce down the road to another facility and get more money. There is such a desire for people…they are hiring them on the spot.'

New Staffing Regulations in Nursing Homes
During this project, CMS has passed new regulations pertaining to staffing levels in nursing homes (for details, see the Biden Administration's announcement (April 22, 2024) and CMS Memo (June 18, 2024)). However, as reported in the Washington Post, care advocacy organizations have expressed major concerns regarding these new staffing requirements. For example, Richard Mollot, Executive Director, Long Term Care Community Coalition was quoted saying, 'It is hard to call this a win for nursing home residents and families' given that the minimum levels were below what studies have found to be ideal. One Ombudsman representative interviewed for this project said, 'This week we got the minimum staffing from the feds but that's just a band aid and a very low-level band aid.'

Relationship Between Poor Staffing Levels and Fear of Retaliation

The issue of poor staffing levels was addressed earlier in this report in the segment titled *Poor Staffing Levels and Inadequate Training* in **Chapter 4** Contributing Factors to Fear of Retaliation and Actual Retaliation.

The segment presented below focuses on representatives' statements regarding a relationship between poor staffing levels and residents' fear of retaliation and actual retaliation against them. Extensive support for this relationship was identified based on statements made by numerous representatives.

That said, variation and exceptions in the perceived weight and influence of poor staffing levels on this relationship was also identified. While rigorous quantitative research is needed to shed light on this relationship and the factors contributing to it (including separate focus on each of the following four aspects: fear of retaliation, threats of retaliation, perceived retaliation, and actual / confirmed retaliation), key pathways and mechanisms potentially underlying this relationship were described by representatives.

When asked whether she sees a relationship between poor staffing levels and residents' fear of retaliation and actual retaliation, one representative said, 'Yes. Absolutely.'

When asked about things that do not currently exist that if existed, would have enabled her to better address residents' fear of retaliation, a representative from another state said, 'Adequate staffing in long-term care homes. A lot of the things that residents don't want to bring up are about not being able to get to the bathroom on time…a lot of things revolve around staffing. So if they have adequate staffing, I think that would be helpful. Staff would be less rushed…I just think a lot of things would go away.'

When asked about the main challenges and barriers in addressing residents' fear of retaliation and actual retaliation, a very experienced representative said, 'I think it's the whole staffing issue. It's the very center of it all where there is not enough, the staff feel like they can get away with anything…and unfortunately, they are a lot of times. I think that is the *center* of it. Compassion is out the window…and I hate to be so negative cause I've been doing it for [de-identified large number of] years. I worked in long-term care before that as well. My whole life has been devoted to long-term care.'

She added, 'It has changed so much and I see at the very center of it…people change, compassion doesn't seem what it once was. I do think the huge issue…the *elephant in the room* is the staffing and the power that staff feel just by coming into work.'

Quote
"*The elephant in the room is the staffing*." – Ombudsman representative

Another representative said, 'Facility staff on all levels from top to bottom they're burnt out, the ratios are terrible for staffing especially with floor staff but that's not the resident's fault. I wish some of the staffing ratio issues and the staff burnout that's happening was focused on more than it is because I think if that was a addressed more, it could help reduce some of the retaliation and issues that we see happening with retaliation.'

This representative confirmed that she sees a link between poor staffing levels and residents' fear of retaliation and actual retaliation, 'Yes. In general, yeah. It's not the only one but definitely, I would say yes, for sure.'

Referring to low staffing levels, one representative said, 'I think this contributes to the frustration, the fear.' When asked how low staffing levels play into residents' fear of retaliation and actual retaliation, she explained, '*Because* they are not getting the dignity that they deserve for one thing. The staff are overworked, they are working double shifts, they are rushing to get to the next resident, leaving those residents feeling unimportant, they're just *rushing* all the time. Because they are working double shifts so then of course they are going to get frustrated because they're tired…they're tired, they still have another shift, these residents might not be cooperating or something and that's where the retaliation comes in I think.'

Another representative explained why she thinks there is a relationship between low staffing levels and residents' fear of retaliation or actual retaliation against residents. She said, 'It almost directly correlates because if they're understaffed, they're stressed and the stress is going to go out to the resident and if the resident is having a rough day, you're playing around with fire. It's a fire waiting to happen.'

Quote
"A lot of staff get mad when they have a lot of people. They put a lot of people on them and they take it out on most of the residents that are there. So yeah, I've seen a lot of that going on." – A former worker in nursing homes Source: Interview for the film *Stop Retaliation in Illinois Nursing Homes*.

When asked if she sees a relationship between low staffing levels and residents' fear of retaliation and actual retaliation, one SLTCO said, 'I would say…due to the level of stress, short fuse, maybe compassion fatigue that staff members experience because there's not enough staff to meet all the needs of the residents, it starts to pile up and it creates a situation where the risk of abuse or the fear of retaliation rises. They're overworked, they're tired, they don't get a break, they go home and they take care of their family members, they're working poor, they can't get good healthcare, and so on and so forth and it creates a condition for more of that to happen and the residents then suffer at the hands of retaliatory acts, abuse, neglect and then the next thing you know it's just rampant in the facility because they just can't keep staff and we've watched this over and over in our state.' To make sure I understood it accurately, I asked whether being short-staffed plays a role in residents' fear of retaliation? Her reply was, 'Yes. Oh yeah, we've seen it.'

Another representative said, 'We know that staffing ratios increase give better care. We know that. It's very possible with shortages that staff are running harder, more residents, less time and it's possible that they could be in a hurry, they could be rude. Could this be retaliation with…say…residents who might be more difficult? That could be a possibility. 'I just can't put up with this anymore and I am going to shove his leg and that's it.' That's retaliation as well.'

When asked about characteristics of care homes with less or no fear of retaliation, one representative said, 'I want to say continuity of care. I want to say staffing numbers.'

She explained how poor staffing levels may lead to retaliation against residents, 'Because I believe some of the retaliation from staff is that they are frustrated. They have 20 residents to take care of…not that it excuses it…I am just saying that adds to it. Is the retaliation coming from the culture or the environment of that facility? If you have a continuity of staff, say, the same staff person that knows the resident, knows their routine, *establishes* that relationship so the residents can say, 'You know Suzie, you were really rough with me this morning. Can you try to do it this way?' Or 'Ouch, that hurts.' For that person to be able to say, 'I am sorry. Let me come back in a few minutes and give you time.' That type of a thing.'

She added, 'I think that the way that it is set up for staff right now is that they are going to rush to get to the next person and they get angry, they get frustrated and if someone is going to speak about their work quality, they get defensive and that's when some of the retaliation comes up. And then the residents…they're not respected. They are just seen as somebody that's kind of living out their life and we don't have to listen and 'I get to do this because this isn't your home and I work here.' It's the attitude that comes along with it.' When asked more directly about the extent to which she sees that poor staffing levels contribute to retaliation, she said, 'I don't think it plays the highest extent. I think there is some level that it plays into the retaliation. I don't think it's all of it but I do think it is some of it.'

When asked about the extent to which she believes understaffing or poor staffing levels contribute to this phenomenon, a representative from another state said, 'Oh, I mean, it's got to be like 90%. It's got to be way up here.' She explained, 'If you have one person to 20 residents and you're running around and then the call lights and then one of them complain to your supervisor, then they get upset.' She spoke about staff frustrations in this context and added that she doesn't think everybody wants to retaliate.

She added, 'Some people just feel the need for revenge once they have been complained on. I don't know if this is the right position for them, but I do feel like when you have one CNA to 20 residents and you're running round and then a resident complains and you have that in you for revenge or to retaliate, then it's just *not* a good mix. Maybe that would not have been happening if the CNA had more staff to help them. Maybe the less staffing brings out the bad side of someone when they're working too hard and they can't manage it.'

Quote
"Maybe the less staffing brings out the bad side of someone when they're working too hard and they can't manage it." – Ombudsman representative

Another representative said, ‘I’ve ran into facilities that are so short staffed that they are afraid to fire someone or let someone go even when they are pretty much aware that the retaliation is happening.’

One representative spoke about understaffed care homes where certain staff members tell a resident, ‘It’s either me or nothing.’ This was described by another representative as ‘Leverage. They’ve gotten away with it. They know they have leverage in that situation.’

Another representative said, ‘Just because someone says, ‘Well, I did this because I didn’t have help,’ you know, as an Ombudsman, we advocate, we make sure regardless of if you say, ‘Well, we didn’t have enough staff and this is why the resident was on the floor for four hours,’ that’s not a good answer. That’s not a good answer. Our role is, ‘Okay, you are to make sure that there *is* enough staffing on the floor. Are they doing their 2-hour checks? Are you holding your staff?’ You look at it from nursing supervisors or what not. ‘What are you doing? Are you holding your staff liable, responsible for the care that they provide to residents?’ That’s what we expect.’

She added, ‘You can’t make excuses regardless. We understand that there’s a certain amount of staff that you don’t have at the time but unfortunately, the residents…they are still going to need care. They are vulnerable and you have many residents in that facility that require full care. I tell administration, ‘It is your role regardless to make sure that you find any way possible to meet the needs of *every* resident in that facility.’ Number two, hold your supervisors, your Directors of Nursing, your nurse managers responsible. Monitoring, making sure that your staff is out on the floor doing those 2-hour checks at all times.’

One representative said, ‘I think that sometimes there are some management or administrators that honestly really don't have time to deal with concerns. I think they're short staffed, they don't want to have to bring an issue to staff thinking we don't want to lose them…it's a body. It does happen so I think honestly it starts from management if there's poor management, how do I know that they're really going to address it with staff and make changes. Somebody could get a write up but then what happens? I always want to assure a resident that it's not gonna happen but it does so I can't say that 100% it's not gonna happen. It does and I think there's a huge increase than five years ago.’

When asked if she can elaborate, she said, ‘Retaliation, treatment of residents…I'm seeing a lot more.’ She added, ‘I think it's directly related to the staffing shortage and there's a lot of agency staff so they can come in, not really care a whole lot, be there for a short period of time, then they can go someplace else. There’s really not a relationship between residents and staff members where they can build that safety and get to know each other.

Without that, it's somebody coming into your home, they're gonna leave and maybe maybe they'll come back…maybe they won't.'

When asked to elaborate, she said (referring to nursing homes), 'Some places have 80 to 90% agency staff coming in. I have a couple that…I usually ask for percentages and one was up to about 90%. And residents will say, 'You know, I'll say something and then staff will come in and do this or verbally abuse me' and they can mention something and by that time that staff could be gone.'

Not all representatives saw a relationship between poor staffing levels and actual staff retaliation against residents. When asked whether low or poor staffing levels contribute to residents being *retaliated* against, one very experienced representative said, 'I don't know if retaliated…I would put it in neglect. I would count it as being neglectful. I don't know if it would be retaliating. But it would be definitely neglectful for residents.' When asked whether low staffing levels could lead to residents' fear of retaliation, she said, 'I don't know.'

Her colleague added, 'I would say possibly…definitely on that one because if there's not enough staff and they're afraid that if they push their call light, it's not going to be answered. Well, they're already low staffed, are they going to get help that evening? So yeah, I think that can play a role.'

A representative from another state described a scenario where low staffing levels is not always an indicator of poor quality of care while adequate staffing levels do not necessarily translate into good quality care. She said, 'Staffing is definitely…I'm sure across the entire states…staffing numbers…not having the right amount of staff is a problem. A lot of times the family wants to report, 'Oh, there was only one aide on the floor' [or] 'There were 2 aides on the floor' what have you. Our role that [de-identified name of colleague] and I teach our staff is…we try not to focus on the actual numbers…we're not regulatory. First of all, we can't do anything about the actual number. We look at what's the impact on the residents. What impact because we have some facilities that have minimal staffing if not under staff but they're doing an amazing job, the residents are cared for, they don't have any complaints. Then we have other facilities where there's a lot…a ton of staff around always but the care stinks because even though there's that many staff, they're not answering call lights, they're not bringing the food when it's hot, they're not assisting to feed…so we've seen it at both spectrums…both ends. That's why when we go in, we're looking at what's the impact on the residents. Okay, they're not meeting a ratio but are they getting fed? Are they getting changed? Are they getting showered? And residents most times even when they are short staffed, 'Yeah, we're getting all of those things.' They're killing themselves. They're busting their humps. They're doing the best they can.' And then, like I said, there's other places that

it's horrible…there's plenty of staff, the numbers support there's plenty of staff but the residents still aren't being cared for.'

When asked what makes it so that despite having adequate number of staff, the care is poor, she spoke about the approach of the administration, 'It's the administration. Honestly. When you have *consistent* administrative staff being the Administrator and the Director of Nursing, then that trickles down to the attitudes of the staff below you.'

Denial About Inadequate Staffing Levels

Certain representatives spoke about care providers' denial of inadequate staffing levels.

One of them said, 'The facilities are afraid of looking bad. They're afraid of getting cited for something. You know, you don't have enough people to answer the call lights in a timely manner. They'll never admit that. 'Oh, we have enough people.' That's what they'll say…they have plenty of people, 'We're fully staffed today' and this resident is sitting in their own wet brief for an hour with their call light on. The facility has to put on a good face. They're terrified of anybody calling them on anything.'

Another representative shared a **story** illustrating how sometimes leadership doesn't recognize or admit (per applicable nursing home regulations) that they are understaffed, 'The one thing that just popped into my head screaming is staffing. Staffing is such an issue right now. It's crazy. I just had a conversation with a facility yesterday…I was like, 'Why is this resident not getting a *shower* when he asks for a *shower* at a specific time?' This resident is recently sight impaired so he's going through this huge adjustment that he lost his eyesight. Now he's in a nursing home and we're trying to ease him in every step of the way and the facility keeps on pushing back and so I called about why he's not getting a shower and the comment from the Director of Nursing was, 'Well, you do realize that my CNAs have anywhere between 12 to 15 residents a piece' and I said, 'Oh, so what you're telling me is you're understaffed' and she said, 'No, that's not what I said' and I said, 'Okay' and she goes, 'In state regulations, I am in state numbers' and I said, 'No, you're not because the little caveat is the bottom line of the regulation and the [de-identified state] statute that 'You must meet the needs of every resident.' You're not meeting the needs, you're understaffed. So thank you for letting me know that.' And she goes [said while making big and fast hands movements], 'That's not what I said, that's not what I said.' 'Yes it is. That's what you said.' She was very upset because she didn't want me to say that the Director of Nursing told me she was understaffed but that's what she told me.'

Staff Burnout

One representative spoke about 'a lot of caregiver burnout in a lot of these facilities. You might get an aide who is *really* good and they just get to the point where they don't really care anymore because the facility is not helping them with anything. You put two aides on the floor, you've got two Hoyer lifts down there…it takes two aides to do a Hoyer and then you've got breaks and med passes. I mean, it's not realistic. Then you have facilities that promise 'person-centered care.' How can you get person-centered care? You can't even get the showers done. I think that's part of the problem. They get burned out and then they don't even care anymore.'

A representative from another state said that staff burnout feeds into retaliation and another spoke about how care staff members become desensitized adding that she 'can't imagine that all these people started out this way.' She added that she believes part of it has to do with being short staffed and 'they're kind of like robots so they're just going through the motions and they forget that they're dealing with human beings.'

High Staff Turnover

Representatives spoke about high staff turnover as a barrier and challenge when it comes to their (i.e., representatives) need to provide frequent education to new direct care staff members and managers in care home with such unstable staffing conditions.

Referring to characteristics of care homes with high levels of fear of retaliation among residents, one representative said, 'Staff turnover is huge and so we don't see a lot of longevity in a lot of the facilities we visit and that's a lot of times the ones that we're in.'

When asked about the main challenges and barriers in her ability to address residents' fear of retaliation, another representative said, 'There's such a high turnover of staff and residents don't stay very long…they're constantly moving and going on. We might be able to tackle it…to have it tackled one month and then the next month it went to 'hell in a handbasket' you know, because go and do it all over again.'

A representative from another state said, 'When I do in-services with staff, I am pretty harsh when it comes to retaliation. We talk about that in a general setting and it really does help. The funny thing is the turnover in staff is so frequent in those homes that anything you teach them, you really need to go back in about two weeks and redo it…because they are going to be different people in there.' She added, 'That's why we do so many in-services and care plans because that *is* our resolution to complaints. And *every* complaint…I can guarantee you…has somewhat of fear of retaliation. They really do.'

Fact
Nursing homes 'experienced turnover of 52% of nursing staff each year' (on average). This means that 'the average nursing facility has to replace half of its direct care staff each year.'
Resource Box
High staff turnover: A job quality crisis in nursing homes. Report. The National Consumer Voice for Quality Long-Term Care (September 8, 2022).

Another representative spoke about the negative consequences of Administrators' turnover, 'A lot of times what we see is that with the turnover of Administrators is that the aides are running the building with no accountability…kind of left to their own devices. Those resident rights, there's no one there to verify and to hold those staff accountable to not violate rights or retaliate.'

Hiring People Not Suitable for Caring for People

Referring to residents' fear of retaliation and actual staff retaliation against them, one representative said, 'This is clear speculation but I speculate that a large uptick in this topic that we're talking about is because some of these aides are just *not* built for *any* work that requires *any* empathy. I don't know if that's a manifestation of COVID in that sort of collective trauma that we all dealt with but in a lot of circumstances it is about one person or a cohort of like-minded people who don't belong in this business…who seem to lack basic empathy.' He described some of them in the following way, 'Most of these folks, I think, are folks who have a 'me first empathy-less persona.''

When asked about characteristics of care homes with less or no fear of retaliation, another representative spoke about hiring 'staff that are A staff.' She added, 'You don't want a B person or a C person but like an 'A' person.'

A representative from another state shared this **story** about cruel abuse of a resident living with dementia, 'I will never forget…we had these baby dolls that some of our residents with dementia *loved*. I remember one aide taking the baby doll from a resident and playing catch with it with another aide so that the resident thought her real baby was being thrown back and forth and back and forth.'

Another representative spoke about the lack of accountability in who care homes hire to care for residents. She said, 'Accountability in who they hire. Being short staffed in *every* building…so they're pretty much hiring anybody to go in there with very little experience.'

Heavy Reliance on Agency Staff

Representatives identified heavy reliance on agency staff as a serious concern in the context of residents' fear of retaliation and actual staff retaliation against them. One of them said, 'We do see a lot of problems involving agency staff.' Another representative said, 'Agency workers is another big thing. They don't know these residents and they could care less. They are going to take their paycheck, do as little work as possible, and go home.'

A very experienced representative from another state said, 'Now the challenge is we have staffing shortages, we have travelers who don't know the community, they don't know the residents, they don't know their coworkers, they're only here for a certain time to kind of benefit from the situation financially to be honest with you.'

When asked if she was referring to out of state traveling staff members, she replied, 'Yes. Many of the homes here are staffing their homes with nurses and other key staff who are not parts of the community, they do not live in this state, they're here temporarily, they're fulfilling a job they're financially benefiting from it in a way that they wouldn't benefit from a job closer to home and I think that has caused a decrease in the quality of care and the experiences of residents. It's just a different kind of commitment to your work.'

Research Findings
A study by Stepick et al. (2024) found increasing trends and worst outcomes with contract CNAs in nursing homes.

When asked whether reliance on traveling staff contributes to residents' fear of retaliation, she said, 'Yes because its residents experiencing a continuous change in staff and its staff that don't get to know residents on a personal or intimate level because they're just here for brief periods of time and they don't invest in the residents in the same way. So I think it contributes to the problem, yeah.'

Lack of Perpetrator's Accountability

Representatives expressed concerns about lack of accountability for perpetrators of abuse and retaliation against residents. They gave the example of ineffective write ups and lack of or inadequate disciplinary actions for perpetrators of abuse / retaliation with not much

beyond that. One representative gave the example of perpetrators for whom the only disciplinary action consists of, 'You may not work your next shift.'

Another representative described how keeping an internal file about perpetrators could be helpful, 'We have a Perpetrator File in our system here so anytime there is any type of allegation, we put that information into our system and if we see a name that's coming up twice or more, I always…and I've encouraged the other Ombudsmen in this office to do the same…to call the facility and have a conversation with the either the Director of Nurses or the Administrator and we just say, 'Listen, just wanted to let you know that we have a number of complaints and it's the same type of complaint.' Because…that's another part of the problem…is you may have a staff member who treats residents like this and there have been numerous complaints. However, if there is no disciplinary action taken, the facility has no way of knowing that there's history with this person.' She added that they also use the Perpetrator File to identify employees who were previously found to abuse and retaliate against residents in other care settings. She said, 'Then we file against their license.'

However, this representative described the issue of lack of effective disciplinary action as 'a real breakdown in the system…it really, really is.' She explained that the problem is that when these perpetrators are fired, they go and work in other care homes.

She added, 'If I am the Administrator and I am going to hire you as a CNA to work for me and we put your name in and your license in and it comes up that you don't have any disciplinary action. I may not know that you have 21 allegations of *abuse* against you, which is a huge red flag to me. When you start seeing people with two…even I think above two of the same type of allegation, there's something there.' She said, 'It would only come up [in the Nurse Aide Registry] if there's a disciplinary action against that person.' The representative added, 'So the facility has no way of knowing. And probably 9.9 times [out of 10] they are not substantiated.' The representative said that a care employee can have 'nine allegations of abuse against her. Guess what? The Department of Health in [de-identified state] are not doing anything about that if none of them was substantiated.'

When asked if she sometimes reaches out to an Administrator and lets them know that there are repeated issues with a staff member, the representative said, 'We absolutely do. [De-identified state], we are a small state. I can't see that happening in some place like Iowa or Texas or California. In [de-identified state], we do do that. And they don't always terminate that staff member. I've had many say to me, 'Okay, we're going to look into this through a different set of eyes.' Some have been terminated but they still go work somewhere else.'

One SLTCO spoke about the value she sees in the Abuse Registry in her state, 'We have something called the [de-identified name] Program. It's checks and balances. It's a system

that maintains information on staff who had either committed a crime against a vulnerable adult or Adult Protective Services found the abuse allegation substantiated.'

She added, 'When it is substantiated, it goes into their system and we have a requirement in [de-identified state's name] that all hiring facilities have to do a background check plus the [de-identified program's name] check. If they come up in that database as somebody who they substantiated abuse against, they can't hire them.'

Resource Box
Background Checks
Background checks and the health workforce: Practices, policies, and equity. A review of the literature and informant interviews by Dunlap et al. (2021).

Unionized Staff

One representative spoke about challenges related to care homes where care staff members are represented by labor unions. The representative said, 'A union facility can sometimes be hard to deal with because they don't ever get rid of anybody…they don't ever terminate anybody.'

That said, it is important to recognize the importance of labor unions in protecting the rights of direct care workers and improving their job quality in LTC homes. For example, findings from a study in nursing homes suggest that 'unions may decrease nursing staff turnover' (Dean et al. 2023).

Inadequate Staff Training

Representatives considered limited and inadequate care staff training as a barrier and challenge in their efforts to address residents' fear of retaliation and actual retaliation against them. One of them said, 'I am convinced…and this isn't something that's Ombudsman-related…but I really believe from a human perspective, when we feel better prepared for our job…so I feel like if these facilities would take a better hand in training their staff and would hire more of them, I don't think you'd get as much retaliation because number one, I don't think you'd get as many complaints to begin with and I think staff would be better prepared to deal with things like that. It really comes down to *education*.'

When asked about main barriers and challenges in their ability to address residents' fear of retaliation, another representative said, 'Aides that are poorly trained, people that shouldn't be aides and because of the shortage of help, not being disciplined.'

When asked whether there are things that currently do not exist that if existed would have helped representatives better address the issue of fear of retaliation and actual retaliation, a representative from another state spoke about the limited scope of CNA training, 'It comes down to staff training and education.' She explained that when she used to work as a non-direct care employee [specific position de-identified] in a LTC home during COVID (prior to working as an Ombudsman representative) she took the CNA training. She did it because she 'wanted to be more of a help because staffing was really bad during that time.' She said, 'So I took my training. I got eight hours of skilled care. That was it. That's what those aides were getting. They were not getting how to take care of a resident properly, how to be respectful. It was truly how to give a bath, toilet somebody, that's the skills that they're getting. They're not really getting how to truly take care of a person.'

Another representative identified a problem with current staff training. She said, 'Staff training is basically the mandates are like Relias [i.e. provider of workforce education]. Stepping outside of that Relias box, I think that would help if they were learning more things. They click and click and click…they don't really have to pay attention. It's the same training year after year after year. I think fresh training that is mandated would be great.'

When asked about what specific new areas she'd like to see CNAs educated about in Relias, she said, 'They could do more on specific issues like we encourage ours to do.' She gave the examples of caring for residents with behavioral health disorders, dementia like Teepa Snow training program, or training on retaliation.' Regarding retaliation, this representative said that she would like to see CNA training on what retaliation means and things staff do that are *seen* as retaliation like rolling my eyes and being dismissive of residents. She said, 'I don't think there's anything really good training out there.'

Labeling Residents

Several representatives spoke about the problem of and challenge caused by labeling residents such as when staff describe a resident as a 'troublemaker,' a 'constant complainer' or a 'chronic complainer.' For example, one of them said, 'A resident who is already labeled as 'a complainer' is more fearful of retaliation.'

Another representative said that labeling may already occur around the admission, 'The minute you walk into a nursing home, you're already feeling some retaliation because they immediately label you, 'Oh, you're from West Virginia…You're kind of a hillbilly or a hick.'

She added, ‘Oh, you were in a in a southern home or something…well those are the worst’ or ‘You're in Detroit so you must have a lot of bad nursing homes’ or ‘You’re rural.’’

Her colleague added, ‘I would agree and say that they do make assumptions about people, they ‘pigeonhole’ people into certain categories and they also, depending on what your element are, they’ll say, ‘He's an amputee’ or ‘This is our diabetic,’ ‘These are our diabetics’ or whatever. They just kind of…it almost seems like…anything to separate people…keep people separated and thinking that they are this type of person or they're that type of people.’

Another representative said that she hates the term ‘chronic complainer.’ She explained, ‘It's just simply the staff not understanding that the family or the resident have a right to receive quality care and not subpar care and so I *always* encourage family members and residents, ‘If there's something that you're displeased with [or] if you do not understand, regardless, you have a right to advocate for yourself and for your loved ones.’ Those who practice their right to be able to vocalize their concerns, a lot of times the staff they take it as someone that is just complaining *constantly* and that is not what they're doing. They have a right to advocate.’

She added a caveat, ‘Now, I always say that maybe some complaints may be because the family members or the residents have a lack of *understanding* of some of the policies and procedures that go along with long-term care and so we have a duty to educate them and we have a duty to inform them of the procedures of their, their mothers and fathers care, their medical plan of care. They have a right. You educate them, ‘Put yourself in that situation. You would want the right to be able to express your grievances *freely* at anytime.’ That's what we encourage…that is on the residents’ rights so they're actually just exercising their right and being a strong advocate for that resident.’

When asked about the potential consequences of being labeled a ‘chronic complainer,’ she said, ‘The consequence is that they *do not* take each complaint seriously. Unfortunately, there are times when they do complain, it may be something very simple or just a lack of understanding but just to be able to just take *every* complaint seriously. For instance, when you have a resident that has some cognitive deficits. They're complaining about something that they don't understand and so facilities they just kind of say, ‘Well, she's just complaining. This person has dementia.’ As an Ombudsman, we have been trained to take *every* complaint seriously, to *assess,* to see what’s wrong, what is the source of that complaint. Not being able to take that complaint seriously and assess…because, ‘They're always complaining about something,’ that is a detriment to the resident and being able to really *see* what's going on and how can we *resolve* that issue or get the help that they need.’

Another representative said, ‘One of the things we stress to facilities is ‘Just because someone may be that “constant complainer” as you might call them, it doesn’t mean that the concern that they have isn’t real for them and valid and taking place.’ So we try to use *facts* and observations to back up why the resident is bringing that concern to them or why we’re bringing that forward on that person’s behalf.’

Quote
“Just because someone may be that “constant complainer” as you might call them, it doesn’t mean that the concern that they have isn’t real for them and valid and taking place.” – Ombudsman representative

One representative spoke about residents in advanced stages of dementia and how their behavioral expressions may trigger labeling and retaliation by staff. She said, ‘Anyone with advanced cognitive impairment. People who may struggle to find words or sentences to convey their needs…and getting staff to be in tune to a behavior, not a verbalization or a statement per se. A lot of people with advanced cognitive impairment don’t say, ‘I am in pain’ or ‘I need this.’ They are going to have a behavior and when that behavior is repetitive, that’s when staff sometimes are dismissive or retaliating. They will say, ‘Oh, they are just complaining again.’ I always hate it when people have a behavior and they are *labeled* by that behavior, ‘They’re just a wanderer,’ ‘They are a yeller,’ ‘They’re a biter.’ No, they are a person who has a wandering behavior. They are a person who has repetitive vocalization. We don’t classify somebody by their behavior. When staff refer to residents that way, it is usually a big red flag for me to know this person is probably dismissive of them and the fact that their behavior is a mode of communication. They are not in tune to that. As a result, they are retaliating in the sense of withdrawing, not attending to or being dismissive of that person’s behavior, which is their form of communication.’

When asked whether her visits with residents in advanced stages of dementia are different than when she visits other residents, she said that observation as her central strategy with these residents. She spoke about her efforts to educate staff about unmet needs as drivers of residents’ behavioral expressions. She said, ‘For the advanced cognitive impairment residents, I would spend more time observing than I would maybe interacting with them. Because again, if they have the inability to really form a quality or intuitive sentence, the behavior for me is the communication. It would not be uncommon for me to try to locate

the resident and try to introduce myself and then if they're…let's say they're in a common area of the facility…the dining area [or] activity room, I might just try to make myself a fly on the wall so to speak and just be there to observe how do they interact with other residents? How do they interact with staff? Maybe how do they interact with themselves? Are they anxious and they're pacing or they're doing a repetitive behavior? Then from that, if the complaint I've gotten that I'm going out to follow up on, I start talking to staff about, 'Does Mrs. Jones always tap something on the table for hours on end? Is that a new behavior? Is that something that's always been there for her?' If she is walking from room to room, is she looking for something? Is she looking for the bathroom? Is she looking for just a familiar face whether it would be family or wherever she is in her cognitive awareness. I try to get a grasp on that so that we can better understand that resident because I think staff while they do a great job, sometimes they're kind of unaware I guess. They're like, 'Oh well, that's just Mrs. Jones. Yeah, she walks the halls all day.' Okay, well, if she's walking the halls, most people just don't…at least in a memory care facility…don't walk aimlessly around. They are usually looking for something or they need something. So how can we help the staff…A, figure out what that need is or B, identify something that they may be missing because they generalized that behavior. They're just like, 'Oh well, yeah. She just wanders.''

She shared a **story** illustrating how a key piece of information from the early life of people living with dementia may underlie what otherwise could be labeled as 'behaviors.' She said, 'I had a male resident who was always trying to leave the facility and it was unsafe for him so given his cognitive impairment and he was always looking for someone and looking for things and sometimes being intrusive to other residents unfortunately. The facility called me because they were so frustrated and they were just struggling on how to help him. I'm not some savant or anything like that but I come in and I watch him for about a half hour and I see he's looking for something and he's calling out for [de-identified name] and I thought okay, female name. What did staff do, 'Oh [de-identified name], your wife, yeah, she's at church right now. She'll be back later.' You know, trying to validate him, trying to provide him some peace or help to reduce his anxiety like that he's lost his wife or he can't find his wife. This went on for about half an hour and I thought okay, the staff had intervened maybe two or three times to try to redirect him, to try to lower his anxiety…it still wasn't working and I'm like [de-identified name] is not his wife but like intuitively I was like [de-identified name] is not his wife. I said to the staff, 'Who is [de-identified name]?' They're like, 'We don't know. We just assumed it was his wife' and I said, 'Why would you assume that? You have a social history that's done.' I went and looked at the records and there's no [de-identified name] listed anywhere like as a family contact or anything and I'm like, 'Who is [de-identified name]?' At this point, I feel like it's a great mystery that I'm going to solve.'

The representative went on to describe what she did to resolve the situation, ‘I reached out to the family and I just said who I was or what I was doing and I said ‘I'm just really trying to help your dad resolve some of his anxiousness and his behaviors with this person’ and I said, ‘I can't find anything about an [de-identified name]. Who's [de-identified name]?’ and the son said ‘Oh, [de-identified name] was his prized cow that he took to the State Fair back in whatever year it was.’ Once that clicked for me, I was like, ‘Oh my gosh.’ I'm like, ‘Do you have any pictures or newspaper articles about it that might have been saved?’ Because he won the top award you could get for that cow that year and he was about 17 when that's happened and now he is 80 and so they're like, ‘Oh yeah, we’ve got some stuff. We can bring it in.’ They brought those items in and they were able to put it in some kind of a play board and show that to him and then they could redirect him. What he was doing by going room to room was looking for his prize cow that he was very attached to as a young man. Staff were just dismissive and just assumed that he was looking for his wife and so when staff would say, ‘Oh, Your [de-identified name], yeah, she's at Church right now.’ That would cause him more stress because why would a cow go to church. Again, that lack of awareness that not knowing the residents and knowing their history. And again, I don't know that staff would have thought it was a cow either to be that was just kind of an obscure thought, but nobody had really thought to research that, nobody had thought to really advance that to find out what was that nugget of knowledge that he was somewhat perseverating on but kind of meet him where he's at.’

She added, ‘So maybe not retaliation in the form of, ‘I'm going to hit you’ but retaliation in the fact that it's so dismissive…that staff just *dismiss* residents in a way that to me is a form of retaliation because they don't want to deal with you, they're tired of dealing with you, they're tired of your behavior, it's the same every day. Those kind of things to me are just as valid of retaliation as it would be a resident that they would say they're gonna threaten to hurt them.’ She clarified, ‘I think that the dismissal part is not intentional. I don’t think it’s an active thought that staff have. But I think it’s a very common practice that happens in a long-term care setting when staff are maybe overworked or whatever the reason. But the dismissiveness, to me, is a form of retaliation and residents tell us all the time, ‘Well, they dismiss me so I don’t ask them anymore.’’

Dismissing Residents’ Concerns

Several representatives spoke about the challenge of staff dismissing residents’ concerns.

When asked about the main challenges and barriers in addressing residents’ fear of retaliation and actual retaliation, one representative said, ‘It’s the people that can make a difference or do something about it. It’s just not believed, it’s brushed off or it’s minimized or, ‘Well, you know, she is emotional’ or ‘He has dementia and he thinks everybody is out to

get him' or 'Oh, it's only Black staff' or 'Oh, they don't like people with curly hair.' There's always some sort of an excuse…reason why it can't be true.'

Another representative spoke about a concerning practice where staff will document in a resident's Care Plan that the resident makes up allegations against staff members. She said, 'Care Planning for made up allegations. When I am looking at a Care Plan and a resident has in their Care Plan, 'They sometimes make up allegations' so [writing that] they can make up allegations to the staff that 'the staff did this, this, and this to me' that are negative.' The representative went on to say, 'What if those are true allegations? I find that their voice is less heard and there is more helplessness. If somewhere in their Care Plan it states that, 'Resident makes up allegations of staff doing such and such and such.' It is actually in the Care Plan, 'The resident will make up allegations against the staff.' I think I've seen before like, 'Low showers numbers' or 'Not giving medications.' I've seen it in multiple Care Plans where it says, 'This resident makes up allegations against the staff.''

She said that it could be a way for staff to dismiss residents' complaints and went on to share a **story**, 'I had one gentleman that I think there was abuse in his background and they could not verify it…Adult Protective Service…Police. There was one allegation where they couldn't find like the people…video cameras…nobody was entering their room at that time…maybe someone has delusions but then some other residents…showers and medications that staff are not serving them well and I am seeing it in a Care Plan where I am thinking, every resident has a right to voice their concerns and I think you're blowing it off a lot because it is Care Planned for. Trying to get a scapegoat in case the state surveyors are coming' and getting the impression, 'Oh, they are supposed to be someone that makes up allegations a lot.''

Individuals Living with Dementia

Several issues related to residents living with dementia were identified by representatives and considered by them as barriers in their efforts to address residents' fear of retaliation and actual retaliation against them when voicing care concerns.

Challenges Related to Residents with Dementia – Especially Those in Mid-to-late Stages

Before describing the challenges identified by representatives, it is important to recognize the great variability in brain disease manifestations across people living with dementia. Specifically, every person is different and has a unique life history, every form of dementia is different in its manifestations, a subgroup of people 'with dementia' actually have 'mixed dementia' (such as Alzheimer's disease *and* vascular dementia), many are misdiagnosed with the wrong form of dementia, the same form of dementia can impact different people in different ways, the classification of people into stages of dementia is often less

straightforward and more complex than it may seem, and the cognitive function of a subgroup of people with dementia may fluctuate over time and even within the same day.

Referring to residents in mid-to-late stages of dementia, one representative said, 'That's the hardest because number one…to be able to identify it. If the person can't speak for themselves, you're relying on somebody else to speak for them…'

When asked about challenges related to residents in mid-to-late stages of dementia in the context of fear of retaliation and actual retaliation, another representative said, 'I think generally speaking, the residents are not always reliable reporters. I've been looking for a man's wallet for 10 years now. Every time I walk in there, he has lost his wallet. That's not retaliation or they'll assure me that they've been slapped…they may have not even been in the building that day. It's just hard to get accurate information from them. That doesn't mean that I don't try or don't want to.' She added, 'We rely so heavily on families and most of our Family Councils come out of the memory care facilities specifically because there is no other way to handle that. Basically, most of the information I utilize when working in the memory care units come from family members.'

She said, 'I am talking about memory care only units. Those are really a struggle for us. Because we get these frantic calls and so often they are not validated in our eyes or the Department of Health's. Ironically, that's where I started. I had my [de-identified family member] in one for three years and I was right near her home so I visited her every day. I saw so much there and I wanted to help but it's really hard to help those with dementia in terms of retaliation, in terms of complaints.'

This representative said that her strategy in 'memory care' units is different than in general population care homes (this issue is addressed in detail below in a segment titled *Observation as Central Strategy with Residents in Advanced Stages of Dementia*). She said, 'It's very much more observational than it is conversational. Watching what the capacity of the resident is, what her or his relationship is to the staff and to the other residents on the floor. That's really where…and of course, everything about their state of being, how their clothes, are they wearing pajamas, it's freezing out, are they wearing [didn't complete the sentence]. All of those very observational things. I can work with that but again, if they come up to me and they whisper some horrible story and I move around to try and investigate it, so many times they are not accurate or it's an old, old story or it's a story that somebody else told them.'

Another said, 'Sometimes, when it comes to residents with Alzheimer's or later stages dementia…is their ability to communicate. If what you're saying…is this actually what's going on or are these just the words that you're able to formulate at the time?'

When asked about challenges related to residents' living in advanced stages of dementia in the context of fear of retaliation, another representative said, 'One of the biggest challenges I see is residents often live in the past,' that is, 'residents thinking when they're young adults.' So are they fearful about something that's happening currently or are they fearful about something that formerly happened? So trying to determine…is it here or then? And then to address the situation is challenging.'

A representative from another state said, 'Residents are afraid and can't always tell us why. Residents cannot recall an event or know where they received a bruise or a mark from. I've witnessed staff and families dismiss residents' concerns because they have dementia or Alzheimer's and they don't feel like it's really happening.'

She added, 'I always try to tell the families, 'It doesn't matter if it happened or not…well, it does matter but it's still their *reality*…that's their perception, their feeling it so we still need to do something to make them feel better about it.'

One very experienced representative said, 'I would say communication…like their ability to communicate with us what they experience and our ability to monitor them. We can't really be visually monitoring staff-resident interaction all the time. I think when we are there, we definitely look at staff-to-resident interaction but when we're standing there and when we're not standing there, we know that the experiences could vary greatly. So I think the inability to monitor and communicate with people who have cognitive difficulties is a huge barrier to really know what their experiences are.'

A representative from another state said, 'It's the biggest issue we've got. These residents are routinely abused and neglected. They have no way to report it or even know it. They are left on hours on end with no care because they know that they can't tell anybody…they don't have the ability anymore. Even if they can tell someone, my experience is if someone with dementia reports any issue…retaliation or anything else, their automatic response is, 'That didn't happen. They have dementia.' It's the 'get out of jail free card' for everybody.'

Resource Box
Mistreatment of people with dementia. Research Brief developed by the National Center on Elder Abuse, 2023.

Other representatives spoke about the common dismissal of concerns voiced by residents with dementia. One of them said, ‘It happens all the time that the facility staff will say, ‘That’s not true. They don’t know what day it is. They can’t give you any valuable information’ or the facility said, ‘Well, it’s not true. They have dementia.’

Another representative said that dismissing complaints voiced by residents with dementia happens ‘all the time. I hate to say that but it does. The facilities will just say, ‘Oh, you know, they have dementia so it was probably a bad day for them and that's why they're complaining.’ That will be the *first* words out of the mouth, ‘Well, you know, the resident has dementia so we're going to take that with a grain of salt.’ Well, why? *Why?* They still have a voice. They can still explain what's going on. Now obviously when it gets to end stage it gets to be a little bit more difficult but it comes back to…it can be extremely trying to *prove* that it actually happened and that there is retaliation.’

When asked about challenges related to residents in mid-to-late stages of dementia, another representative said, ‘I think that particularly with those dementia residents and/or residents that have behaviors…if you want to label them like that…staff make assumptions about these residents. We all have good days and bad days, but staff aren’t willing to give them the benefit of the doubt because they have had a previous bad experience whether that is aggression when they are changing them or providing some kind of care or maybe they’ve had a poor dining experience with this resident. I feel like it is almost actual retaliation and some neglect because they think, ‘Oh well, that individual is beyond my help essentially.’’

When asked how the retaliation manifests, she said, ‘I feel like they are almost retaliating against their disease. Well, they’ve been hit before so they’re just not going to do that so they won’t get hit again, for instance. They’re withholding care from these residents.’

A representative from another state said, ‘The dismissal, ‘Oh, they have Alzheimer’s’ or ‘They have behaviors.’ You hear that a lot. Or ‘They are combative. They have behaviors.’ Now we know that people…regardless of what stage they’re at, there are different ways people communicate with us…but again, it’s just very dismissed. And proving it…if you will…is next to impossible.’

One representative said, ‘As we know, dementia…you come in and out all day…you have some reality and then you don’t or you have some of your past experiences and then you’re in reality. It’s very challenging when they want to put the label on them and tell us that they don’t know what they’re talking about.’

When asked about unique challenges in addressing fear of retaliation among residents in mid-to-late stages of dementia, an experienced representative said, 'This one is hard because residents with dementia aren't always heard, [they're] ignored, or they won't remember so there's that fear there of complaining because they are just put in this shelf where 'Well, what they're saying isn't actually real. They have dementia, you know.' She added, 'It's double vulnerability.'

Another representative said, 'I have had residents tell me that they just hope they don't get dementia because they see what happens with the folks who do have dementia and do not have the ability to speak out anymore.'

Referring to residents in mid-to-late stages of dementia, representatives identified the challenge manifested in their difficulty *recalling* details of incidents and difficulty *communicating* details of events and mistreatment. One of them said, 'The main part is when you're trying to figure out what's going on, you can't really get any information unless they have a camera or their family is around or somebody reports it. That's the difficult part…is they can't remember that it happened. Then, we really have no basis to go on, we have no proof of anything and that's what makes our job most difficult when you're dealing with a dementia diagnosis.'

When asked about challenges in her efforts to advocate for residents in mid-to-late stages of dementia in the context of fear of retaliation, a very experienced representative said, 'Well, just that…the dementia itself…the cognitive impairment…the lack of being able to remember what happened and effectively tell you because of speech impairment that accompany that. You see someone that is black and blue and the staff says, 'Oh, they fall and fall. They just fall and fall.' Yeah, there's no way to actually know because this person can't relate to you what's going on.'

One representative said, 'Obviously, communication can be a challenge…and getting details.' She went on to caution, 'We have to be really careful…we don't want to add stress or anything like that to residents so it can be difficult.'

She went on to speak about the importance of listening and validating concerns voiced by residents with dementia, 'We instruct all staff and Administrators that what residents tell us if they are verbal at all…and even if they are not verbal, they can communicate sometimes. If they communicate to us an issue, it is an issue. And until that resident feels safe and it is resolved, we are going to work through it. Many times people can tell you things…particularly in the early-to-mid-stage. We try to pick a time of day that is good for them to go and see them and then to react. One thing that I share with staff a *lot* is, 'Their perception is their reality. If they feel like they're being intimidated, they're intimidated.''

Quote
"Their perception is their reality. If they feel like they're being intimidated, they're intimidated." – Ombudsman representative

Referring to challenges related to people in mid-to-late stages of dementia, an experienced representative said, 'I think just their inability to communicate those concerns. You have to catch it in the act because they don't have that ability to verbalize a form of retaliation that they may be experiencing.'

When asked the same question, a very experienced representative said, 'What's challenging [is that] those residents are not able to tell us. We're directed by their wishes first of all. And making an attempt to figure out if they are able to engage with us to tell us what may have happened, they are not able to do so. It's very difficult to get a handle on whether or not we can get an idea. If it's something that's visible like the hands or what not that something did occur, then that's something to go on but if you can't visibly see it and they are not able to communicate to you, you can't really again corroborate what is going on with that resident. I go back to the burden of proof and it's really disconcerting and [missed word] to a resident if we can't help them figure out what happened.'

She added, 'My other barrier is why retaliation occurred in the first place with a resident who is *not* able to tell you and so medically compromised? Why would you retaliate against a resident in that condition in the first place?'

A representative from another state said, 'Some are unable to say what is happening to them. You can watch their body language with somebody…if staff comes in there and they are fearful of them. How staff treat residents in general…if you go into a building and you see a staff who is not even nice to a resident who is cognitive, you can imagine what they're like with somebody who is not able to say… Sending them off to Geri psych instead of having adequately trained staff, 'We can't deal with this behavior so we're going to send off' even when it is just a natural part of the disease process that they should be able to manage.'

When asked about challenges related to residents in mid-to-late stages of dementia, one representative said, 'This is definitely the most difficult because we can't get information from residents of course so it's directly coming from family members…so sometimes it's their perception versus reality. I work a lot of times with family members that are actually

more difficult. A lot have worked in nursing homes. I'm seeing a lot as a CNA and as a nurse.' She added, 'family members either do or did in the past and I think they take their experiences and bring it to where their family member was. It's really hard again not being able to get any information from a resident. It's difficult because if there's somebody with severe cognitive impairment even when I go there to monitor, it's very very hard. Staff interact…engage much differently than a regular nursing home.' She clarified, 'We have in [de-identified state] nursing homes that are secure…they are just for dementia. A lot of the time it's people with *severe* cognitive impairments and they're just run differently and staffing differently. So I think it's really hard because it's just based on the family's perception and that's it. A lot of times it's family against staff and it's sort of a battle. It's really hard as an ombudsman being able to be in there and see it or get more information.'

When asked if hidden cameras play a role in addressing fear of retaliation among residents in advanced stages of dementia, she said, 'Yeah, that's come up a *lot*. Families wanting cameras in the room for a few reasons… fear retaliation, to be able to see their loved one without actually being present. Some families may live out of state. It has come up a *lot* where families don't see why they can't have cameras.' She said that in her state hidden cameras are not allowed to be installed in residents' bedrooms in nursing homes and assisted living residences, not even with permission and after informing the care home.

When asked what she thinks about it, she said, 'It's interesting because I have some residents that have an iPad or something that's a video that can show half the room and it's on full time for different family members…so it's kind of a video camera. It is pointed on them but it's used as assistive technology. They'll have their iPad but it's not considered a camera it's more of assistive device because that person can't necessarily use a phone and hold the phone but if they have the camera…so I feel like we're kind of half there. I think there are definitely some benefits for camera.'

She added, 'I think family members that might live out of state or people that work or multiple family members to be able to see. Sometimes family members…when a staff comes in to do this or that, they want to hear what they're saying if the resident is not really able to repeat that. I think there's a lot of reasons. Some just want to make sure they're being treated properly.' She said that the device does not run at night but during 'many hours' during the day.

She added that for residents who do not have the ability to operate it, 'They would have to get a staff to come set it up and turn it on, which they do and then to either have them turn it off or the person on the other side of the camera turns it off so there's nothing on the screen. You just can't have a camera up on the wall. You can have a camera as an assistive technology device.' When asked if it is a way around not being allowed to install cameras,

she said, ‘They may see it as a privacy issue. It’s a tough one. It’s a tough one. I definitely see both sides of it. But as a family member, I probably want to see what's going on.’

When asked about unique challenges related to residents in mid-to-late stages of dementia, a representative from another state said, ‘That is a lot harder to address because this population can’t speak for themselves so they can’t tell you what’s going on. A lot of the time in my experience, the only way I’ve come across a situation was because the family got involved, the family noticed the issues and the problems that their family was facing.’

Her colleague spoke about how a resident’s cognitive abilities may fluctuate during the day and how that personal knowledge guides her in terms of the time of day in which she approaches the resident, ‘I’ve seen both sides because I’ve been here a little bit longer. Residents with dementia, they have different capacity…so they may be good in the morning but not good in the afternoon. It’s just learning when to be able to talk to a resident. But residents with dementia can’t tell you if someone is being mean to them or are not providing care. Some of them can.’

When asked the same question, a representative from another state said, ‘Well, obviously the residents can’t tell you what has happened half of the time.’ She added, ‘The ones that are very aggressive, they’ll put them in their rooms, close their doors, they’re crying…and once they’re closing their doors, their cries are going unheard.’ She said, ‘They’ll close the door purposely so they’re cries go unheard and they’re not getting checked on like they’re supposed to be…because they might be a little combative. But nine times out of ten, they are being combative because their needs are not being met. I mean, it’s just like a baby…there’s a reason why. They cry…there’s a reason why…they need to be changed, they need to be fed, there’s something wrong.’

Another said, ‘I think we need to keep an open mind when we’re dealing with dementia residents.’ She explained, ‘We don’t know…are they having a good day or a bad day? When we first meet them, we don’t know…is this a good day for them or is it a bad day for them? Open mind means we have to establish some type of baseline as far as what the residents’ capabilities are and kind of go from there. There are cues that you can pick up on…body language and the way that they might be getting upset. It just varies case by case.’

When asked about unique challenges related to residents in mid-to-late stages of dementia in the context of fear of retaliation and actual retaliation, one representative spoke about enhanced vulnerabilities of residents living in ‘memory care units.’ He said, ‘Number one…talk about facility or staff feeling empowered to do whatever they want and treat residents however they feel, there is no more of a situation than on a PM shift on a

memory care unit or anytime where residents really lack the capacity to communicate what's happening to them. We've had some very clear cases of staff being physically abusive or verbally abusive to residents. Sometimes it happens when staff is kind of set off by the behaviors of the residents and they're sort of put over the edge if you will and kind of cross that line to actually strike or be verbally abusive. Oftentimes, that will never be known unless another staff member reports it. We now hear family members wanting to put video and audio recording devices in their loves ones rooms and it's not allowed.'

When asked to clarify, he said, 'Not the audio. The video can be done if you jump through a bunch of hoops. It certainly can be done in hallways and things like that but yeah.'

When asked about his role in addressing this issue in 'memory care units,' he spoke about helping Family Councils with their 'ability to communicate with management about their concerns.' He went on to talk about challenges related to high management turnover and lack of managers' presence during the PM and night shifts (see detail below).

When asked to elaborate about his work with families, he said, 'This really is about opening lines of communication. They want to know what kinds of training the staff are receiving in order to work with residents that have dementia so that they know how to treat them with dignity and respect and reduce negative outcomes. That's really a big thing that we're working on right now is trying to find out what trainings are out there, what training facilities are using, have that information shared with family members so that they can then feel better that the staff know how to better care for their loved ones.' He added, 'We're trying to find out what trainings are out there that staff could receive and use so that it will ensure our family members that their loved ones are being cared by people that know how to do it.'

Regarding management turnover as a barrier in his advocacy related to residents with dementia living on 'memory care units,' he said, 'Now we have a lot of management turnover. That should be another issue of what's a problem here of resolving this culture change thing. it's just revolving door of management…but especially so in the memory care and assisted living communities where we have a lot of turnover…not necessarily the most highly qualified candidates and trained candidates for these positions and it's really hard to deal with changing management, changing staff, untrained staff and just these cultures of not really dialing things in well enough to have an environment that is conducive to positive things. We hear complaints of not enough management on the PM shifts, on the night shifts. Who do people call? There is no management at night. How are those people on their own? There are people up at night. Who is watching all that? Who do they report to? It' just very problematic.'

A representative from another state described situations where residents admitted for rehabilitation may *temporarily* experience cognitive impairment (such as during their recovery from surgeries). She said that some of these residents may be labeled as having dementia when they do not have dementia, 'Another trend that I've been noticing is that a lot of these buildings are…and I don't know if it's always directly retaliation…it can be in some cases but I've noticed that they are quick to diagnose you with dementia or some cognitive impairment so that they can control your situation or control your discharge or control whether you can leave the building or anything. They are quick to say, 'Oh, you have a cognitive impairment,' 'Oh, you can't go anywhere' 'We need to get you conserve' so that we can control pretty much your life because they don't want to hear what you're saying, they don't want to address your concerns. They just don't want to bother.'

She said, 'What I've noticed is that people could have a traumatic situation happen to them physically…whatever it is…and they go to a nursing home for rehab…a lot of the times, they are still recovering…this incident was happening just two weeks ago and they were in the ICU and they are still recovering…the hospital is quick to discharge you. When you go to the nursing home, you're very fresh from this incident and a lot of the times they are still loopy on drugs and recovery and you're not yourself. The building is *so* quick to be like, 'Oh, this person has a cognitive impairment. We need to get them conserved' or 'We're not going to address some of their issues' or what they're telling us because when they walked in the door two weeks ago, they had a BIMS [score] of 3 out of 15 [severe cognitive impairment] and 'I am not going to listen to.'' Note: BIMS stands for Brief Interview of Mental Status

When asked if some of these people may bounce back to their baseline pre-surgery cognitive function, she said, 'Which they have and that's the problem.'

She went on to share this **story**: I had a situation where a lady walked in cognitively impaired because she was high on drugs from all the surgeries that she had on her [de-identified body organ]. They put her in the system that she had cognitive impairment, a BIMS of 3 out of 15 and when she called us because they wouldn't give her permission to leave the building a month later…she is perfectly fine at this point…she has recovered tremendously, the building would not acknowledge her request because they said that she is cognitively impaired.'

Misconceptions About People Living with Dementia

Representatives spoke about misconceptions related to residents with dementia in general and their ability to recall and communicate details of incidents. These perceptions, along with the stigma and labeling commonly attached to these individuals may reflect, shape,

and result in dismissive attitudes towards them and their care concerns as they are written off, disregarded, and retaliated against.

One representative said, 'There's societal perception about people living in long-term care facilities and the fact that…they may have dementia, they're not telling the truth.'

Another representative said, 'We try to say, 'Just because that person has some cognitive impairment, doesn't mean that their concerns should not be taken seriously.''

Quote
"Older adults living with memory loss don't lose all memory. They remember things that are important to them. They remember emotionally colored things, happy times, sad times and traumatic events. Scary or painful events are imprinted." – Vicki de Klerk-Rubin, Executive Director, Validation Method, email communication, March 11, 2024

Research Findings
A study by Brod et al. (1999) found that when dementia-friendly interviewing conditions are created, many people with dementia were able to appropriately respond to questions about their quality of life. The researchers concluded that many people living with mild-to-moderate dementia can be considered good informants of their own subjective states. A study by Kasper et al. (2014) found that 'people with dementia, especially those in early and middle stages of disease, are often able to communicate their choices, share their preferences and values, and report abuse.' A study by Richmond et al. (2020) among older adults in emergency departments found that for 59% of those with cognitive impairment, 'assessors were confident or absolutely confident in the patient's ability to report abuse.' Specifically, 'assessors expressed confidence in reports made by 11 of 12 patients with mild cognitive impairment and 7 of 11 patients with moderate to severe cognitive impairment. However, the researchers stated that the ability of those in advanced stages of the disease to recognize and report mistreatment 'may be more challenging.'

The latter representative described the uniqueness of each resident living with dementia, 'We see that every person who has dementia presents differently and it progresses differently. In today's climate there is such a turnover with staff, the care is not as person-centered as any of us would like it to be in most situations. When you couple that with how they may 'sundown' in the afternoon, they may eat certain foods really well but not others,

it makes it harder to focus on resolving the concerns…maybe there's some chaos in the facility between staff and they can't get their ducks in a row to be able to care for the person in a way that the person needs to be cared for.'

She added, 'Residents who have dementia sometimes they may be having hallucinations or they may be paranoid about things as part of their disease and the staff will just label them, 'That's how she always is' or 'She always calls out like that.' They're labeling them as such and so they don't even look past that to see if there's a root cause to this problem or what is the reason that the resident is acting the way they are.'

Research Findings
"Hallucinations"
A study by Cohen-Mansfield & Golander (2012) has shown that a subgroup of direct care staff members use the term 'hallucinations' despite the fact that they could not easily explain it, 'demonstrating their lack of understanding of the resident and/or the phenomenon they termed hallucination. The study also found that most visual and auditory hallucinations were not associated with a negative affect. The researchers also found that 'some hallucinations occurred out of boredom, which exacerbated the sensory deprivation experienced by these persons, thereby increasing the likelihood of hallucinations.'

A representative from another state said, 'The biggest challenge there is when you're talking about an individual that has a dementia diagnosis, that only aggravates their risk of being dismissed amid what could very logically be fact.'

He added, 'Because so much of this kind of stuff happens on a one-to-one. Put yourself in a situation where you have early-stage dementia. You do have good mornings and you [have] sundowners…but until 2:00 during the day, you're the same old [de-identified name] and then all of a sudden something happens because the staff just simply dismissed your cognitive status in the morning and then you go and report it to someone and then they just dismiss your voice because you have a diagnosis, yet you know what is fact.'

He observed, 'The level of marginalization and de-humanization that happens with that potential construct is just crazy. It tells you the level of vulnerability.' He clarified, 'Their cognitive status evolves as the day goes on and they progressively become less and less aware of their surroundings. Something happens in the morning when they're cognitively intact and then they bring it up at any point in time probably in the morning and then they're dismissed even though they're still have their awareness of fact and history at that time.'

He added, 'The level of dismissive perspective that comes with that or the empowerment or marginalization I mean there's a lot of different words for it but what you're telling me is it's my word against yours and you have dementia so no that didn't happen. By the way, it

would be a performance issue for me if I conceded to the fact that I did do that to you this morning [de-identified name]. There is no way I am going to admit that. So much of this is person to person…right. So that is one of the challenging dynamics with cognitive decline. He went on to say that the most valuable thing he has found in this context is the installation of camera and electronic monitoring in residents' bedrooms.

Another representative also identified the challenge caused by 'the level of dismissive perspective or the marginalization' of residents in advanced stages of dementia.

When asked about the main challenges and barriers in addressing the issue of fear of retaliation and actual retaliation, a representative from another state said, 'I would say a unique challenge is in most cases taking the complaint seriously. Mostly from the staff and I see that a lot with residents who have cognition deficits. That is the challenge because in most cases and even for some families, 'Well, you know, mom has dementia.' I don't get it so much for families but mostly for staff. Or if they have behavior problems, in most cases those incidents of retaliation fall by the wayside and that's very frustrating to me because they assume that because this person has cognition deficits, you know, that they have dementia, they're forgetful or they're just hallucinating or what not, you have to take what they are saying with a grain of salt.'

She described how she handles these situations, 'In most cases, I ask them, 'Have you assessed? Have you investigated? Have you followed up? They have a right regardless. You are mandated…regardless if you feel that their complaint is validated or you could substantiate it or not. As an Ombudsman, we are mandated to investigate any and every concern regardless of how small. I encourage the facility to do that as well regardless of if you know that this person has cognition deficits, you still need to investigate it because there have been some cases through their investigations that they were able to see some things.'

She went on to describe how camera surveillance can sometimes be helpful in showing what actually happened to a person with dementia. She said that assistive technology 'has been useful in some cases that I've been involved in.' She shared a **story** about 'a person who has cognition deficits expressed a complaint against a staff member but they use it as a [missed word] where this person has dementia, this person has mental health disorders. Luckily in this case, the Administrator did take the complaint seriously, was able to look at the surveillance camera and saw something totally different and we were able to substantiate that abuse did happen. It was in a public place where the camera caught the incident and so I was very pleased that we were able to get that on surveillance camera.'

She shared another **story** illustrating how a surveillance camera was helpful, 'I've had an incident where a family member was saying, 'I know that my loved one is neglected.' The resident had a bed sore. Of course, the staff member who was caring said, 'Well, I checked up on this resident and I always provide my 2-hour checks. This is what I've done.' If I could remember, it was an incident that happened with a particular staff member…a neglect issue. I can't remember everything but the only thing I do remember is the Administrator was able to look at surveillance and was able to look at the system that records the time in which it took the staff member to answer a call light and what not. They were able to look at those things and they were able to determine that this resident was left in that situation for quite some time. That's the challenge of just really not taking the resident seriously especially those who have cognition deficits or behaviors.'

When asked what she sees as the missed opportunity when residents with dementia are written off by staff, she said, 'I think we're missing compassion for human life. If you did have the compassion in the care and you understand that these are vulnerable individuals that you are serving and knowing that your role as a caretaker…they *need* you because they cannot provide these care needs for themselves…that's why they are there. If you have people who are not compassionate and they are there because 'I need a 9 to 5,' this pays more as a CNA than somewhere else, they're going to see more tragedies. It's a lack of compassion.' She added, 'You're going to see more incidents of neglect and just people brushing it over to the side…not really *caring* enough to say, 'This person has dementia but their complaints *matter*.' I don't care if they are repeating themselves, I don't care if it seems a little 'foolish' or they may be hallucinating, I care enough as a caretaker to step back and see what's wrong, what's going on, let's investigate.'

Quote
"*This person has dementia but their complaints matter.*" – Ombudsman representative

For a study I led titled *Complaints Matter* that demonstrated the importance of mistreatment complaints in nursing homes nationwide (the study was not dementia-specific though most nursing home residents have dementia), see Liu et al. (2022).

When asked whether she knows of situations where concerns expressed by residents in earlier stages of dementia were dismissed but it turned out that the concerns were accurate, another representative said, 'Oh, a hundred percent. We get calls all the

time…they're like, 'Don't even go visit them. They have dementia. They can't tell you what's going on' and we're like, 'No, we still need to go visit with them. We still need to ensure that what you want to happen is what they want to happen. So yeah, a lot of time people see that dementia diagnosis and they immediately write people off as, 'They have dementia. They can't voice anything for themselves.'' She added, 'Even with the state of dementia you can tell me that someone's not being nice to you, you can tell me that they're giving you things to eat for dinner that you've said you don't want to eat…absolutely.'

When asked whether there were situations where a concern voiced by a resident in mid-to-late stages of dementia is written off but then upon her close look, the resident's concern proved to be valid, another representative said, 'Oh yes. Absolutely.' She went on to share a **story** about an assisted living resident who she believed was in mid-stage dementia. She said that while she was visiting the care home, the resident 'told me that he had bed bugs in his room. I asked the Administrator if they had been bugs in the facility and she said, 'No.' And I told her this resident said he had bed bugs and she said, 'Oh, he's crazy. He doesn't know what he's talking about.' Then I went to his room and saw them *everywhere* in the room. He was ignored because of his diagnosis…just assumed to be crazy and imagining things when in all actuality they had a *bad* infestation.'

When asked if the infestation was found also in other bedrooms, she said, 'Yes. Upon further investigation, once we found that, then we started reporting to the appropriate agencies…Social Services, the Health Department. They found it in every room in that building.' The representative confirmed that the Administrator 'didn't bother' coming in and sitting with the resident and listening to them. She added, 'They were just ignored. Their concerned were ignored because of just assuming their condition.'

A representative from another state said that at times accounts expressed by residents with dementia are written off but that sometimes taking the time to listen to them reveals a truth in what they're trying to convey. She said, 'Especially when you let a resident talk for a long time about the issue, then you can find a little bit of truth in it or something to go on, something you can grasp on to' and 'then we'll advocate in their best interest.'

One representative shared a **story** about a resident who needed to get a tooth pulled and they went to the dentist but the dentist wouldn't see them because they didn't see an aide with them. She said, 'The facility told me, 'Oh no, they went and they did it all. He just doesn't remember.' When we actually pulled the records from the dentist, the resident was exactly right. They did not send an aide.'

Referring to residents in advanced stages of dementia, a SLTCO said, 'When people make accusations…sexual assault accusations, physical assault accusations, what I have found is…there is almost always a thread of truth in there. Something has happened. People don't just out of the blue start saying things. They'll say, 'Oh, it's coming out from the past.' It came up for a reason. Something dredged that out of somewhere. And when you sit back and you watch on the unit watching people interacting with them, you'll see someone is interacting with them in a way that is triggering that emotion. That's when you need to intervene. They may not be able to verbally express to you that something isn't right…but they are experiencing something that isn't right for them.'

When asked what residents can do when they witness abuse or retaliation against their roommate who is in advanced stages of dementia, the SLTCO said, 'Roommate can report it. Roommates can talk to the Resident Council President. Roommates can call the Ombudsman…they can call the Regional Ombudsman and say, 'Hey, this is what's happening. I need help with this. Can you help support me?' The Regional Ombudsman can reach out to the person's family member. They can talk to their social worker. If they are not comfortable talking to the social worker, there should be someone they should see as an ally in the facility and they should [reach out] to that trusted ally. There is usually someone. If not, they can always call the Regional Ombudsman to support them.'

Need for Staff Education in Dementia Care

Several representatives spoke about the need for specialized staff education on caring for people living with dementia. When asked whether there are things that do not currently exist that if existed, would have enabled her to better address residents' fear of retaliation, of them said, 'Higher staffing ratios to resident of long-term care staff.' Then she added, 'More training for staff for dementia care and mental illness. And less agency staff.'

Her colleague said, 'I think that the training piece is very important. You know, the training that is required for an Ombudsman that volunteers for us is *more* per year than it is for a staff person in a facility. That's like a real thing. So I think more training in the areas particularly that [de-identified name of colleague] talked about for staff.'

One representative shared about a care home (that was cited for numerous complaints) where staff held problematic perceptions of residents' behavioral expressions. Specifically, the representative said, 'Staff seemed to think that the dementia people are doing things on purpose to deliberately bate them instead of just having a diagnosis.' She added that when she educated the staff, 'We had to go through different scenarios because they didn't believe that this was a dementia behavior [but rather that] it was something direct 'to make my life miserable.' This perception was considered as a barrier 'because if we can't have

them see people as people and not as a diagnosis of, 'I'm trying to attack you,' how can we fix this if that's your response to their behavior?'

Another representative addressed the issue of staff perception of intentionality among residents with dementia when they do things staff perceive as being done deliberately to upset them. She said, 'Let's face it, this is how I like to say it, 'These residents don't do these things on purpose.' Like I'll tell my buildings sometime, 'This isn't a country club. This is a nursing home. They're here for reasons.' They might push their call light five times or something like that but they are not doing these things on purpose. They are in a nursing home. They are here. This is their home. You work here in *their* home. That's why they're here.' That's basically the bottom line.'

Another representative shared, 'I've begged some of my Administrators, 'Let's pilot a project together. Let's do an *involved* multi-part training to train your staff in dementia care.' The Administrators won't do it. The representative explained that they refused because 'every minute that staff is in training, they're not on the floor.' She added, 'They're just putting out fires. They're not thinking about the future. They're putting out fires today.'

Observation as Central Strategy with Residents in Advanced Stages of Dementia

Several representatives reported that they use observations as a central strategy with residents in advanced stages of dementia such as in care homes dedicated to caring for this population. One of them described her use of observations as a central strategy with residents in advanced stages of dementia, 'I think sometimes and especially for those individuals who may not be able to communicate or they have cognitive impairment, we use our observation skills a lot in that…our senses. If family maybe have a complaint that they're not getting changed or repositioned, we're looking what the room looks like, we're looking at the environment, the bedding…is it soiled? We're looking for odors, we're looking at are they sitting in a tattered wheelchair and their breakfast is still on their clothing at 3 o'clock in the afternoon. Those are the signs that we can see.'

She added, 'We also have the ability to view records. We might ask for the person's Care Plan in terms of what staff should be doing or we might suggest that they educate their staff and update the Care Plans if we think that there might be something that's effective. I think that's where legal representatives and family members and the people who visit the residents can really be instrumental in helping resolve issues because they are there trying to be a support system and an advocacy system as well for their loved one.'

Another representative said, 'A challenge that I see is that it's tougher to interview these residents. The residents are pretty much 100% dependent on the staff. So when I go out to my memory cares, my visits are a lot different. It's not much me hands on interacting. It's

more me being in the background and kind of trying to observe and see what the staff are doing. That's what I see as definitely a challenge.'

One SLTCO said, 'When we're in an assisted living home and nursing home where people have cognitive impairment, we're really going to rely on our observation skills…so it's *constant observation*. I remember being in a locked memory care unit during my local Ombudsman days and I would just go around and talk to people but then I would just sit maybe I would sit at the table with the residents while I'm observing staff to see what they're doing, how are the residents responding to the staff member. You really have to *rely* on that when you have somebody that can't speak on their own behalf.'

When asked if sometimes staff would 'put on a show' when the Ombudsman is in the care home, she said, 'Yes but you would be surprised at how many caregivers will either tell you something, you know, especially after you start building that relationship or say something that leadership wouldn't want them saying to us. So you show up often enough, you build that relationship or you sit there long enough and watch, you're going to catch *something*.'

When asked about challenges related to her ability to address fear of retaliation and actual retaliation against residents in advanced dementia, another representative said the following when she referred to a resident with dementia experiencing paranoia, 'I see what I see when I'm there but of course they know I'm there so I don't know what's happening to her when I'm not there because we've got lanyards and everything like that. So dementia…it's hard to know what's really occurring but I also don't negate it because it's their voice. It's a challenge.'

A representative from another state described the importance of observing the body language of residents in advanced stages with dementia when they interact with staff members. She shared a **story** for illustration, 'I've had resident who…it's called like "word salad" where she's saying words that are not making sense but she's saying it in a way and pointing to an aide that gives you the impression that she doesn't like that person but those aren't the words that are coming out of her mouth. It's all body language and reaction to this aide being near this resident.' She added, 'This particular resident that I am thinking of she lost the ability to make sentences but she had words. The words were expressive in how she was feeling but they weren't words that would make a sentence that would say, 'I don't like that person. I don't want her near me.''

This representative went on to describe how residents in advanced stages of dementia may respond nonverbally to care staff members in a way that indicates that they feel safe around them. She said, 'From experience, I can say that there are certain staff members that just have more patience, are more suited for a resident that is challenging or have

better behavior management skills with someone like this and there are some staff people that just don't have it. It's almost like parenting…and also everybody has a bad day, you know. And we say that, 'Everybody has a bad day and there are times where you need to walk away.' She added, 'Yeah, there have been times where I've seen residents who just *light up*…non verbal, end-stage dementia, in a Geri chair, completely contracted but when they see a certain staff person, they'll smile, their eyes will get wide, and their body language will say, 'I feel safe.''

"Reflexive" Retaliation Against Residents Living in Advanced Stages of Dementia

"Reflexive" retaliation against residents in advanced stages of dementia is essentially staff verbal, psychological and/or physical abuse of these individuals which occurs *in response* ("reflexive" reaction) to them verbally and/or physically rejecting disrespectful, undignified, unskilled, and/or unsafe personal care such as during assistance with showers or toileting. This form of retaliation can also occur in public spaces of the care home such as when staff administer medications to these residents or assist them with eating in dining rooms.

Quote
"The issue makes me angry because I know how easy it is to address it." – Vicki de Klerk-Rubin, Executive Director, Validation Method, Zoom communication, March 11, 2024

CMS states, 'When a nursing home accepts a resident for admission, the facility assumes the responsibility of ensuring the safety and well-being of the resident. It is the facility's responsibility to ensure that all staff are trained and are knowledgeable in how to react and respond appropriately to resident behavior. All staff are expected to be in control of their own behavior, are to behave professionally, and should appropriately understand how to work with the nursing home population.'

The Federal agency went on to state, 'A facility cannot disown the acts of staff, since the facility relies on them to meet the Medicare and Medicaid requirements for participation by providing care in a safe environment.' The agency added, 'CMS does not consider striking a combative resident an appropriate response in any situation. It is also not acceptable for an employee to claim his/her action was 'reflexive' or a 'knee-jerk reaction' and was not intended to cause harm. Retaliation by staff is abuse, regardless of whether harm was intended, and must be cited' (CMS State Operations Manual, October 21, 2022).

Quote
"*Retaliation by staff is abuse, regardless of whether harm was intended, and must be cited*." – CMS

Resource Box
For an excellent resource that could assist direct care staff and nurses in better meeting the needs of residents in advanced stages of dementia during showers, see the book: Bathing without a battle: Person-directed care of individuals with dementia (Barrick et al. 2008).

Nearly all representatives who were asked about the term "Reflexive" retaliation were unfamiliar with it. This may represent a knowledge gap that needs to be bridged.

For example, one very experienced representative said, 'I am not familiar.' Her colleague said, 'I actually don't think I have heard that.'

A representative from another state said, 'I am not.' Her colleague said, 'I am neither, no.'

While many representatives were unfamiliar with the term itself, they *were* all familiar with the circumstances surrounding it, most commonly residents' rejection of personal care (such as during showers) that may trigger staff verbally and/or physically reactive abuse towards them.

In those situations where representatives said that they were not familiar with the term, I described to them what the term entails and then asked for their thoughts about it.

A very experienced representative said, 'For me, when I was introduced to it, I was appalled to be honest with you. How could someone do something like that to a resident? I mean scratch a resident, pull a resident and so on.'

A representative from another state shared this **story**: 'I have had a couple of experiences with that where staff hit the resident.' She went on to describe one of these incidents, 'There were three staff members holding the resident down physically to force the medication in their mouth. It was their anxiety medication to help calm him down but they of course were spitting at staff so weren't going to take the medication. So they held the

resident down…it was restraint like and there were bruises…all sorts of stuff [said while touching her arms] and I do believe it was a reaction because they wanted to get the medication…just starting to hold the arms and the legs.' She said, 'That actually happened when I was in a building.' When asked if she heard the resident say anything or scream, she said, 'Yeah. I mean, this resident was pretty advanced so their speech was fairly garbled…it wasn't super clear but yelling and screaming.' She said that she 'walked into the end of it.' When asked if she saw anything nonverbal from the resident, she said, 'They were pulling their arms…trying to get their arms free from the staff. You saw that body language. They were trying to get away from the staff. They were in a wheelchair…so kind of hard movement-wise but.' She added, 'I couldn't see the face from my vantage point.'

Another said, 'You'll see certain residents with dementia are more amicable or amiable to letting a certain staff person provide a shower whereas other staff members will say, 'Come on Mary, let's go take a shower…now.' And they leave it at that. Other aides and nursing staff are able to say, 'Let's go take a walk' or 'Wouldn't you like to do this?' Their approach is so much more different. There are some who are meant to be in that role and there are others who just don't want to be bothered. You say, 'No,' well, we're not going to try any other approach.' She added, 'I think the consistency in staff provides the continuity of care. If they are seeing different faces often, they are fearful because they don't have that trust whereas if they have the same staff [missed word] not just on day shift but on *all* shifts, that's what helps them to want to cooperate and get their needs taking care of. Otherwise, they are not trusting anybody.'

When asked about her thoughts related to "reflexive" retaliation against residents in advanced stages of dementia, an experienced representative said, 'Poorly trained staff. They are the professionals here. They need to step back' and 'you don't reciprocate.'

In response to the same question, another representative said, 'Due to their disease, they may have aggression or negative actions, which definitely puts the resident at a greater risk of retaliation and abuse.'

An experienced representative shared her thoughts about "reflexive" retaliation, 'We know residents with dementia are not always easy to take care of and it comes with the territory but staff needs to be given the training to work with the residents. Why are we getting to that point with this person? What are you trying to force them to do…quickly? It usually comes down to the approach and the training of the staff so that it doesn't get to that point. What is going to be the worst thing if this person doesn't get a shower right now?'

When asked about her thoughts related to "reflexive" retaliation against residents in advanced stages of dementia, another representative said, 'Just more training for staff I feel

like would be necessary. There shouldn't be any 'reflex' to that…I can't see any reason for that…training, more training for staff on that.'

Her very experienced colleague shared a **story** about what she believes was a retaliatory discharge after a resident in a secure nursing home rejected personal care. She said, 'I recently had a situation…a resident didn't want to take her medication or she would hit them in the shower.' She said, 'They were saying, 'Well, we have to discharge her' and the Administrator would not listen to any kind of suggestion that I would suggest. The answer was, 'Oh, we can't do that.' The representative said that the documented reasons for the discharge were 'exit seeking' and that they 'couldn't care for her in a proper way basically.' They would not say that it was due to her hitting at staff or spitting.' She added, 'The family did file an appeal but they finally decided that they would not go on to the hearing and move their loved one into a locked unit…a dementia unit.'

A very experienced representative recalled how staff retaliated against a resident when she was just starting to work as an Ombudsman representative. She shared this **story**, 'Aides that would stick their tongue out and make funny faces.' She added, 'Being [young; age de-identified], I didn't know what they were doing. It was terrible.'

When asked what has led to this staff reaction, the representative said that the aide was a 'heavy set woman' and she walked by the resident who called her 'fat ass.' The aide turned around and stuck her tongue out. The representative added, 'The resident with dementia who has behaviors that are culturally and socially inappropriate nature but they're saying these things because they have dementia. The aide will take it literally and nonverbally react to it or verbally react to it.'

When asked for her thoughts about "reflexive" retaliation against residents in mid-to-late stages of dementia, another representative said, 'Normally, when they push a resident or something, it is because they're always so rushed…these staff members. Instead of saying [in soft tone of voice], 'Come on, Mrs. so and so. We'll take our shower now' and be gentle and take their time with them, they rush them in there and they [the residents] don't know what's happening…they turn the water on…most of the time it's not even warm. That's why they get aggressive. She added, 'There are certain tools…that's where all the training comes in involved. These staff that are in these Alzheimer's units or just dealing with memory care residents need so much more training.' Her colleague said, 'I see that as abuse' to which her colleague responded, 'Yeah, of course, definitely.'

The colleague shared this **story** about a resident 'in the later stages of dementia who experienced retaliation and fear of retaliation in an assisted living residence: 'A CNA was yanking around on a resident, she slapped her, she made her try to bend over and pick up

staff when she can't even walk…and she fell on her head. There was a hidden camera in her room because the family kept seeing bruises on their mother that they couldn't explain. The facility actually told them that she was falling out of her bed…so they went in and adjusted her bed to the floor…did things to try to prevent the falls and the bruising and they kept coming. They put a hidden camera in her room and they caught abuse and this woman is in the prison system right now and she got [several] years [number de-identified]. That is real abuse and it is *criminal* abuse. Any time you hit an elderly person, that scales it up.'

The representative added, 'I sat in the court proceedings. I listened to the whole case be played out because facilities aren't going to tell me all the details. I wanted to know what happened to a resident I was watching and I as her Ombudsman, why didn't I see some signs? There were a lot of emotional issues that went on so I wanted to sit in the trial and I listened. One of the things that was said in the trial that was so alarming to me that I hope this facility for sure learn from is…the original supervisor that hired this lady to come into the facility…she was on the stand first and the first thing she said, 'Oh yes, they were all in hot water from the first time they met.''

She added, 'They didn't get along. The resident and the staff never got along. Well, when they don't get along, you do not keep them together because it was dementia…she could have resembled someone in the past that has done something to her. I mean, you don't know. With dementia, their behaviors that come out…and I am not going to call it behaviors…I am going to call it symptoms…the symptoms of dementia could be that they're mean, they could have racial slurs, anything can come out because of the way the brain is at this moment. So you're looking at this [said while making hands' gesture illustrating collision] and you kept them together for three years?' The representative said that 'her quality of life suffered because of that. It was horrible.'

When asked about the events that led to it, the representative said, 'I don't know what got to that point where this woman was so abusive. She was going in her room at the wee hours of the morning, screaming out her name, making her go to the restroom… there was no call light…she was waking her up in the middle of the night to use the restroom…they call it toileting schedule. I wouldn't want that. If you woke me up at 2 o'clock in the morning, that would frighten me. I know that's what was going on. It could have been that when it first started, she may have been combative [making hands' gesture flailing in air] at first…I don't know. That might have been how she got control of her. I don't know. But it was evident that there was definitely something there that caused…and yes, that definitely was retaliation of sorts because she was making her pay for something.'

She added, ‘I know she was afraid of her because when you watch the videos, she would talk differently with this staff member than she did with the others. She was fearful. You could tell. You could hear the quiver in her voice and all the things.’

When asked about the end outcome for the resident, she described the long-term trauma experienced by the resident, ‘I would visit with her afterwards just to see…and the decline was evident…we’re in the final stages, and she has been abused…and she was scared of anybody that resembled anybody that looked like the lady so they had to be really careful about who they’d put with her…and eventually, it wasn’t long after that, she ended up in skilled nursing…she wasn’t mobile anymore.’

Expert’s View
A key principle in understanding a person with dementia engaged in behavioral expressions labeled as ‘aggressive’ is the effort to understand ‘the meaning of the sequence’ of events that led to the behavioral expression. – Professor Jiska Cohen-Mansfield et al. (1996)

Research Findings

A study by Somboontanont et al. (2004) analyzed the 5 seconds before "assaults" by people with dementia during showers in nursing homes.

Videotapes of 18 residents with dementia (12 with severe cognitive impairment and 6 with mild or moderate cognitive impairment) who physically "assaulted" nursing assistants during showers in 15 nursing homes were analyzed.

105 "assaults" took place during 27 showers. An "assault" in the study included hitting (or attempting to hit), kicking (or attempting to kick), biting (or attempting to bite), spitting (at a caregiver), and throwing objects at a nursing assistant. The most common behaviors were hitting (65 episodes) and attempting to hit (26 episodes).

Nurse aides' behaviors that occurred more often during the 5 seconds before the "assault" included: Confrontational communication, invalidation of resident's feelings (e.g. saying 'It's not hot' when the resident complained about the water temperature), failure to prepare or alert the resident for a task or an impending action; disrespectful speech; any touch; and hurried pace of bath.

"Assaults" were more likely when nurse aides:
Sprayed water without a verbal prompt.
Touched the resident's feet, armpit, or perineum (i.e. the initiation of touch, rather than the touch itself, was the trigger for the "assaults," perhaps caused by startling the resident).
When residents showed signs of temperature discomfort.
When multiple caregivers were present (this was associated with throwing objects).

"Assaults" by residents were frequently triggered by nurse aides' actions that frightened, hurt, or upset the residents. These nurse aides' behaviors can be characterized by failing to promote dignity and respect.

The researchers concluded, 'The idea of 'getting the job done' should be replaced by personalization of bathing and concern to the resident's dignity and preferences.'

Note: When referring to people living in advanced stages of Alzheimer's disease, the term "assaults" is inappropriate in most situations. This was the term used by the researchers in their study that was published 20 years ago. Language has evolved since then and we should consider using more accurate and stigma-free person-directed care terms.

Another representative shared a **story** about a resident who engaged in behavioral expressions towards staff in a nursing home. He said, 'I had a case where the male resident was being quote "behavioral" while they're being symptomatic. We're suggesting by calling them "behavioral" that there's some decision-making capacity going on but they're progressively in a state of decline.' The resident 'started lashing out or physically swinging at a male CNA. I wasn't involved in any of this. So they're working with his primary care physician. Things just never got perfect, but the resident continued to become more and more medicated. But still had problems.'

He added, ‘I got involved when the daughter of the resident [de-identified information] witnessed the staff member being physical with the resident doing that reflexive abuse is ultimately what it was. So now here we are weeks later, this guy's all done up with a whole bunch of new medications to turn around and find out it was the staff member that was actually initiating the abuse in the first place. The resident’ s response was reflexive. In fact, I think the sister witnessed the staff member slapped him.’

A representative from another state said, ‘I think it’s ridiculous that it gets to that point. I have zero tolerance for a staff having that reflex because here is my thought process. If you're there…if you know when you start a job or you're working that type of job, you should know that there's going to be situations that okay your reflex may be to punch, to slap, whatever but you have to understand this resident is in their own little world at that time and it's not like they’re intentionally doing that for you. How traumatizing is it for this resident who is going to the shower…I have had dementia residents don’t necessarily like showers because as the resident told me themselves, ‘Sometimes the shower can feel like pins hitting their skin’ and they don’t want to take a shower. They don’t want to take an excessively hot shower or a cold shower and now adding to the fact that sometimes they feel they’re being stabbed multiple times. So they’re going to react…maybe they can’t express and speak that they don’t want to go there but they are going to react by hesitation and if they’re shoving them in there, now you’ve already made an already traumatic experience even that much more so because you’re not taking the time to think of this person as a *human*. I don’t have tolerance for that. I really don’t.’

Her colleague added, ‘I think there’s needs to be more staff training in regards to dementia and dementia residents. I think that may help alleviate some of the retaliation that takes place if they understood better how to handle them or what those residents’ thought processes could be or not be due to the dementia…staff training especially in our memory care centers and the amount of training hours needs to increase and I think we would see a little less of the retaliation from the staff if they understood and were trained a little better.’

Another representative said, ‘I specifically offer training for that.’ She added, ‘I have a specific training that I do that I created. It’s got kind of amalgamation of theory and interventions that I’ve taken from people that I’ve learned from over the years. It’s the most popular training. At least once a year, most of my facilities will ask me to come and do it. I call it: “The Conflict Management Training.’”

She said that the late Naomi Feil, founder of Validation Method (a communication method for older adults living with Alzheimer’s disease) delivered a whole day training to their LTCOP. Referring to Feil’s method, she said, ‘I really think that she is on the right track’ and ‘I am able to work into some of my training’ those slivers of Validation Method.

When asked whether she believes the Validation Method could help staff better prevent and respond to residents' rejection of personal care and avoid staff "reflexive" retaliation, she replied, '*Oh gosh*, yes.'

She said, 'I tell the staff, '*You* are the professional in the room. Especially with someone with advanced dementia. They're no longer competent and responsible for what they do. *You* are the professional here. Just because they call you names, it doesn't mean you call them names back. Just because they squat at you, doesn't mean you squat back.' She added, 'Most of them are just reactive because they don't have training in how not to be reactive.' The representative confirmed that when she trains staff on 'reflexive' retaliation, she tells them that CMS considers it abuse.

Resource Box
Validation Method
To learn more about the Validation Method, visit the Validation Training Institute: https://vfvalidation.org/ To watch Naomi Feil's Workshop: Naomi Feil in Workshop - VTI Store - Validation Training Institute (vfvalidation.org) Skill building Blocks Training: VTI Courses - Validation Training Institute | Education (vfvalidation.org)

When asked about her thoughts related to 'reflexive' retaliation, one very experienced representative said, 'We know that staff has certain attitudes about people who refuse care. They don't like it. They see their role there and their job is *providing* care and when a person says 'No,' that's disruptive to them as a care provider but we know that people have the right to decline. We also know that people with cognitive disorders have particular concerns around bathing…it's a very vulnerable time, you're not clothed, you experience temperature fluctuations, you may not understand what's going on.'

She added, 'There were efforts many years ago to create a teaching tool called Bathing Without a Battle so there are many different ways to try to approach people, try to find out different times a day, different care providers might have a better way with an individual resident and that there might be other ways to bathe them that's not a shower, a bath. It could be a bed bath, it could be some other [way] that you have to continually try to reapproach and try to meet that particular need but at the end of the day, it should never be forcing something like a bath. It's dangerous for them but it's also dangerous for the caregiver and you're just gonna get into a very difficult situation. I think our attitudes towards hygiene and cleanliness standards are very different with this particular generation

that are in nursing homes and what their comfort level is with it. So that, in coordination with what might be a person's personal choice around it or their ability with their cognitive issues to understand it, that all has to be taken into balance.'

She added that they incorporate these messages and strategies into the training they provide to care staff members, 'We put that into our Resident Rights presentation…talking about the right to refuse care and why that's important and how they need to respect that. We include that in some of our educational work.'

One representative who didn't hear about the term "reflexive" retaliation said the following after read her the definition of the term: 'I think Teepa Snow would have some great responses for some general care, which I wish I could spend hours on her things. But it's not okay reflex retaliation. With dementia, it's another whole game as well. Even if a resident has some issues and is throwing tea or something like that, a lot of Administrators will say, 'Okay, step out of the room and gather yourself first and also get someone else…remove yourself' because, yeah, the abuse is not okay to reciprocate.'

Resource Box
Teepa Snow
Positive Approach to Care: https://teepasnow.com/

When asked about her thoughts related to "reflexive" retaliation against residents in advanced stages of dementia, one representative said, 'Years ago before they did any kind of decent training for the CNAs…early on in my career, you would see CNAs get very very frustrated with residents that were hell bent on going down the hallway this way but their room was over here and they needed to go and it's something where [de-identified name of her colleague] will back me up on this…we try and educate staff to say, 'They don't have to take a shower today…it really is okay if they're not comfortable if today is not a good day, try a whole bunch of different interventions to see if you can find the good space so that they want to do this.' But yeah, it's a real thing that aides who are working short staffed are under a lot of pressure and we always tell them, 'Go get your supervisor and walk away. Go get another staff person come in and take a break. Do what you need to do to take care of you so you can be the best person for the person you're caring for.''

When asked about her thoughts about "reflexive" retaliation against residents in advanced stages of dementia, her colleague said, 'We've had several cases where a resident grabbed an aide and they've turned around and punched them or they've thrown water at them. I am telling you, it has been *unprecedented* the instances that we have…reported to us. It

happens. They do it. They just couldn't take it anymore. They backhand them. They threw water at them in retaliation for a resident who either grabbed them or threw something at them or tried to get something off the med cart. Yeah, it happens.'

When asked to describe their role in addressing these situations of "reflexive" retaliation, this representative said, 'In those type of instances, what we do is we make a referral to the licensing and certification agency to let them know that this person has done this. We find out what the facility has done about it…if they terminated that person or if they are working on re-education and more oversight with them. But for our purposes, the most that we can do is A, make sure they are not assigned to that resident again…whether it's a nurse or it's an aide and B refer their license, that's all we can do.'

Incident
A person lived with a 'major neurocognitive disorder" in a "secured memory care building" of an "Assisted Living with Dementia Care." The resident didn't want to move to another table so an aide moved the resident's chair, with her in it, to another table. The resident got upset and tossed her lemonade at the aide. Then the aide took water and threw it on the resident. A witness stated that the aide also told the resident that she was not afraid to throw hot liquids on the resident. The aide walked away, leaving the resident wet. The incident was reported to the nurse on call who reported it to a manager. The aide was escorted out of the building immediately and her employment was terminated. The Minnesota Department of Health investigated the incident and concluded that 'abuse was substantiated.' Source: State Rapid Response Investigative Public Report (August 25, 2024). Maltreatment report #: HL265854201M

Individuals Living with Serious Mental Illness

One representative spoke about a subgroup of residents with serious mental illness whose illness manifestations pose a challenge for representatives' efforts to address issues related to fear of retaliation and actual retaliation.

She said, 'It's *hard*. It's hard because their mental illness makes it so they're not always labeled as "reliable reporters." Is what they're saying truly happening? Is there any sliver of truth into what they're saying with the retaliation? And do the staff take it seriously and investigate the retaliation? Because retaliation is essentially akin to abuse of some

kind…physical, psychological, verbal. Any retaliation allegation should always be investigated by the facility with an incident report sent to the State [Survey Agency]. Whether that's done or not [said while making a facial expression as if to indicate that it is unclear] because especially if someone is severely mentally ill, they're gonna a lot of times chalk it up to, 'Well, this person has a history of making false allegations' and put it like in their plan of care. It can be really hard for them sometimes to retain that encouragement that we give them, the guidance that we give them, it's hard for them to retain that sometimes with their mental illness issues.'

She added, 'It still can be hard for them especially if they're manic. I find a lot with people that have Bi-Polar, if they're manic, Schizophrenia if they're actively psychotic, is *really* hard for them to retain and do any kind of action plan that we come up with or give me any feedback or knowing, even from my perspective, knowing what truly happened? What did happen? so that I can help you and help the staff figure out what's going on…like when their speech is so disorganized, I can't understand what they're saying.'

Incidents Particularly Complex and Difficult to Resolve

Representatives shared stories about incidents that were particularly complex and difficult to resolve. Examples include their belief that management is recording residents inside their bedrooms; residents expressing many complaints on a frequent and ongoing basis; a resident disliked by a manager; residents who are nonverbal and require a lot of physical care; a care home that tried to evict a resident because he was considered difficult; and issues related to residents with serious mental illness.

Another representative shared this **story**: 'This isn't earth shuttering but it is a thorn in my side. There is a home where I have been visiting for at least 10 years since the home opened. *I know* in my heart that they are recording these people in private areas [residents' bedrooms] and I feel like they are listening. The homeowner I believe has recording devices.' The representative said, 'The reason I believe they are in the rooms is because people are *terrified* to talk. In all the years I've been serving that facility, the only complaint I get are when someone discharges. No one ever talks about anything wrong. It's a huge red flag. If no one ever talks about what's wrong, something's wrong. That has been extremely frustrating…that this is continuing and the fear of retaliation is so great, they're afraid to even confide in me.'

Quote
Unvoiced Concerns
"*If no one ever talks about what's wrong, something's wrong*." – Ombudsman representative 'Problems sometimes exist in a facility without anyone complaining to the Long-Term Care Ombudsman Program (LTCOP). One unique role of the LTCOP is to determine when and where there are problems experienced by residents, even when residents don't express them. An absence of complaints may not mean that all residents are receiving quality care or experiencing an acceptable quality of life.' Source: Trainee manual: Initial certification training curriculum for Long-Term Care Ombudsman Programs. Module 7 (page 13). The National Long-Term Care Ombudsman Resource Center (2022).

When asked if that is just a gut feeling or there is more to that, she said, 'Well, it's more than that. The residents…many residents have told me [whispering; referring to their bedrooms], 'Don't talk in here. Don't talk in here because she knows.' Okay, several people…every time…every time have told me that.'

She went on to say, 'I had a situation where in one incident I actually I did receive a complaint from someone in their bedroom that did not give me permission to act. Before I was 10 minutes away from that facility, the homeowner called me to say, 'I understand folks were telling you about this and the other thing' and I said, 'No. What would make you think that?' I've shared that with regulators and so forth who also agreed with me but you can't find it.' She added, 'You cannot find the camera' and 'of course, I am not going on a police search but…it's bad. That is a *huge* situation of fear of retaliation when people are so afraid. You know they've got things to tell you.'

When asked if she recalls a situation that stood out to her as particularly complex and difficult to resolve, a very experienced representative from another state shared a **story** about a resident with anxiety, depression, and possibly some cognitive issues in a residential care home. She said, 'I've thought of a situation that involves fear of retaliation where the resident actually was able to work with me to kind of push against it. I had a situation where there was a resident and the manager disliked this person. Through many interviews with him and many interviews with her and the description of their interactions…I'm just going to cut to the chase and just say she definitely disliked him and

because the manager disliked him, it went from the top down so her staff began to dislike him, began to see things he said only through a negative lens. They were very unaccepting of him despite him having some cognitive issues and with certain ways that he kind of wanted things done. They just were confrontational about him on all levels. They gave him a discharge notice and when someone is given a discharge notice, they have to present a reason for the discharge and in this particular notice, they said the reason was his lifestyle choices. I've never had that appear in a particular discharge notice. We did appeal that and we won but she [the manager] just kind of reset her efforts and wrote another discharge notice.' The representative reiterated, 'This manager just had a personal dislike of him. That's what was at the core of it'

When asked what the manager meant by 'lifestyle choices,' she said, 'I thought it was headed in a certain direction and it really was just trying to say he's difficult, he's negative, they describe something like he raised his cane at mealtime. Well, what he told me he was doing is that that was his signal to the wait staff that he wanted his tea but they were trying to make every little thing that he did sort of to be seen in a negative light. They decided to subscribe that as a lifestyle choice. I thought it might have meant something else like it was some type of a commentary on his personal interpersonal interactions or something, but it really was just a little bit of…I don't think they had a good reason to give the discharge notice.'

She added, 'She really reorganized herself and she gave him a second discharge notice but what I did is that I decided to look at all the things that he described to me that were difficult for him and I reported those complaints to the survey and certification agency. When they came in to do an investigation, they found that he was not being provided with the appropriate and adequate care and services from this home. They weren't meeting his needs and so he did act out in some behavioral or verbal way because he wasn't getting his needs met. He had been retaliated against for an *extended* period of time. I bet if we looked at this entire situation, he had experienced retaliation for a year before we really got to a point where it was recognized and it was addressed and it was actually found as a deficiency for that particular…' She went on to say, 'I'll use only one example. They asked the manager, 'What kind of training about cognitive [issues] you have within your home?' and her response was like, 'I've worked in this field for 25 years. We don't have to have a training about cognitive issues here.' It was completely recognized that they weren't really meeting his needs. I am very happy that he was willing to trust the process and to step into the fear of retaliation to improve his situation and to this day he continues to live in this residential care home. They now have a whole new management team and he has people there that he can work with and have his care needs met. I'd like to think I had a hand in helping him get to a better place.'

When asked about the nature of his fear of retaliatory discharge, she said, ‘His fear was that he was going to be put on the sidewalk. He would tell me that. He said, ‘It weren’t for you, it would be wintertime, and I would be walking the streets.’ I said, ‘Well, that wouldn’t happen. We wouldn’t let that happen.’ But that was his fear. That’s what he thought would be the outcome.’

A representative from another state shared a **story** about a resident living in a nursing home, ‘I have a resident [whose] [de-identified family relationship] is her guardian. She is nonverbal and she is non-ambulatory. She is not responsive in any way like her eyes are open but there is nothing…there is no kind of response there…no gripping of the hand…there is no way to really communicate with this resident because of the condition she is in. Her [family member guardian] does have a lot of concerns. I would say 90% of them are valid concerns because of the level of care she needs. He feels like that some of the lack of care is retaliation because of his constant complaints, which I agree with because they’ve tried to discharge her twice now because of that.’

She added, ‘It is really challenging…this is an ongoing situation because they don’t provide the care. She had a wound, she needed to be hospitalized on antibiotics because of it. Obviously, she can’t move herself…so somebody is not moving her. So he has valid concerns but because of the constant concerns he brings to them…and he is *aggressive* verbally when he does so…he is very aggressive. We’ve tried to talk about maybe how he presents those because it is off putting for the staff and like ‘We don’t want to be yelled at,’ which I get but… So this is a situation that we continually open and close complaints with them because they don’t address him or they’re not addressing him. He feels like it is because he complains too much…those are his words…when the reality is that most of his concerns are actually valid. She is supposed to be elevated…I’ve walked in and she has been flat on her back. It is just a lot…it is an ongoing…and because she can’t communicate, it’s really hard to validate some of these because she can’t communicate so we have to go based on the condition she is in. It is hard without having that verbal piece or any kind of communication from the resident. She doesn’t really respond if there’s pain or anything…there’s not really any response.’

When I asked whether the resident understands cognitively, she said, ‘I don’t know. I don’t know because she can’t respond in any way, so it is hard to know if she understands.’

She added, ‘I’ll be honest…because there are all these concerns, it does make it really hard to resolve each concern because they’re like, ‘Oh Gosh, here we go again.’ And I am like, ‘If you just did what you were supposed to do, we wouldn’t be here.’’

When asked about incidents that are difficult and complex to resolve, another representative said, 'It 'goes back to when we want to do something to make things better but the resident is afraid so nothing gets done. That resident goes to the hospital and they can't come back and it just adds the layers on…you just worry about that negative outcome.' She shared a **story** about a resident who didn't want her to intervene, so things got worse. She said, 'It has to do with his benefits and he is really feisty and he'll complain.

She said that he doesn't always go about maybe the right way and the facility is saying, 'Well, we don't think you need to be here. You're not at the nursing home level of care.' And the resident, in all of his feistiness, didn't want to, 'I don't want you to do anything. We'll just see where this goes. They haven't given me anything in writing.' And the facility went to the extent of getting the [de-identified name of agency] to say that his benefits won't pay for him to be at the nursing home anymore. I think this goes back to his fear of retaliation where maybe we could have prevented that from getting that far and helping him about how he goes about things in the facility. So it gets really complicated.'

When asked what type of benefits, she said, 'So the [de-identified name of agency] was paying for his care completely in the facility. And the nursing home went to the [de-identified name of agency] and said, 'This guy doesn't need to be here anymore' where they didn't have to do that…nobody is coming in to check…and it was just because he is difficult and there could be a guy in the room next door to that with the same situation and that wouldn't have happened.' She added, 'He is screaming about all these other things and doesn't want to deal with this issue and it just kind of snowballed.'

Social Workers – Potential Conflict of Interest

The role of social workers in improving the quality of care and life of LTC homes is varied and critical (Acero et al. 2024). Several representatives reflected on the role of social workers in addressing residents' fear of retaliation and actual retaliation while sharing their concerns about a potential conflict of interest inherent in the role.

One of them said, 'I think some facilities have social workers that are engaged but I've been to Resident Council meetings and have asked, 'Do you know where your social worker is?' Some residents say they didn't have any idea there was a social worker in the building.' She added, 'In the larger facilities, they just maybe don't have time to meet the residents or don't get to know them. So I think sometimes they are a great resource but in residential care assisted livings there is no social worker so there really is sometimes nobody.'

Another representative said, 'Most [nursing] facilities would have a social worker. Personally, I always thought it's a little bit of a conflict because that social worker is supposed to be working for the resident…somebody the resident can go to for support but

it’s the facility who signs the paycheck at the end of the day. It can be a real [didn’t complete the sentence] yeah.’ She added that sometimes social workers call her and say, ‘This is off the record because it can’t be coming from me.’ She said that they do it that way ‘because they fear retaliation.’

A very experienced representative said, ‘The role of the social worker in the facility is to represent residents too and what residents want and being there for the resident but that is not what happens always. They are a facility staff person and they have to respond to the Administrator [missing words]. We have social services folks who will call us on the downlow and say, ‘This is going on in the building’ but that is few and far between. Sometimes the social services person has to do the dirty work that the Administrator should be doing…so residents don’t see them as someone who is there for them.’

When asked whether this has to do with the fact that that social workers in care homes are ‘between a rock and a hard place,’ she said, ‘Yeah. That’s a really tough position. You need to be a resident advocate and yet the Administrator is breathing down your neck to discharge people unsafely.’ Referring to the fact that the social workers receive their paycheck from the care home, she said, ‘So they can’t be really resident-centered.’

When asked about the role of social workers in addressing residents’ fear of retaliation and actual retaliation, a SLTCO said, ‘I think that it’s very important and again in [de-identified name of her state] it's a mixed bag in nursing homes. We have some facilities that have master’s level social workers, we have some that have bachelor’s level social workers, we have some that are designees, and we have some that don't have social workers at all. They are all supposed to have social workers, but the reality is [didn’t complete the sentence].’

She added, ‘We rarely see a psychologist in the building. The mental health support is *really* sad. It's mostly about medication, ‘Oh, how are you feeling cause you're taking an anti-depressant?’ Great. Okay, I'll see you later.’ It's not about therapy, it's not about adjustment, it's not about having a therapy session in that sense.’

She went on to say, ‘The reason I say all this is because I think that the social work role and or psychologist, therapist, psychiatrist, whatever whoever's providing mental health support is exactly that…is to help that person deal with the experience that they're having and that fear and then if they are really retaliated against, then the consequences of being abused and that's perfectly fits within the guidelines of what a social worker should do…addressing not just psychosocial needs but the psychological needs and the impact and how it affects the overall health and well-being and also dealing with trauma. There's a whole movement about trauma-informed care and all that. This is clearly within that discussion too but no, I think there needs to be and again it's just so frustrating to me that

there's not enough support in this area just in general and especially when there's a crisis like fear or actual retaliation or both is a crisis as far as I'm concerned.'

When I said that she just opened a window for a separate project on the role of social workers and psychologists in addressing residents' fear of retaliation and actual retaliation, she said, 'Absolutely and I think it would be a great thing to do because it'll help people recognize…but the problem is money. Who's going to pay for it? We can't even get people to do dementia care properly and we can't get people to deal with adjustment to nursing homes. The social workers are tasked with doing all this other stuff, which really is important, but it doesn't have anything to do with overall mental well-being. Then you throw in a fear of retaliation and that person's scared all the time so you're dealing with somebody that's scared all the time and what happens as a result when you're scared all the time. It's horrible.'

A Word About the Role of the Nurse

One SLTCO said that beyond educating the staff, the role of the nurse is 'to address it right away and report it if she thinks retaliation is going on. These aides are only going to do the right thing if the nurse does the right thing. If the nurse doesn't care and she doesn't check and she is not in there seeing what's going on, they don't care.'

Barriers Outside the Care Home

Concerns related to Regulatory Oversight and Enforcement

A series of concerns were identified related to CMS and SSA's oversight and enforcement of nursing home federal regulations pertaining to dignity, quality care, quality of life, and safety of residents, including fear of retaliation and actual retaliation.

At a high level and not necessarily related to retaliation, one representative said, 'Who is the number one payer of this whole entire industry? It's the government and until CMS really stops payments on obvious fraudulent and problematic things…as long as they keep getting the money, their behavior is not going to change.'

At the end of one interview, I asked a very experienced representative whether there's anything I didn't ask about that she thought is important to recognize about this issue of residents' fear of retaliation. Her reply was, 'The only one I would just plant the seed is what is the role of enforcement around this particular issue? Because I think certainly the enforcement agencies at the state and federal level know that this issue exists and I think that they don't necessarily recognize it or maybe do as much with it within their investigations. I just wonder…I don't have an answer but I'm just planting the seed that I think that one of the many supports we have for quality of care and quality of life and good consumer experiences is the enforcement process. I think that needs to be brought into

this topic so that we can feel that at a *minimum* they have an awareness and a sensitivity and at a maximum maybe they see themselves as playing a role in alleviating the concern around it. I don't quite know what that would look like but I think it deserves some exploration.'

Reflection Question
"*What is the role of enforcement around this particular issue?*" – A very experienced Ombudsman representative

Representatives identified a gap between CMS regulations pertaining to residents' right to voice care concerns without fear of retaliation (reprisal or discrimination) and the implementation and enforcement of these regulations.

One experienced SLTCO said, 'I think it's a *great* requirement but what does it look like in real life and how people feel about their living environment at the most vulnerable time of their life when they're needing very intimate care? You really want to put that regulation in practice and or highlight that regulation and use that education information to empower families and residents to speak up. It's the *environment* and how they're treated in what is really a strong barrier to say, 'Alright, there's this great regulation but I am not feeling comfortable or safe exercising that.''

Quote
"*Alright, there's this great regulation but I am not feeling comfortable or safe exercising that*." – Ombudsman representative quoting a resident

Several representatives saw a need for stronger CMS and SSAs' oversight and enforcement of federal nursing home regulations. They described ways in which this could be achieved.

One of them said, 'Punitive measures. Our state regulators need more teeth. They need more specific, more punitive guidelines in order to hold facilities accountable. I think that retaliation needs to be viewed from a legal standpoint as abuse and there needs to be action to follow because it is abuse.'

She added, 'I think surveyors need to be given authority…whatever regulation they need to be able to say, 'If a resident said it happened, it happened.' For instance, regulators come in…they want to see proof, proof, proof. I know they have to be able to stand in a court of law because it is a legal situation. If you are a victim of a crime at home…God forbid…and the Sherrif's office comes in and they talk to you, they take your word for it…now, are they looking for evidence? Of course but they take your word for it. *Why* don't they take the word of a nursing home resident? *Why*? I think there's needs to be…I don't know how to get it…if I did, I would have already started but if I am the legislative or the regulatory standpoint, there needs to be more teeth, more punishment.'

Reflection Question
"Why don't they take the word of a nursing home resident? *Why*?" – Ombudsman representative referring to state surveyors

Speaking about challenges and barriers in addressing residents' fear of retaliation, another representative said the following about Adult Protective Services and the SSA, 'I am not seeing them backing up the retaliation claims or complaints with tags, deficiencies, fines. I am a fairly new Ombudsman but…I'll be honest, sometimes I don't feel like they have our backs with the residents. I think it's a very hard thing to quantify I guess and to investigate but hopefully with your research or others…but those [agencies] are the ones that put people on Abuse Registries or can put fines and tags, but I don't see the force coming.'

During a forum dedicated to the topic residents' fear of retaliation, a SLTCO shared her concerns about the small fines imposed by the SSA after deficiency citations (F-tags) are issued to car homes, 'Whenever facilities do get tagged, then these payments that they owe are miniscule, 'Yeah, I'll take the tag…it's a hundred bucks' or whatever. It's not a significant amount. I don't recall with the abuse when they're tagged for that, what they will have to pay but I am sure it's not enough. Increasing those would be something because everybody on this chat has heard, 'I'll take the tag.' It's because it is miniscule and why not? It's a slap on the wrist. To make that significant I think would be helpful.'

Quote
"I'll take the tag"
"*It's because it is miniscule and why not? It's a slap on the wrist. To make that significant I think would be helpful*." – Ombudsman representative explaining why some care homes have no problem paying small fees for violating regulations

Low Substantiation Rate

When asked about the main challenges and barriers in addressing the phenomenon at the center of this project, several representatives spoke about SSAs' low substantiation rates of complaints alleging violations of federal and state regulations in general and related to residents' fear or retaliation, threats of retaliation, and actual retaliation against residents.

When asked about what she sees as the main challenges and barriers in addressing residents' fear of retaliation, a very experienced representative said, 'Another frustration…a barrier is when we do refer to another agency, we don't see any results.' She confirmed that in her response she was referring to their SSA. When asked what underlies it, she said, 'We're still trying to figure that out.'

Another representative said, 'I don't remember one time ever filing a complaint with the regulatory system…with the Department of Health here where they have substantiated a complaint of retaliation. Not once. I don't think I've ever seen that happen.'

A representative from another state said, 'We just started tracking here in [de-identified state] how many complaints we submit versus how many come back actually substantiated. The numbers are not good. So maybe for last year we submitted…I want to say 400 and some complaints…and obviously there are way more complaints that we don't always submit to the state surveyors. I want to say 16 came back [substantiated].' That is a substantiation rate of only about 4%.

Another representative said, **'**I do use Medicare.gov and all that data all the time and I see how many times people complain in formal complaints and how few times that they are cited. I've filed complaints for 10 years and I think I've gotten only 2 that have been found to be founded.' She explained, 'So that's one thing. If the facility is not feeling the pain when they are not doing the right thing, they are not going to change that.'

When asked what she thinks underlies the low substantiation rate, she said, 'They are required to be in the facility for a survey once in every 9 and 16 months. But they are supposed to respond to complaints outside of that but in our state at least since COVID, they 'ball' all of that up for survey time. So when they go into survey that week, they are not only doing their survey work for compliance, they are also looking at the 30 complaints that came in during the course of the year.'

When asked how surveyors can have depth when they 'collapse' complaint investigations into the annual survey, she said, 'Right. You're not only…A, the depthness but the response time and the data that supports whatever the complaint we had is long been buried, gone or literally dead. I am sending them in to handle cases of a resident who is not even alive anymore…I mean…not when I wrote it but by the time they respond to it.'

When asked what made the SSA 'collapse' complaint investigations into the annual survey, she said, 'They lost so many surveyors during COVID and leaders in the [SSA]. I think they are just struggling now staff-wise and money-wise to back their core of surveyors.'

Inexperienced State Surveyors

One very experienced representative spoke about problems related to inexperienced state surveyors. She said, 'The surveyors bring in newly trained folks to become surveyors. They are not seasoned enough to identify those types of issues and the nursing home ends up smelling like a rose because it was unsubstantiated because of their not understanding *how* this works.' She went on to speak about 'poor investigative surveyors that are not well trained. And then the outcome of the inspector fails the resident when the complaint cannot be substantiated. That's how I feel about it. That's my take on it through all these years…it's the same thing.'

Quote
"*The surveyors bring in newly trained folks to become surveyors. They are not seasoned enough to identify those types of issues and the nursing home ends up smelling like a rose*." – Ombudsman representative

Delays in SSA Investigations

Several representatives spoke about substantial delays in SSA investigations and the problems these delays cause to residents and in holding care homes accountable.

Referring to her SSA, one of them said,' They're busy too so it could take months, months for them to go investigate something.' When asked whether her observation also applies to allegations of mistreatment, she said, 'Yeah…so those can be a priority, but it could still be a while…maybe that staff has gone by the time they go there. I can only do so much in my role. I really wish I had more say and more of an influence sometimes.'

When asked about what can happen during the period between the filing of the allegation with the SSA and when surveyors conduct their on-site investigation, she said, 'I think things could continue. You might have one resident that actually reports it and then you may have 15 others report it. So what else is going on? Lots of things could happen that we're not aware of. Things could get worse.'

One SLTCO said, ‘The other piece…and we’ve seen that time and time again…is highlighting that as a concern and even when a resident or a family member wants to speak up and file a complaint to the state survey agency, how quickly can they get out there to address that? How much are they really enforcing that? It’s hard to say.’

When asked about the potential consequences of delays in SSA’s investigations of retaliation or fear of retaliation, this SLTCO said, ‘I think the consequences are at the detriment to the resident first and foremost because the State Survey Agency is the only agency that can investigate, cite, fine, and enforce and potentially save lives of residents. I think with the delays that we've seen throughout the pandemic and what we're still seeing now, our State Survey Agency has an outgoing message that says, ‘We don't know when we're going to be able to get back to you.’ How discouraging is that for somebody that's calling in even for a higher-level concern of abuse or neglect that has actually occurred? I wonder what the process is then for making those determinations around what rises to the level of more of an urgent matter because to me the fear…the installation of fear, coming down from leadership or even just some caregivers, should rise to a higher level because to me that's an indicator that there's more abuse potentially going on…more pervasive abuse.’

When asked about challenges and barriers in addressing residents’ fear of retaliation, an experienced representative said (after describing the barrier of the burden of proof), ‘The second would be if there is retaliation, the response time from the state. Because in our office as the Ombudsman program, we respond in one to four days when we receive a complaint but when it's turned over to the [State Survey Agency], it could be *months* before it's investigated and the resident may not remember, may have moved on, passed away…it continued and really no evidence left. That I think is the biggest concern…is when there *is* retaliation and I *cannot* resolve it at my level…when you take it to the next level, there's such a time period that you're waiting for it to be investigated.’

When asked what these delays mean for residents, she said, ‘It’s really hard. They feel like they are not heard and they’re still living there. They are still dealing with it. It has not been fully addressed. We’ve been unable to address it and prove…they are left just sitting and waiting. It may be continuing until something is done further.’

When I moved to ask the next question (the one about a situation that stood out to her as particularly complex and difficult to resolve), she returned to the same issue, ‘Waiting for the state to respond when I moved complaints. When I know that they have called me, they’ve been retaliated against, my role is to take it higher, and when I take it higher, that period of time is *such* a long period of time before they come in and investigate. And it often leads to unsubstantiated.’

Later during the interview, when asked whether there are things that currently do not exist that if existed would have enabled her to better address the issues of residents' fear of retaliation or actual retaliation, her response was, 'Response time from regulatory agencies in dealing with retaliation.'

Media Report
80-year-old Marjory Aldrich was recovering from pneumonia in a nursing home in Minnesota. She felt fluid building up in her lungs and became frightened when her antibiotics were discontinued. She asked an aide if they could resume her medications but said that she received no response. When she asked a nurse to call a doctor to renew her prescription, a nurse came and slammed a phone against her chest 'so hard she almost passed out.' She said, 'I laid there for 20 minutes, too petrified to move.' After her complaint to the State Survey Agency was delayed until later that year, she said, 'This is why no one knows about these crimes. It's not because we don't have a voice. It's because people in power deliberately choose not to listen.' Reflecting on her efforts to advocate for herself, she 'wondered why she bothered to call the state agency instead of 911 or local police' (Serres, 2017b).

A representative from another state shared her deep frustration about this issue. She said, 'Regulatory can also be that barrier to what you think needs to happen because when I am out there involved in something, like when I went to that particular Resident Council meeting where they tell me all these bad things, I get permission from them to make a state regulatory complaint and I go to my car and I call my regulatory manager and I tell her, 'This is going on and I've got to make this complaint' and I am torn up over this because there's a lot of people being affected by this. So I go ahead and she says, 'Yes, get that turned in quickly. This is very important.''

She added, 'I get it turned in and then that barrier happened when I turned it in…I think it was April but it didn't get looked into until June. Where is that P1? It should have been a P1? They made it a 14-day but it was well over a 14-day before they got there. Those are true barriers for Ombudsmen and I don't know how to get that fixed. I wasn't happy so I am digging, digging, digging…trying to get help in the building…trying to get help…it was very important for me to get help in the building and I couldn't do it…I lost sleep…the whole nine yards. Those are very very hard times for Ombudsmen…when we build this urgency and can't get it.'

Her colleague added (referring to allegations that are not P1 or P2 (P1 and P2 allegations are 'normally for abuse, neglect, and exploitation'), 'I'll get one today that they're

investigating one from four or five months ago. Some of them aren't even being looked at until their full book when they're in there or the full book survey.' [i.e., annual survey]

When asked about things that do not currently exist that if existed, would have helped her in better addressing residents' fear of retaliation and actual retaliation, a representative from another state said, 'I feel like there should be some regulations surrounding the turnaround when it is submitted to [the state survey agency]. If it's considered abuse or neglect, I think there should be regulation on how fast they come to address these concerns. I think that there should be timeframes for addressing complaints.'

Her colleague clarified, 'They are working on 2018 *complaints* in our state. The timeline for nursing homes is within 24 hours, that's already set, that's regulatory. Them coming in to investigate the abuse or neglect or whatever the complaint might be, they are two years back. That's what she is saying…there should be some legislation put in place so they are required to come in right away on certain complaints and they don't.'

The first representative tied delays in SSA's investigations to residents' fear of retaliation. She said, 'That's the reason why they *don't* want to file a complaint. That's the reason why they *don't* want to say anything. And honestly…and the worst situations ever, some of these residents die waiting for the [SSA] to come out and address some of these concerns.'

Quote
"*That's the reason why they don't want to file a complaint. That's the reason why they don't want to say anything*." – Ombudsman referring to delayed investigations by State Survey Agency

She added, '[De-identified colleague's name] was just telling me she had a case with a lady…because of the neglect that she faced with her wound, she is now on hospice dying. This is the reality that we face every day. As much as we want to help the resident and address things, we need just as much support from the [SSA] because we're not.'

Her colleague said, 'Yeah, we're not an enforcer. We can't tag. We don't have any teeth. The [SSA] has the stick where they can tag and fine them. We don't have that.' She added, 'That's where you were saying, 'What is missing?' I think that if we were able to…because we go into nursing homes quite often…more times than the [SSA]. We're there more…so we can see where there's neglect and abuse and if there was a way where we could tag or have a way where our complaint could be the complaint that the [SSA] looks at and make their decision

on but they have to *see* it. Because the [SSA] has to *see* it, more than most times, the nursing homes are already trying to change the record, fix the problem before the [SSA] even comes in. So now they're okay.'

The first representative added, 'When surveyors go out to the building and they do survey and you tell the surveyor, 'Please look at these trends. They're always having issues with staffing. I've walked into the building…they are not meeting regulations. Even their own staff are telling you they're having issues with staffing.' They can't do it. The [SSA] will come and tell me, 'Well, I have to catch it in real time.' You know that they are just going to get agency [staff] and cover it up and, 'If I can't catch them in real time, I can't tag them for it.''

When asked if she feels the state survey agency takes her word and input, she said, 'They will look at it and consider it but they don't ultimately use it. No.'

Her colleague said, 'They can't use it. They have to see it in real time. When [de-identified name of representative] talked about they'd rather get a tag for resident rights, I think that should be changed as well. Residents' rights should have some kind of penalty or fine towards it so they'd take residents' rights into consideration so that retaliation, if they get tagged for retaliation, not following grievances, dignity and respect…all that stuff, they would respond better I feel…if there was more of a weight on the resident rights tag. They would do better in education staff on residents' rights.'

When asked whether she finds that delayed SSA investigations contribute to residents' fear of retaliation and the lack of complaints of mistreatment, the first representative added, 'Absolutely. I feel like it plays a big part…especially when you submit a complaint today, you send it to the [SSA] and you don't hear about it for a year or two years. I have people calling me now sometimes…I've had one call from the [SSA] that wanted my opinion on a case where I wasn't even an employee. I said, 'I don't have any information for you. I wasn't even here.'' She concluded, 'It's very disheartening and it's hard. I encourage my residents to make the complaint regardless to fear of retaliation but there are days where I don't push the subject because you don't get the support that you would need to address these fears.'

A representative from another state shared her frustration with times when the SSA is experiencing a backlog of investigations.' She shared a **story** about a resident who calls her 'the most' with care concerns. She said, 'I had a call out to the [SSA] and when I called them…I'll just be honest…she was like, 'You are the sixth call for this woman.' She is having a lot of people call and I am not going to file a complaint number with this because it's just a similar complaint.' So we're waiting. I know they are backlogged. I do appreciate their work very much. I was like, 'Okay' so when I wanted to follow up later with just to see where we're at with this because I am getting so many calls continually for her, 'Well, you don't

have a complaint number' so I stated the issue. Then I just recently called again because I had some other people say, 'Yes, you can tell the surveyors my name.' Some will say, 'Don't say it in house,' some will say, 'Yes, you can say it in house' but now I have a complaint number and I am going to be calling again too. I know they are backlogged but it's an explanation but not an excuse. You know, these residents are still suffering.'

When asked whether there are things that currently do not exist that if existed, would have enabled her to better address residents' fear of retaliation, another representative said, 'A different way that the [SSA] substantiates and unsubstantiates complaints. The pathway that they currently have in our state…it causes them to unintentionally miss things and not think outside of the box…so if you don't check this box, that closes this pathway, we don't really explore it further and we just go on to the next pathway. It excludes things in my opinion. It's not the surveyors' fault. That's the pathway they have and the process they have to follow. The reason that's an issue is because when we're trying to deal with a concern that's also been called into them, the facility's response is, 'It's unsubstantiated' and then it makes it more challenging. If there was a better process and the same thing…specifically even around retaliation, which is really hard to prove…I think because how closed the process is, they do miss things unintentionally.'

When asked whether this flowchart is from the Federal nursing home regulations or that it Is an internal SSA flowchart, she said, 'I don't know. I actually observed it when I've shadowed a survey team…that's actually the system that they use on their computers…I would say it's an assumption. I am assuming it is federal process but I didn't ask that specifically, but the surveyor told me this is what they have to follow…that it basically takes an act of Congress to overturn a closed decision tree.'

I asked, 'Do you know whether Ombudsmen have authority to examine survey inspections and complaint investigation reports and if you find gaps or lack of evidence you know exists, you can call it out and request a follow up survey or investigation?'

Her colleague said, 'We've tried it and we've been shut down.' She added, 'Well, I don't know about [de-identified name of her colleague] but in our program, we have had circumstances where things were 'unsubstantiated' so we've gone back and said, 'Hey, what about this?' [And the response from the SSA was], 'No.''

She shared a **story**: 'I had a resident who was completely cognitively aware and she took meticulous notes. This was related to a dining issue and she took notes on her menu. She was upset. She knew it was unsubstantiated and she called following her hotline and when I reached out to state office, I was told that they're not going to take the resident's word. Again, these were written notes…not going to take the resident's words over the staff notes… so even though they were inaccurate, that's what they [went with].'

Her colleague added, 'We've had volunteers actually observe something and they still won't take our observation into consideration, and it was still unsubstantiated because they couldn't prove it in documentation or anything like that.' The first representative said, 'We've had previously…if the state agency is not there, that it basically doesn't happen.'

While most representatives addressing this issue thought that there are substantial delays in their SSA investigations of allegations of abuse and retaliation, one of them said that their SSA is doing a good job on this front and that his SSA's response time to allegations is adequate, 'Our licensing agencies, depending on the situation, they're fairly quick responders depending on what the allegation is. Now, it may take them six months to two years to fully close out a case but they will get to it fairly quickly.' He then recognized that the survey agency's response time may vary 'county to county. It might be state to state.'

Lack of Oversight and Enforcement of Harmful Retaliation

One representative identified lack of adequate oversight and enforcement when it comes to harm level retaliation, 'I really don't think they get cited as actual harm especially when it comes to retaliation or being afraid of a certain person.' She went on to share a very disturbing **story** about a White CNA in a rural care home who had tattoos all over his body. When he would go into two African American residents' bedrooms, he would always pull up his sleeve and there was a hangman noose tattoo on it. 'It was a lynching scene is what it was.' She said that one of these residents in her 80s 'was terrified of him. I was terrified. He was a very scary individual.' She said that the care home refused to remove him from providing care, saying, 'We were low on staffing…so he stays.' The SSA 'didn't even cite it. How can you not see that as being…I mean, I look at it as almost criminal to do that because he was *intentionally* doing that and they even had him on camera. When he would walk outside her room, he would flip his shirt down. There were only a couple of residents that he did that to and on the cameras it showed that every time.'

The representative reflected on this incident, 'I was so upset with licensing. Number one, he should have been fired instantly because he showed that, but they didn't view that as actual harm and even the resident had told them that she was very very afraid. It's those types of things.'

Her colleague asked, ‘So how do you make a person feel protected in a situation like that?’ The first representative added, ‘I was completely lost on that one. We did get that he would not assist them [the two African American residents]. That was the only change but even then as they are sitting in their rooms…watching him go by all day.’

When I asked the colleague how that CNA action would have made her feel if an aide did it to her, she said, ‘I would feel violated. I would feel like you might as well put a rope on my neck. If you’re going to show me your rope, you might as well put it on my neck. That’s like pulling a gun on somebody. If you show me your gun, that’s what it amounts to. Everybody knows their history. You know how many people died at the end of the rope. For him to go in and show that to somebody is just *cruel*.’

Higher Weight to Staff Input

Several representatives said that during investigations state surveyors tend to give more weight to staff / care home’s words and documentation when compared to residents’ words and reports. When asked about the role of surveyors in addressing residents’ fear of retaliation, one SLTCO said, ‘I think the surveyors need to listen to the residents and believe what they’re saying and not just listen to staff.’

Referring to her state, she said, ‘I think we are lucky here and they are tuning into it more.’ She added, ‘I think staff would say, ‘Oh yeah, they are confused.’ They poo poo it. But surveyors have to really really hone in on that and ensure that the residents know that it’s safe to talk to them, that they are going to believe them, listen to them, and follow up. I think creating that trust and talking to the Resident Council and understanding…have these issues come up before? What are the issues been? Those types of things.’

A representative from another state said that with regards to complaints related to abuse, neglect, and retaliation, ‘A lot of the time the surveyor will come and speak with staff first and then speak with the resident.’ Her colleague added, ‘Or they don’t speak with the resident at all.’ The first representative said, ‘Sometimes the surveyor doesn’t even speak with the resident.’

She said that certain staff and managers try to influence surveyors, ‘If the staff person gets in and says…the Director of Nursing says, ‘Listen, you've been in this business just as long as I have. This resident is a *problem*. You can go and talk to them but I'm going to tell you how this how the story goes.’ When asked if the surveyor will then go and speak with the resident, she said, ‘Sometimes they don’t, sometimes they do.’

She shared this **story** about a same-day ‘facility-to-facility transfer’ within the same company: ‘The first facility was saying, ‘We’re going to become sub-acute rehab.’ So they moved [several; number de-identified] residents to another facility and we found out about

this. When we went to go interview these residents who had been moved, one of the residents that we met was in bed at the time that I visited her and I said, 'Can you tell me about the day that you were transferred? What was it like?' Not realizing that this woman was blind. She said, 'I was having lunch and they came and told me that it was time to move to my new home' and because she was faith-based, it was 'Okay' because God was with her so she moved. She didn't know she was getting on a bus…she didn't know any of what was happening.'

The representative said, 'They got fined. They did get fined.' Her colleague said, 'After we pushed and pushed and pushed.' The first representative said, 'We pushed because none of the surveyors interviewed any of the residents that had been moved.'

She added, 'There was something in the admission agreement that said it could be a facility-to-facility transfer…there was some loophole that the Department of Health came up with that they just never interviewed the residents.'

She went on to share about a situation in another care home, 'My staff people went to interview residents who were alert and oriented and they said, 'No, we never spoke with the Department of Health' and the Department of Health validated that.'

When asked about her expectation from the SSA with regards to interviewing residents during these investigations, she said she expected surveyors to ask residents, 'Did you want to move? This was your home. You had friends here. You were in the town that your daughter lived in. You would want to know what the person's plan was and as the survey agency that can validate the resident right violation. If you go to the staff person first and the staff person says, 'No, they wanted to move. We have it documented. We have a social worker note. It says right here.' We asked her, 'Are you okay to move to this facility? She said, 'Sure.' That's good enough for the state survey agency. But if the surveyor then went to the resident and said, 'How do you like living in this home?' and the resident then said, 'I don't know anybody. This is not my home. I don't know where my things are. I am not allowed to go out and smoke like I used to. I don't have the same choices anymore.''

Her colleague spoke about the pressure exerted on the residents so they'll agree to move, 'This same facility told one resident, 'You should go now so you can be with your friends there. If you don't, we don't know that you can even be roommates…so you probably better off going right now.' They were coercing them to go together so they could get rid of them quicker.'

Research Findings
A study by Kusserow (1990) conducted 232 interviews with state, national, and Federal organizations in 35 states (organizations involved with receiving, investigating, and/or resolving nursing home abuse complaints or those knowledgeable and concerned about nursing home or elder issues). The study found that 'surveyors short duration of interviews with residents limits their ability to overcome residents' fear of reporting the abuse.'

Representatives spoke about SSAs' challenge of proving retaliation against residents. One of them said, 'Retaliation is so hard to prove and it's hard for state investigators to substantiate these cases as well.' She added, 'To me, that is a very very big challenge because a lot of the state surveyors say that if they don't see it, they can't substantiate it. I've seen some things that are crazy but it's hearsay. I've seen a bad infection control issue and I told the surveyors but they can't substantiate it if they don't see it. So *that is a big barrier* I think.'

Quote
"A *lot of the state surveyors say that if they don't see it, they can't substantiate it*." – Ombudsman representative

Her colleague added, 'Yes, getting things substantiated with state regulatory is always a barrier with most specially staffing whether it's retaliation from the staff or not having enough staff and they are the first ones who will say, 'It's really hard to write that tag.' Well, I get that but also you go about what is written by the facility but if you have a resident's voice saying, 'Hey, this is what happened to me. This is how it went and this is what happened,' what is the credit of that compared to what's written down on paper? If I am going to write something on paper, I am going to write something that makes me look good. That is my biggest frustration. The notes from the facility don't always match what's really going on. As an Ombudsman, I will tell you this…every word that comes out of the resident's mouth is truth to my heart. I know that they're telling me the truth.' She added, 'If they're telling me that they're scared of a staff, I know that they are scared of the staff' and 'If they're telling me things that happened, I know that they're telling me what *they know happened*.'

Quote
"*Every word that comes out of the resident's mouth is truth to my heart*." – Ombudsman representative

She gave an example, 'Sometimes when we all get to the Care Plan meeting and we start talking about those things and you see what's written in those charts, it doesn't match what the resident says and that's why I always say, 'There are three sides to the story. There's usually their side, the resident's side, and the truth. And the truth is somewhere usually on the resident's side. More on the resident's side than the staff's and we really, really, really do advocate for residents. We are resident-oriented and not staff oriented and it's not just because of how we're trained but it's because of what we experience in the field.'

Quote
"*There are three sides to the story. There's usually their side, the resident's side, and the truth. And the truth is somewhere usually on the resident's side*." – Ombudsman representative

Another representative spoke about situations where the SSA 'doesn't always validate what the resident or what we see.' She gave an example, 'A resident will say, 'I feel like I can't talk here' [and] survey doesn't take that as a retaliation. It's more of a, 'Oh well, the resident just doesn't want to talk.' They don't validate the resident as much as we would like.'

Her colleague said that the SSA not validating residents' fear of retaliation is 'definitely' a barrier and added, 'To me, that's a *huge* issue. I don't want to throw anyone under the bus but our Department of Health when it comes to that does not do our residents any favors. They should be the strong [said while making a fist gesture]. The Department of Health are the ones that license these facilities…for crying out loud…we should have their full backing, and I just don't feel like that's happening with the residents at times.'

One representative shared this **story** about a resident who did not have dementia, 'I've been in a facility where I saw an aide combing a resident's hair. This resident had very very thin hair. She had this *hard* comb and she was raking it against this woman's head and the woman was saying, 'Stop, stop, please stop. You're hurting me.' I witnessed this. This aide was referred. Months later, we went to court. The aide defended herself. I gave my account of what took place. The judge ruled that he was not going to let five minutes of poor decision-making ruin this aide's career.'

When I asked whether she considered the aide's act as abuse, she said, 'It could have been. I couldn't verify that if she was just not skilled in doing that, but my point is that the societal perception was the resident wasn't there to defend herself. It was just my word against the aide. The aide defended herself and the judge kind of thought, 'Well, you know.' I don't know what the judge thought but my perception of what the judge thought or what society thinks is that people in long-term care facilities are not always telling the truth and it's easier to non-verify than it is to verify.'

Referring to the state surveyors, another representative said, 'I think they believe what the residents tell them, but we have challenges with our state regulatory agency and for us resident abuse, neglect, and retaliation seems *nonexistent* for our state agency to verify.'

Variation Across SSAs in Giving Sufficient Weight to Representatives' *Input*

Representatives perceived variation across SSAs when it comes to taking their (representatives) input into consideration when doing their surveys and conducting their investigations. One very experienced representative described a frustrating barrier. She said, 'When we do refer to the [State Survey Agency]. We don't see any results.'

Another representative said, 'Sometimes we as Ombudsmen feel that we work with the residents, we have them file all these complaints, and sometimes we feel like the State [Survey Agency] does not support us in what we see.' Two of her colleagues agreed.

The representative added, 'When the state goes in and investigates a complaint, if it's not written down, it didn't happen. That is how I heard it. Whatever the nursing home has written down, then that's what really happened. So somebody who says that they haven't had a shower in a month, if it's written in their books that the person had a shower, then they can't substantiate the fact that this person didn't have a shower.' She said, 'Residents can file all the complaints…they can file complaints every day but if nothing is done about it, then how do you think they feel? They're feeling like, 'What's the use. Why should you file a complaint if nothing is going to be done?' Her colleagues said that the residents feel 'unheard.' The three representatives said that they educate residents to document care concerns (e.g., 'Write it down' and 'Take pictures. Record it').

One of these representatives reflected on times when the SSA took representatives' input more seriously, 'At one time they said that if an Ombudsman sees it happen, then it's a go for surveyors. If the Ombudsman writes it up and sends it in, then there is no question or there should not be a question. But somewhere along the wayside, it just fell off.'

When asked what may have underlie the change, the representative said that she believes it has to do with who is the state Governor, whether it's a Republican or Democrat and then whatever body they pick to be the head of licensing or something like that.' She went on to say, 'We had good years with [de-identified name of a former director of state licensing agency] when [s/he] was the director' adding that they 'understood that but our people now it's kind of like we're always butting heads.' When asked if political appointments trickle down to the polices of their SSA, she nodded in agreement and gave an example, 'Like what the surveyors are going to focus on or what they're going to be more lenient on.'

A representative from another state spoke about her wish that the SSA would give more weight to representatives' observations, 'State surveyors need to be able to rely on the Ombudsman…our observation.'

Another representative said, **'**I think the frustration is that we don't have the final say. The Department of Health goes in there and we truly know what's happening…the Department of Health goes in there once a year or based on complaints and I think that kind of gets frustrating.' A representative from another state confirmed that typically representatives spend more time with residents than state surveyors.

Representatives from other states said that their SSA does give adequate weight to their input. One of them praised their SSA and highlighted the importance of good working relationships with state surveyors, 'I think we are fortunate in the fact that our regulatory agency is very good and they…if we send and we refer something to them, they will reach back out to us if there's any questions because I think we've developed that respect issue and they know if we're referring something to them, it's something serious. It's something that we've been trying to deal with and it's just not working and we need them involved to get this rectified.' When asked whether she feels as though her voice carries weight with the state surveyors, she said, 'I would say so…yeah.' Her colleague agreed, 'I think so.'

Another representative said, 'When regulatory go into the buildings for their annual surveys, they call us…they let us know they're there. We attend a Resident Council meeting with them or we can also attend the exit meeting with them…just depending on where things at and what's going on as to how we participate.' Her colleague said, 'They always call us before they enter a building and they'll ask us what's going on. We have to follow that same confidentiality. I am always asking of my residents when I am asking for consent to address

an issue, I will ask them, 'If I am contacted by a state surveyor, do I have your consent to talk to them?' I kind of give that with my blanket asking for consent.'

She went on to say, 'They'll call us and they'll ask us what we know and we're able to talk about that. It *certainly* carries weight because we can elaborate…because nine times out of ten, they are there for the issues we know about.' She added, 'Most of the surveyors will tell us what the resident's name is but some of them won't…but they'll tell us and then we're able to elaborate. I have consent already so that certainly carries a lot of weight. They'll look and they'll ask if there's anything else that we've seen. So if it's a building that has a lot of food concerns, I am able to talk a lot about their food concerns and they'll look in that kitchen where they do a little bit more investigation because of our input.'

Her colleague said that there is a variation across representatives when it comes to the quality of the working relationships with different regulatory teams at the SSA in one large state, 'We have different regulatory teams that work with each program and as far as my program goes, we have a *really good* relationship with our program managers. They help me a lot…I can call…because they want to help me to get resolution so they don't get all the calls too. They are very very helpful with my program. Some programs don't have that luxury but some of us do and I really really appreciate that.'

A representative from another state said she'd like to see 'protocols that the surveyors support our complaints and cite them. That would be nice.'

A segment titled *Importance of Ombudsman Representatives' Presence During SSA Investigations* is presented in **Chapter 7** Strategies for Addressing Fear of Retaliation or Actual Retaliation.

Ombudsman Representatives Not Having Enforcement Capabilities

Several representatives brought up the fact that they do not have enforcement capabilities and care homes know it. One of them said, 'I don't have authority to do anything to anybody. I am just an advocate.' Another representative suggested, 'If the Ombudsman had the ability to provide fines or some kind of penalty, that may help.'

When asked about the main barriers and challenges in addressing residents' fear of retaliation, one representative said, 'We're not regulatory. There isn't anything we can do about it.' She added, 'The one thing that is the most frustrating is that we don't have regulatory authority. Honestly, there is *nothing* we can do about it. We can refer the staff person to the certification and licensing agency for example. If it's a nurse, then we can refer to the Board of Nursing. In our state, it takes them *years* to do an investigation, to do anything about it. The one thing that gets facilities' attention is when you give them a deficiency and/or a monetary penalty. Then they're all ears. They don't want to pay a

penalty for any type of deficient practice. Not having regulatory authority has always been one of my pet peeves. I understand our role as advocates but sometimes I think for these types of topics it would be nice to be able to be a little stronger…little strong arming them into making sure that they are handling that and dissolving that fear of retaliation. No one should have that fear to be able to speak against something that's wrongdoing.'

Weak State Regulations in Assisted Living Residences

Several representatives spoke about the weak and harmful state regulations in assisted living residences (e.g., regulations not requiring provision of special diets; no requirement for employing a social worker; and permitting 30-day discharge notice 'for any reason').

One representative said, 'I think one of the biggest barriers is just no regulation or rules…federal regs being updated or keeping current. For example, in [de-identified state], the Residential Care Facilities or assisted living as they are called…those state regulations have not been updated since 2008. Since 2008 we've seen tremendous growth in that market. More buildings pop up…a lot more people moving into that type of care. But you have regulations that are so *dated* that they have not really kept up with the boom of that business. That is a *huge* barrier for us to get over.'

She went on to give an example, 'The regulations say that the assisted living is to provide three meals and a snack a day. That's what it says. That's all it says. It doesn't say quantity, it doesn't say quality, it doesn't say special diets if you are maybe a vegan. It doesn't say that they have to provide that. In 2008 people weren't as tuned to special diets. Fast forward 2024, you have residents with sometimes complex medical situations who have to or choose to follow a certain diet and you have regulations that don't require the facility to provide it. Then the resident is at a loss and now has to either prepare their own meals…go grocery shopping and require the ingredients to prepare their own meals and then they're paying for a service that they don't get because they can't eat in the dining room or it's not the choices that they would want to make for their health. That's again a big barrier for us but we tell people, 'They're not required to offer you a low sodium diet or a sugar free diet…they're not required.''

The representative said, 'I've complained to the management. I've complained to the kitchen but they're not doing anything about it so why should I complain about anything? I'm fearful that they're never going to listen to me, they're not going to respond.' Whether it's a valid complaint that they can deal with. Let's say it's a care complaint they could handle. 'Well, they didn't help me with that so they're not going to help me with this.' That fear of retaliation is present because the primary experience that they've had has been the facility saying, 'Well, we don't have to do that. We don't have to help you.''

Industry's Powerful Lobby

One representative said, 'I track the LeadingAge pretty heavily. They are such a strong lobby group. I just wish the consumer side lobby would be stronger. I'm not saying that Consumer Voice doesn't do a great job and Richard Mollot [Executive Director, Long Term Care Community Coalition] doesn't do a great job but compared to what the industry does, I mean, they put out a notice, 'Send a letter to the legislature on that' and they just crank them out. It's just a much more powerful tool and I just wish we had more forceful…'

Another representative spoke about industry's strong lobby as a barrier for systemic change. She said, 'I am not able to lobby at the state house or at the Federal level but I am allowed to speak to legislators about this…to give them education because our perception is the lobbyists for the nursing homes and the assisted living…at least in our state have a pretty strong lobbyist group that bend the ear of the legislatures and getting them geared to their agenda. Because we are not able to lobby, we talk to them but we don't lobby like a typical lobbyist does. We are a little more ineffective or we're just not constantly in their face…whereas the paid lobbyists have the ability to bend their ear at any time…they're taking them to lunch, they're doing whatever they're doing in their lobbyist activities. We don't have that ability…for one, we just don't have the manpower. But two, we don't have the ability to be forging that campaign as a collective group.' She added, 'We don't get hardly any calls from legislators about situations that they've been made aware of from their constituents where they're seeking out information to help the legislator understand the problem. In my tenure, I maybe talked to 10 legislators in my [over 15; exact number de-identified] years tenure. That's not very many.'

For an example of how the industry lobbies against proposed legislative changes related to staffing levels, see Harrington et al. (2016). Political influence has been 'a major factor preventing the adoption of higher staffing standards in nursing homes.' Other strategies include 'campaign contributions, association lobbying, and educational activities.' The authors stated, 'Consumer organizations…have faced a constant financial struggle to survive' and 'the imbalance of power between the nursing home industry and consumer advocates has prevented the establishment of higher federal staffing standards.'

Chapter 7

Strategies for Addressing Fear of Retaliation and Actual Retaliation

A series of guiding principles, practices, and strategies were identified by Ombudsman representatives as effective in addressing residents' fear of retaliation and actual staff retaliation against them when voicing care concerns.

The first set of representatives' statements presented here is at a high level:

One of them said, 'I think we're certainly a catalyst of helping mitigate either real or assumed retaliation. Now, I wouldn't say that we're absolute…and we're obviously not in enough places all the time…there's not enough of us. That's just the way it is with long-term care in my opinion.'

A representative from another state said, 'Normally, when a resident allows us to report retaliation, nursing homes listen. That is one of the things we tell residents, 'Us being involved is actually going to help you' because once they now know, they back off. When we get calls regarding retaliatory practices or even when they call the Ombudsman, we try to inform them to say, 'Listen, talking to us is actually going to help you because we are solution-focused, we're not trying to 'We *got* you.'' We're more solution-focused and we want to resolve the concern. Normally, when we get involved with retaliatory practices, we can put interventions in place to support the resident. They don't know that until they allow us to help them but their first thought is, 'No, I am going to have retaliatory practices.' But normally, when we are involved, we can be a support to the residents.'

A very experienced representative said, 'I think it is something that we will *never* completely solve. I think it's part of the human condition that we can be fearful of things and this particular population is quite vulnerable on both a physical and emotional level and I think we can't control caregivers, you know, individual personalities, their strengths, their weaknesses, the way they see their job. We can educate to the best we can, but I don't think it's possible to completely eliminate this condition because we're working with humans. I think it's just something that's difficult to get everything lined up so a resident can feel completely protected from this vulnerability.'

Another representative shared her concern regarding the short duration of the effects of some of her interventions, 'Somewhat more painful is…it works only for a short period of time. You know, she is always the last person to get her meal…the way the trays run…and we finally get her to have hot food for the first time and then within a week, she is back to the old way and gets the cold food. So she feels the risk that she took was not worth it. And they think of it as a risk.'

A representative with over a decade of experience in this role said, ‘I can tell you, I personally cannot think of an example where I have had success in protecting someone from retaliation outside of just saying, ‘Call me anytime you want to, call me if you need to talk, anybody on my staff is available to talk to you, we'll come in and we'll visit with you’. It's not something that I can give an example of where I've had any success.’

When asked about effective practices and strategies in addressing residents’ fear of retaliation, one SLTCO said, ‘It starts with hiring a good Ombudsman that has all the characteristics and the skills that you’re looking for. I think that what comes with that is good interpersonal communication skills, active listening, and I am going to say emotional intelligence…those kinds of things. Somebody who can role model what we are expecting to see from the staff.’

A very experienced representative said, ‘A lot of residents call me because they know I am very effective. I am proud of that. I am not going to sit here and say that I am not. But it’s not about me. It is my skill set – to make certain that the needs of these residents through my education and training – is effective. I like being effective and it puts a big old smile on my face.’ She added, ‘Residents understand that Mrs. [de-identified name of Ombudsman] is going to bring order to their home.’ Later she added, ‘I have a lot of tricks in my rabbit hat that I use if I need to get the attention of the facility to protect the rights and the lives of the people they serve.’

The following section identifies practices and strategies representatives consider as effective in their efforts to address residents’ fear of retaliation and actual retaliation (beyond their educational efforts, which are described in **Chapter 8** Ombudsman Representatives’ Educational Efforts):

Triaging Visits in Poor Performing Care Homes

One representative said that she focuses more heavily on problematic nursing homes, ‘In those nursing homes where there is a lot of retaliation, I visit those homes a lot and my presence will kind of alleviate some of it. It makes it a little bit better but it doesn’t stop it.’ She added, ‘I do more visits…they see me in there. I'm not coming in for any specific person. I'm just visiting and talking to people.’

Another representative spoke about triaging presence ‘in the poorly-rated nursing homes. It is sort of how we determine triage. We get the calls…we get the Hotline calls. We have follow-ups from former cases or cases we’re working, but if I have people [representatives] that need to go out to the community, I am sending them to the worst.’

She said that she consults with CMS Care Compare 5-star Quality Rating System website to plan more frequent visits to those low performing nursing homes, 'I send people [representatives] out to the homes that have the most problems and I use that rating system to make that determination…who is my 1-stars.' She added that she focuses heavily on the staffing star ratings 'because anything else could be anything but if you don't have good staffing, everything is going to fall apart.'

She qualified her statement, 'It's not that there aren't any problems in the better ones. I'll give you an opposite problem that I see in the really high-end ones. We have two that are extremely high-end…very expensive. A lot of them even have private aides on top of facility aides. What I see in those situations is that a family puts their mom or dad in this gorgeous facility with fountains and they leave town….mom and dad are taken care of…I am going to [de-identified state with warm climate], I am going there. And this poor soul, it doesn't matter how pretty things are, feel abandoned. And many of them will shut down too.'

Resource Box
5-Star Nursing Homes
Serious care-related problems in nursing homes rated with five stars were reported in a *The New York Times* article: Maggots, Rape and Yet Five Stars: How U.S. Ratings of Nursing Homes Mislead the Public (March 13, 2021).

She shared a **story**, 'I have one lady, she is totally…[de-identified serious health condition] probably in her [age de-identified], very very disabled and is totally reliant on the staff. And in my mind, having come from a 1-star facility, she is doing great but she doesn't feel like she is doing great and she won't complain because her fear is this is all I have, my children are no longer living around me anymore. So I go in there and at least try to take away some of that anxiety and try to encourage her to [missed word]. As a matter of fact, she is the only person I've ever worked with that asked me not to wear my lanyard when I come in because she was afraid that she is even talking to the Ombudsman. I don't think it was a mental health issue. For the first time in her life she felt very alone. Again, if I looked at it, I'd like, 'My God, you're getting so much better care than any good place in the region' but it doesn't really matter if she feels afraid.' She added if her family is not visiting often or 'not visiting at all or making phone calls. Her daughter would call and then she would scream at her mother. I was there. She'd scream at her mother, 'You can't just sit there' and I'm like but

you're in [de-identified name of a state with a warm climate] totally alienating her and she doesn't want to feel that…if something goes wrong, she will have no back up.'

Prompt Response / Making it a Priority

One SLTCO spoke about the importance of a prompt response when representatives become aware that a resident is fearful of retaliation. She said, 'If there is abuse…because I consider fear of retaliation…that would be a priority for the Ombudsman to respond to the resident as quickly as possible.'

Another representative spoke about her prioritization of retaliation against residents and how it ties to trust, 'We just try to make the resident as comfortable as possible. I have explained…we've explained to them that retaliation is illegal…it's punishable…we can go that route. I personally will explain to them that once we get the hint of retaliation, it's not acceptable…that's high on my radar…it becomes a priority for me.'

Quote
"*Once we get the hint of retaliation, it's not acceptable…that's high on my radar…it becomes a priority for me*." – Ombudsman representative

She added, 'We have so many facilities that we're dealing with…so many residents that we're dealing with but the retaliation truly does become a priority. It has to because if we're trying to convince the resident and or the family, 'We're going to take care of you….this is not going to happen' and if we're not true to our word, they are never going to trust anybody.'

'*Our presence is our superpower'*

A very experienced representative spoke about the importance of regular presence of representatives in care homes. She said, 'Our presence is our superpower.' She added, 'That we're there. I've decided after all those years…that is our superpower.'

She explained, 'We can't cite the facility. We can't make people do things. But being there, over and over again and having that presence helps people to trust you… They see you, they see you as someone that is dependable and that really helps I think with retaliation or that fear of, 'Okay, I've got this person. They are going to follow up, they are going to check on me, she is going to come back. She doesn't go away.''

One representative who regularly provides training to her colleagues said, 'Eyeballing the resident and being in his or her space is really really important because what you hear over the phone whether it's from him or anybody else involved in this drama, it's usually very hard to read over the phone. So get your butt out there and not sit at your desk. If you can, make sure you put eyeballs on the situation.'

Quote
"Get your butt out there and not sit at your desk. If you can, make sure you put eyeballs on the situation." – Ombudsman representative

One SLTCO said, 'We strive to have a strong presence in the facilities. We say, 'That's where the work happens. That's your job. Your job is to be present there. Your job is to get in front of as many residents as possible…the Resident Council, Family Council meetings, and to educate on the Ombudsman program…who we are, what we do, and that we work for the residents, we take their direction.'

When asked about effective practices and strategies for addressing residents' fear of retaliation or actual retaliation, another representative said, 'Being in the building, being seen…they know I am going to be there. They know I can't fix everything. I don't act like I can. But if they know that I am going to be there with regularity, it goes back to that trust. You have to build a *record* of being there.' By record, the representative also meant, 'a record of doing what you say you're going to do.' In a sense, it is a record of credibility.

Role of Volunteer Ombudsmen / 'They're priceless'

Several representatives said that Volunteer Ombudsmen are very important to their ability to protect residents' rights in general and in the context of fear of retaliation.

Resource Box
What is a Volunteer Resident Advocate? Understanding Their Role in Long-Term Care Educational video developed by the Connecticut Long-Term Care Ombudsman Program

One representative considered volunteer Ombudsmen as ‘very valuable.’ She explained, ‘Eyes, connecting with residents, time to sit down and visit. In all honestly, we go in and we're on a mission. We’ve got X amount of time to go in and ‘hit’ so many people. Our volunteers have time. They can sit down…they can actually engage a little longer and they learn and hear more.’

She added, ‘They’re trusted when they come in there. They come in once a week. Whenever you volunteer, you agree to give us three hours a week so you’re in there in that one facility or your two facilities and so they start to recognize your face and realize that you’re on their side. So it is so important to have volunteers and to have them in each of the facilities so they feel like they can go to that person and they can trust that person as an advocate for them.’ When asked if volunteer Ombudsmen might be able to pick up on residents’ fear of retaliation, she said, ‘Yes. They’ll pick up on who is the good, who is the bad, and who is the ugly in the facility.’

A representative from another state said, ‘If you think of it in terms of a new Ombudsman…we talked about the importance of building relationships in order to help residents feel secure. I think that’s also the value of the Ombudsman volunteer where we are able to do that. They have a better ability to build those relationships because they are able to be there more regularly and that’s really the big value of having that.’

A very experienced SLTCO said, ‘The more volunteers you have, the more you can go in.’ She added that volunteer Ombudsmen do ‘a good job’ with monthly walkthroughs in care homes ‘because they are usually in the same facility and the residents get to know them.’

An Ombudsman representative who prior to her current position worked as a Volunteer Ombudsman said, ‘I think to do a good job in this work, you have to love what you do or you have to care about people enough to want to do a good job. I think that if you care about people, you will do a good job in this as a volunteer.’ When asked about the value of Volunteer Ombudsmen in addressing this phenomenon, she said, ‘I think volunteers are very valuable.’ Her colleague added, ‘More people…eyes and ears in the facility.’ She considered them as ‘boots on the ground.’

Representatives also identified challenges related to Volunteer Ombudsmen:

One of them said, ‘They’re priceless. I don’t have a lot of volunteers right now but I have had some good good volunteers. It’s just being able to be in the homes more. I’d look at real problem facilities and that’s where my volunteers are going into on a regular basis and they are able to attend Resident Council meetings for me and getting residents so they are able to vote. The volunteers…they are just priceless in helping with *everything*…when you can get them and keep them. It’s not easy to get them.’ She added, ‘I definitely had volunteers

who have been really good volunteers who said, ‘You know what, I can’t do this because I feel like I am banging my head against the wall and nothing is changing and I am losing sleep at night because we’re not helping these people. So that happens. I’ve lost two really good volunteers…yeah, sad. So lot’s of work to do still.’

A representative from another state said, ‘It’s hard to get volunteers trained enough if they only volunteer 10 hours a month. I don’t care how amazing they are or even their background is…if they are doing 10 hours a month or whatever, to get up to speed, you need enough to really provide a high level of investigation and response.’

Another representative recognized her program’s need for additional volunteers, ‘We could use more volunteers of course and we can use more staff.’

Importance of Ombudsman Representatives’ *Presence During SSA Investigations*

Several representatives reflected on whether their presence during state investigations carries weight into the investigations and their outcomes. Their views varied.

The question I asked the representatives was: ‘Do you feel as though when you’re present during a State Survey Agency’s inspection or complaint investigation, the outcome of the survey or the investigation is different? I know it can vary depending on the circumstances, but do you feel that it makes a difference?’

A very experienced representative said, ‘Every case is different but I actually keep this printed on my desk [missing words] and we’re mentioned in the survey and it is about staffing levels in the facility which you *never* see a citation for in [de-identified state] and we are listed along with half of the residents that they surveyed or talked to who were complaining about staffing and the outcomes and the facility got cited and it was beautiful. So being there and talking to the surveyors and helping residents feel comfortable talking to the surveyors about it, got the citation. It was beautiful.’ She confirmed that the citation was issued for insufficient staffing levels.

Another very experienced representative shared a **story** about a situation that happened ‘many years ago.’ She said that she was participating in a state survey when a resident approached her and said, ‘Oh, I knew you’d be here. Can you do something about…they’re getting non-verbal residents up like at 4 o’clock in the morning.’

She added, ‘It was the ones that couldn’t communicate. And this resident was dependent on me and was waiting on me and I handled that situation by attending the state survey meeting with the resident and I shared the concern. The surveyor didn't know where it was coming from…it was coming from me. She asked that question in the Resident Council meeting if they were getting residents up at 4:00 in the morning. We verified that was

happening.' She added, 'These are residents who are non-verbal and bedfast and they get them up at 4 o'clock in the morning and put them in their chair and they stay there the rest of the day…for convenience.'

She went on to say, 'They got a deficiency for that and that's the way we handled it. The resident wasn't comfortable speaking up on her own, but she was comfortable speaking to the Ombudsman to handle it without using her name and she protected other [residents]. She was alert verbal resident and she was seeing what was going on ('she was observing and knowing what time they get up') and we *depend* on those residents to let us know.'

When asked about the outcome of the intervention, she said, 'They quit getting them up at 4 o'clock and getting them up more like at 8 o'clock…more at a reasonable time.'

When asked the same question, a representative from another state said: 'No.' Her colleague added: 'It can be defeating at times…I am not going to lie. It is frustrating to know that the home is more likely to take action to improve somebody's quality of life if they have reason to…reason meaning they have been 'slapped on the wrist.' It is very frustrating to know that they would rather just wait until…number one, I leave or number two, until they actually have to do something about it.'

I then asked, 'Do you feel like when you are present during complaint investigations or survey inspections, that your voice carries weight into the process and outcome of the investigation or survey? One of them said: 'It carries weight when it relates to a discharge matter. That's the only time I've seen it carry weight.'

Research Findings

A study by Berish et al. (2019) aimed to determine whether deficiency outcomes vary with the presence of Ombudsman representatives during state survey inspections. The dataset consisted of 95,237 surveys from 14,996 unique nursing homes during the 2009 to 2015 period.

Types of deficiencies (F-Tags) examined included: 1. All deficiencies 2. Quality of care 3. Quality of life 4. Administration. The Administration F-Tag (the requirement that the nursing home be 'administered' in a way that ensures the ability of all residents to achieve and maintain their highest practicable mental, physical, and psychosocial well-being') includes: 'In compliance with all applicable federal, state, and local laws;' 'Must not use nurse aide for >4 months unless competent and has completed nurse aide training;' 'Nurse aide registry verification, retraining;' 'Proficiency of nurse aides;' 'In-Service training of nurse aides;' 'Laboratory services;' 'Documentation that is in accordance with professional standards of quality;' 'Must not release information that is resident identifiable;' 'Detailed plans to meet potential emergencies and disasters;' and 'Train all employees in emergency procedures.'

Results: The presence of an Ombudsman representative during state survey inspections varied greatly across states (range 0.8% – 82%) with an average of 29.9%. The results showed that ombudsman representatives had 'a higher probability of being present at surveys of nursing homes with persistently poorer quality, though there is still a wide variation within states and across the nation in whether Ombudsmen are present at surveys.'

Ombudsman representatives' presence during surveys was found to be 'associated with more deficiencies and higher deficiency scores.' Moreover, the presence of representatives had 'larger effects on deficiencies related to quality of life and administration, two areas of care about which Ombudsmen would potentially have accumulated important information in the course of conducting their duties.'

Their presence seems to 'lead to additional deficiencies and higher deficiency scores, even after accounting for the fact that Ombudsmen are more likely to be present at nursing homes with persistently lower quality.' The researchers concluded, 'This suggests that Ombudsmen may serve to bring issues to the attention of the surveyors that they might otherwise have missed.'

In accordance, the National Long-Term Care Ombudsman Resource Center (2018) stated, 'If a resident says s/he was abused and wants to file a complaint with the agency that serves as the state's 'official finder of fact,' such as the state licensing and certification agency, the LTCOP representative should support the resident during the agency's investigation to 'assist the resident in voicing and realizing his or her goals.''

Nelson et al. (1995) explained, 'When the survey team enters the facility, the Ombudsman office is contacted and takes responsibility for notifying the volunteer of the survey team's presence. Once notified, Ombudsmen are expected to share their informed concerns with the surveyors and to take part in the exit interview.' In addition, 'Volunteer Ombudsmen typically report serious concerns to paid Ombudsman supervisors, who may contact the licensing agency and ultimately influence the inspection process.'

Note: State Survey Agencies don't always notify Ombudsman representatives when they go into a nursing home to conduct complaint investigations or annual surveys.

A representative from another state spoke about her frustration with Administrators that are not listening and not taking action to address concerns. She said that it goes into one of their ears and out the other. She explained, 'It does get frustrating because we're not the end result…we have to send stuff up to the Department of Health. They could go in and easily put in what we see…they could go in a month to five months later and say there is no problem.' Her colleague added, 'Because we brought it up and they fixed it before the Department of Health can go in and cite them.'

She gave an example, 'Let's say the residents start being dehydrated…they're not getting water and we bring it to the attention of the Department of Health. Five out of seven people did not have access to fresh water or call lights. We bring it to the Administrator, 'This is what happened. These people didn't have call lights…they didn't have fresh water. We're going to have to send it up to the Department of Health.' Then the facility fixes it, the Department of Health comes in a week later, a month later…it's already fixed because they have already put a plan in place. So there are no citations because we went in first, brought it up and they fixed it. It's like they've never did anything wrong.' She added, 'They already fixed it.' Her colleague said, 'There is no discrepancy. There is no deficiency because they had checked and everybody had water and everything is good to go. What we saw there as the problem, it was expressed as the residents are sharing stuff with us, we are writing up our investigation, our findings but we are not the final say, it's the Department of Health. So when they come in, absolutely, there is nothing to find then or to hold them accountable for the wrongdoing that has happened to these residents.' The representative described it as 'tremendously' frustrating.

When asked if they see a way to overcome this challenge, one of them said, 'I would love to see the Department of Health get us involved like when we get a complaint of retaliation, that maybe we even have somebody from the Department of Health go *with us* so they can identify and see it right then and there…to see what we see when we go in there. To hold the companies that are making money off of these residents…they call them 'head in the bed.' They are making money…this is a business now for them…it's no longer about their health. But if we can hold hands with the Department of Health, go in there together so they can see what is being done or not done for residents, I think the accountability would start there for these companies.'

Her colleague said that when they as representatives bring the care problem to the attention of the care home, 'It's a good thing because they are getting their water and their call lights closer to them but are they just allowed to do it over and over again?'

Breaking the Isolation

Representatives highlighted the importance of assisting residents in breaking their isolation. Mairead Painter, Connecticut SLTCO, said during a Zoom interview held prior to the project (March 16, 2023): 'Whenever you talk about any type of abuse, there's a power dynamic. The person is using that to isolate. They start to carve the person out. They keep them alone. They keep them in fear. And so, when you align with someone, you break some of that dynamic down. That is what we would really encourage people. And that's where the role of the Ombudsman comes in too.'

Another representative said, 'It is about safety in numbers…Ombudsman developing relationships with residents. Helping residents to get together with residents so that they feel safe…Resident Councils are huge…'

A representative from another state said, 'I would encourage residents to 'Find your group in that nursing home' or 'Go to activities more…at least you'll be away from that CNA.' Once you're out of these 'dungeon rooms' …a lot of them because they're just small rooms…and I think residents when they're sitting in those rooms, they feel very 'boxed in' …like 'I am stuck in this little sardine can but if I can get out and be with other residents,' that will slowly empower them…maybe not all of the residents but I have seen residents…once they start venturing out and getting around other residents, that does empower them…just to see them or make a friend and I think when residents hear other residents or I always tell residents, 'If it's happening to you, it's happening to other residents and you're not alone.' I always kind of do that because I think that's a good way to empower.'

Her colleague added, 'I think that COVID kind of stopped that. I am just now seeing people coming out to lunches or dinners or councils or activities.' Surprised, I asked, 'Only now?' To which she replied, 'Only now, yes. Some of the facilities still have not encouraged congregate dining at *all* and I push it and 'They don't want to' is what they say.'

One representative spoke about situations where certain staff members conveniently encourage residents to stay in their bedrooms and beds, 'It is a lot easier to leave someone in their room, in their bed, feed them in their bed if they are not able to say, 'I am not able to get out of my bed this morning. I want to get out of here. I want to go to the activity. I want to join this.' If they aren't able to do that, it's easier for the aide to say, 'You know what, she is more comfortable here. She'll be fine,' or 'They don't need to go outside. They don't need fresh air.' Her colleague added, 'Or 'They refuse to get out of bed' to which the first representative said, 'They refused.'

The need to break the isolation of residents fearful of retaliation also stems from an observation made by another representative who said that residents less fearful of retaliation are those who 'participate in community activities or are part of the Resident Council or even attend the Resident Council…have other residents to rely on.'

Monthly Walk Throughs / Checking in with Residents

Other strategies described by representatives included doing monthly walk throughs. As explained by one SLTCO, 'We do monthly walk throughs in the assisted livings and the nursing homes. We are required to do that. Now, a walk through is when you go and look at certain residents and say, 'Hey, how are you doing? What's going on?' We pick up a lot of things that way and the volunteers do a good job with that.'

A representative from another state said, 'Every time when I come into the building, I make sure to come and check on the resident and say, 'Hey, how are you?' and staff see you…they immediately notice you…you're not in scrubs so they know you're not an entity of their group and so when you constantly come and visit a resident and say, 'Hey, I just wanted to say hello,' I think that's also something that's helpful.'

Ability to Meet in Private

Representatives highlighted the importance of being able to meet residents in private.

One of them said, 'I know sometimes it is not possible, but I go out of my way to avoid staff because that's usually a question I get when I go to a resident like, 'Did staff see you?' In a lot of facilities, you walk in and it's the front desk and Administrators up there…it's like a circus up there.'

Note: The description of this representative's strategy was redacted from this part of the report. It will be shared with Ombudsman representatives for internal use only.

Another representative said, 'Depending on the situation and what I am there for…if it's a call light issue, I really like to come in, go into the resident's room, talk to the resident, get the consent, and then hit the call button to see how long it takes someone to come in and assist the resident.' She said that in this situation, it is important for her that staff won't see her as she is walking into the resident's bedroom. She said that otherwise (i.e. knowing that she is there) staff may not attend to the resident's call bells within their regular response time (i.e., they'll respond to it faster than their typical response time).

When asked how she comes in without staff being aware of it, she said, 'Sometimes when a complaint…says it's retaliation…the complaint itself…so I know that fear of retaliation…I know that the resident is afraid and it's going to be harder for me to get a consent to advocate for this resident. What I'll do is knock on multiple doors before I get to that

resident's door so it looks like I am doing a routine visit. Then when I leave that resident, I'll go a couple more doors just to make sure that the resident…and I let the resident know what I am doing as well so they can feel more secure…like, 'I am knocking on a whole bunch of doors so you're one of the doors that I am knocking on.' I tell the resident, 'I am going to knock on two doors before yours' because I see it as fear of retaliation.'

Depending on the circumstances and issues, some representatives make their visit known to the care home staff and managers. While circumstances and considerations vary across situations (i.e., in some situations, making the representative's presence known to staff and/or managers might be beneficial), the following **story** illustrates a potential downside of representatives announcing to care home employees that they are in the building.

The representative said, 'I had a resident call me from independent living that I had done an investigation for. It was a food-related issue. It was kind of like, 'There weren't enough peas in my chicken pot pie' kind of complaint that it is what it is, but it was anonymous and we kept it anonymous. We asked the receptionist for her room number, we announced that we were in the building, [and] we went to go visit her in her room privately.'

She went to say, 'She called me [shortly after the visit; exact time de-identified] and said [in an upset tone of voice], 'Why did you tell the Dining Director that I had a problem with the food?' And I said, 'I *absolutely* didn't.' She said, 'He came right to my room, knocked on the door, and said, 'Why did you seek the Ombudsman on me?' And I said, 'We absolutely kept it confidential.' But the staff…because we announced that we are in the building and we went to this resident's room, the person knew that this resident complained about food often [and] went to the Dining Services Director. We never disclosed what we were there to talk about [it]…went to the Dining Director and said, 'I bet ya anything they were in here because of you.' And he went right to her room.'

The representative added, 'I can't prove that he said that because I wasn't there. This resident is alert and oriented. It's one of those things that is very difficult to verify.'

She added, 'In a situation like this, I told her, 'Just keep in touch with me. Let me know if anything else is happening. We'll do whatever it is you want us to' but she said, 'I don't want you coming back out here. I don't want you talking to anybody.''

The representative offered the resident, 'I'll do an in-service for staff, I'll do something [about] the Ombudsman Office so they'll understand what we do is confidential.' But the resident said, 'No, no, no. I don't want you coming back in here.''

When asked about what made it so that she notified the care home that she is in the building, she said, 'When I say announce, I let the receptionist know that I am from the

Ombudsman Office and that I am in the building…because this way if other residents want to talk to us, that they know that we're there. It's signing in. It's just a formality.'

It is important to recognize that due to fire code, Ombudsman representatives may need to sign in when they enter the building of a care home (this was mentioned by one SLTCO). Representatives need to adhere to requirements in applicable laws and regulations.

Using the "Masking" Strategy

Many representatives said that they use what some described as the "masking" strategy in effort to protect (i.e., avoid revealing) the identity of a specific resident they are meeting to discuss care concerns.

When asked about lessons she learned in her efforts to address residents' fear of retaliation, one representative said, 'I would like cover or disguise a complaint if I am particularly concerned about retaliation for a resident. What I mean by that is that I've had residents that you can just tell from your interaction with them and/or the staff if you're exiting after a visit, that they just anticipate that so and so got a hold of you and you spent 45 minutes in their room because they are never pleased with their care.'

The representative added, 'When you talk about new Ombudsmen, you hold your cards close so that they can't tell, 'Yeah, so and so was the only one that complained.' You know, more so concealing the resident's identity than maybe they even needed you to because you can just read the room and know that as soon as I leave, they are headed after that person because they know that they monopolized your time…that type of thing. So really protecting them if you have a situation where maybe they were the only complainant or the loudest complainant or whatever the case may be.'

Another representative said, 'If I am going in to see a resident specifically who is saying that somebody is harming them or retaliating against them, when I go into the facility, I never go to speak to that resident like 'out of the gate.' I'll talk to five or six other residents so that they don't know…we don't identify who we are there to see…so hopefully they are not able to know who it is.'

A representative from another state said, 'I will go there and I will visit 40 residents so the nursing home never knows and the staff, 'Oh, it must be [de-identified name of Ombudsman] doing a 'routine' visit because she is talking to everyone' and then I get to that resident or other residents see that is my process, then they do start to feel a little more like, 'Oh yeah, [de-identified name of Ombudsman] is not just gonna walk in that door and 'B-line' to my room. [de-identified name of Ombudsman] is going to be visiting everybody so we never know what is really [going on]. That's huge. That's sometimes daily.' She added, 'Anytime I go out…even if it's not a complaint…[she gave the example of a

resident saying], 'I want to be able to do this or go on an outing,' I will still visit all kinds of people just to build that trust with the resident.'

Another said, 'I would do what I can do to mask the visit. I would make sure that I wasn't walking in and I'm going right to this room. I would make sure that I am visiting with other residents. I would make sure that I am spending an equal amount of time with all of the residents…just to make sure that it's difficult to trace the steps of what I am doing.'

A representative from another state said, 'Not just go into that one resident's room. Any time you go into a building, you always make it look like you're going throughout the building. You stop in multiple rooms so they don't…because if the resident don't give you direct permission to say, 'Hey, this is what's going on,' you have to figure out a way to keep it anonymous…so you almost do like a quarterly visit to kind of minimize them figuring out who the resident is you're trying to discuss or you meet in a Resident Council meeting so to kind of minimize some of the retaliatory practices if there's going to be some.'

When asked about strategies she uses to reduce the likelihood that staff will retaliate against a resident she just visited, a very experienced representative said, 'I think we try to visit as many people…if we're there to talk to an individual about a situation, we try to visit as many people as possible so they don't identify this one person that we're trying to target and so they're not singled out in any way. That's kind of the main thing that we try to do because it's very hard for us to not feel monitored by these homes.'

Quote
"*We try to visit as many people as possible so they don't identify this one person that we're trying to target and so they're not singled out in any way*." – Ombudsman representative

When asked about lessons learned in addressing residents' fear of retaliation that she'd like to share with new representatives, an experienced representative said, 'It is important to visit with as many residents as possible and that helps to keep the confidentiality of the resident who has these concerns. The more people we visit with, the better.'

She explained, 'It protects the original resident who has the issue so they don't know who we were there to see. It is *so* important. So that we don't just go in to see a resident in 301. That we are making the rounds in the facility and they see us everywhere so that they can't figure it out…that's *really, really* important but it is super easy to go into the facility and see

a resident in 301…because I've got to get to a resident down the street and then the building further down the street. Everyone is really busy and it's hard but that's *really* important to visit with as many people as possible so that they know us…we have a presence and it protects residents' safety and confidentiality…so that's *really, really* important. And we *always* listen to the resident. The resident directs what we do. And that gets really hard because it is not always the easiest.'

She added, 'Because we want to do something just as a human being. We want to protect people…as social workers, as people in this kind of work. We want to make things better for people so we think we know what's best. We don't.' She confirmed that this has to do with the distinction between what professionals think is in the person's 'best interest' versus what is the resident's 'interest.'

When asked about the idea behind the "masking" strategy, one representative spoke about her use of a General Complaint. She then added, 'Or we can have an all-resident case even if we're not getting *multiple* complaints. We can open an all-resident case even though this individual does not want to be identified. We're going to open an all-resident case even if we don't find 3, 4, 5 complaints about that, we could still address that issue as long as it won't identify the resident. It can be difficult at times but yes, we can open an all residents even if there's just one resident complaining.'

Challenges Using the "Masking" Strategy

Representatives spoke about potential challenges when using the "masking" strategy.

One of them spoke about the "masking" strategy but then she went on to describe a challenge in small care homes. After relating to situations where residents fearful of retaliation choose not to speak up about their care concerns, she said, 'We definitely want to follow up with them but we're just very careful about it because we don't want to make the situation worse by staff knowing that we're [said while nodding her head a few times].'

She added, 'Actually, I teach my staff how to do those visits. Like, if you have a resident that wants to be anonymous or you have a resident who is afraid, how do you visit that resident without the staff knowing that you're coming specifically to see that person or follow up with that person? I talk to them about how to be a sneaky Ombudsman [laughs] in order to foster that relationship with that resident but to protect that resident as much as possible.'

She then described a challenge in small care homes, 'It's really tricky in small nursing homes and small assisted livings…because often the retaliation there is…there's a whole host of problems that happen when you have a small assisted living with one cognitively intact resident complaining to you and that resident is afraid. What do you do? It's much more challenging…it's horrible everywhere but it's really challenging in those little places.'

She added, ‘Trying to go at certain times of day. I do a lot of the teaching for Ombudsmen so I always say, ‘If you’re going to visit somebody who might be in this type of situation, go visit some people, then visit the person you *really* want to see, then go visit some other people. And also do the sneaky…actually, is somebody following you? We do have staff that follow Ombudsmen around….I learned how to do that.’

She continued, ‘But also like I said the time of day. So maybe if we know the person is afraid of you and you work in the evening, then we’re not going to go in the evening, we’re going to go at another time of day. So we might plan our visit around when it’s going to make the resident feel more comfortable and more likely to welcome a visit.’

Speaking on the phone or even texting with a resident is another way this representative communicates with residents to reduce the likelihood that staff will know she is in touch with them. She said, ‘We’ll also talk to people on the phone if this is somebody that can communicate with us on the phone or we do have people that text us. It’s not my preference but sometimes we do it this way because they don’t want the staff to see us with them. So that’s another thing we do.’

Strategies to Reduce Retaliation After Ombudsman’s Visit

Representatives shared strategies they use to reduce the likelihood that after they visit a resident and leave the building, staff will retaliate against the person. They were asked this question because prior research showed that some residents experience staff questioning, aggressive confrontations, threats, verbal abuse, and other forms of retaliation after Ombudsman representatives visit them and leave the building (Caspi, 2024).

One representative described ‘the questioning’ residents are ‘going to get, ‘Well, why were you talking to that person? What were they asking you about? Were they talking about me? Did you discuss me? Don’t be discussing me with anybody.’’

This staff practice is concerning in general but also because it can instill fear in residents, cause them psychological harm, and leave them silenced with no action taken to resolve their care concerns, neglect, and other forms of mistreatment.

In the words of a resident as quoted by one representative (a few residents were quoted saying versions of this statement), ‘You get to go home at night [de-identified name of representative].’ The representative said, ‘It is a reminder that we do get to go home after that and they’re left there.’ Another resident was quoted in the report ‘*They make you pay’* telling a state surveyor, ‘What am I supposed to do when you leave? I still must live here. I don’t want to talk anymore.’

One very experienced representative said, ‘I thought this numerous times…as I am advocating for residents as all residents and not using names, I’ve walked out thinking…cause the Administrator says, ‘Oh, I know who you’re talking about. It’s so and so’ and I remember walking out thinking, ‘Oh, I hope they’re not going to retaliate because they’re using the wrong name of the resident.’ She added, ‘Throughout my years of service, I’ll be talking, ‘Oh yeah, Jonny Brown’ [pseudonym] and you have to be really careful with your facial expressions and your body language. I have walked out *numerous* times and maybe a little fearful because, ‘Oh, I hope there’s no retaliation.’’

Her colleague shared this **story**, ‘I had a situation just like that. I opened an all-resident case, talked to the Administrator and said, ‘This is about Hoyer lifts,’ and the Administrator said, ‘Well, I know who complained…so and so complained and I’ve already talked to him’ and I said, ‘Look, I don’t know what you’re talking about. Thank you for sharing that this individual is having an issue, but I am talking about all residents.’ She added, ‘They do assume…and they’ll let us [know]…even if we’re doing our best to mask their identity.’

Referring to a strategy for addressing this practice, one representative said, ‘We purposely…when we’re speaking with residents, we always go into a closed area…we don't try to meet in an open area…so nobody can just walk by. It depends…it's a case-by-case thing. I hate to say that but it truly is a case by case. It depends on what the allegation might be, depending on what strategies we deploy.’

She added, ‘To be honest with you, sometimes I don't even think we know what strategies we're going to use and it may take us visiting with the resident and talking with the resident and still not knowing what's the right strategy to use leaving the building and calling a coworker and talk to each other several times and we'll be like, ‘I've got this situation…help me out’ and just bounce it off of somebody else because sometimes we're not sure what would be the best approach. Then, once we had a chance to kind of step away and re-evaluate, then we can come back in and have a better idea.’

The following strategies were described as ones used by representatives to prevent and address post-visit retaliation i.e. after they visit a resident and leave the building:

A very experienced representative spoke about using the “masking” strategy and having a direct conversation with the Administrator, ‘If I am not given permission to act, I would make sure that that person would not be seen as the only person that I saw. I visit many other areas to make sure that it seems quite routine. I do everything that I can in my power, if not given permission, to not make that person stand out.’

She added, ‘If they do give permission…say to go to the Administrator with their concern, I let that Administrator know that there’s an obligation of protection, that there is a federal

law against retaliation, this person must need to feel safe, and if not, it is a criminal offense. I have a very frank talk with the Administrator and then I go back often to make sure that everybody knows I am looking.'

One representative described how she promptly addresses a situation where a resident give her permission to intervene, 'When I have a resident who is fearful of retaliation but then gives me permission to bring it up because oftentimes, they still don't want to but 'It will be okay if I bring it up?' I address it right away before I even leave that building.'

She explained, 'I think addressing a resident's concern immediately…because that's what takes so long in these nursing homes. I try to address everything the same *day* and go back to the resident and say, 'This was discussed. Etcetera, etcetera.' That reduces…that has an impact on the resident. Somebody cared, somebody addressed it right away. Not just waiting for something to happen. Getting back to them is very important. The more you're showing them you care by addressing it certainly as fast as you can, I think they are more likely to tell you something again.'

Another representative said, 'I would ask the resident if we could have a meeting with them [i.e., the care team] sitting right by their side.'

A representative from another state said, 'I always make sure to ask the resident if I can follow up with the social worker…usually with the administrators…I'm well known to them…to let them know…it's really about letting them know so we can all work together. I think it's really important for administrators and staff to see me work collaboratively rather than maybe just bringing concerns and blaming them. I think it's really important to do that. I also will typically have a meeting to follow up on things after a little bit. I always follow up with the resident. I stick around for a little bit and I make in-person visits.'

Another representative said that she always tells residents, 'Listen, if anyone says anything to you, you let me know. They are not supposed to ask you what you were talking about with me or anything.' She added, 'If the situation calls for it,' she'll tell the Administrator, 'This person is very very fearful and I would hope that nothing is said to them when I am away from this.'

Another representative said, 'I give them my direct number so they can reach me immediately and know that they have somebody *right there* that they can count on to address it. We visit more often…let them know that we're going to be back. Then I will loop in the administration and say…with permission obviously…that this is the resident's concern and that they need to be on top of their staff to make sure that nothing is misconstrued…nothing happens that's at all retaliatory in nature.'

Her colleague added, 'I think if there is a situation where there is a specific staff member, getting the name of that staff member is the biggest tool because figuring out who is creating the problem. Is there a problem just against this resident? Against multiple residents? But these aides…they don't push wearing name badges. Half the time most of them are not wearing name badges and the residents say, 'They didn't have their name badges on today so I couldn't even tell you their name.'' The problem of staff not wearing name tags is addressed below in the segment titled *Addressing the Name Tag Game*.

One representative said, 'I certainly let them know 'call me right away' if they have that. If *anyone* addresses anything with them…says anything that it's in a retaliatory manner, to call me directly. I leave my number and contact information. To let me know and I will go back and visit again to see if they have any further issues. And just encouraging them that I can still reach back out, 'Don't be fearful to reach back out and we'll address it *even more*.''

I presented this representative with a situation where after she visits a resident, a staff member comes up to the resident and tells them, 'So, the Ombudsman was here. What did you talk about?' I then asked the representative for her thoughts about it.

In response, she said, 'I think that is inappropriate. That feels intimidating. And that, to me, can be a form of retaliation. I should feel free to talk to who I want to and I should not be questioned for doing that. I think that's a big issue.'

Quote
"*I should feel free to talk to who I want to and I should not be questioned for doing that. I think that's a big issue*." – Ombudsman representative quoting a resident

Another representative said, 'Residents have cell phones and residents are given my *direct* number after I've left (she later added, 'Some of them can even send me an email'). If something occurred in the way of retaliation because that resident voiced a concern, that resident is able to contact me *immediately* and inform me what occurred after I left. So far, based on intervention by myself, I have not had a resident call me to let me know…other than things are looking up, 'Things have gotten better since you were here.' And my question when I follow up with the resident is, 'Tell me about the staff attitude after we have investigated the complaint? What happened afterward?' 'Well, the attitude changed.' You know why? An Ombudsman was involved in that issue with that resident and the resident is respected after that.'

Quote
"*Tell me about the staff attitude after we have investigated the complaint?*" – Ombudsman representative asking a resident

Referring to the resident they just visited, another representative suggested, 'Having them call us after that staff member isn't there.'

Another representative said, 'We have work cell phones in this office that are on 24/7 so they can contact us at any time and we go back in if we have to…but it's tough, again, the retaliation can be very subtle.'

One representative said, 'I make sure I let everyone know the case is far from being closed. I request updates from the staff…from email, phone calls, follow ups…as many follow ups that it takes. I encourage other Ombudsmen to discuss retaliation in the community or just follow up with that resident if they're in there for something else or walk down that hall…their presence being down that hall.'

A representative from another state said, 'I find that…if I have a case like that…that there's a concern whether it is mine or the resident's…that I just stay maybe a little bit more involved…involved longer…keep the case open longer than maybe I'd traditionally might for what the complaint is. I have more communication with the resident. I increase my communication with the resident and I may increase my site visits. A lot of our follow up can be done by telephone but I might sprinkle another site visit because I find that when it is perceived that you're "on top of it," they see you, they'd rather work to resolve it at that point because you keep communicating with them…so that's what I tend to do.'

A very experienced representative said, 'If the facility *knows* that you were there to visit that resident…that we've done an intervention and we're working specifically with this resident and they *know* it, that's different of course from visiting with multiple residents so that they don't know. The facility needs to know that we're coming back…that we're going to be back, we're going to be there to follow up, we're going to check in on this person to see how it's going. That whole presence part is really important and the facility needs to know that they can expect to see us again soon.'

Another representative said that when during a visit she senses that something is going on, she leaves and returns an hour later, 'I've even left for an hour and come back again.' She said that she used this strategy for 'many years' and that it is effective because staff don't expect her to return, 'They never expect it. I've been stopped at the door, 'Why are you back

here?' The Administrator would roll their eyes and go, 'Are you *serious*? Didn't you just disrupt my staff during your previous visit?' Always the subtle turn of pointing the blame, which they do to the residents too, 'Why is [de-identified name of Ombudsman] here? You caused that,' you know, pointing at the resident.'

Other representatives also emphasized the importance of follow-ups in the hours, days, and weeks after their visit. One of them said, 'We always follow up with them and it's not always in person. If they're worried about the Ombudsman being in their rooms, we might follow up with a FaceTime call or something like that so it's less obvious that they're involved with the Ombudsman.'

Another representative said, 'Follow up. Follow up quickly. If I have somebody that I am generally worried about, I let them know that I am *not* going away and I will be a "thorn in their side." When I say thorn in their side, I don't mean that we go in and do anything bad…but they don't like us to be in their building…so we're a "thorn" just because we're there. The more often we're there, the bigger headache they have. If we have somebody we're worried about and we go in and check and if there's still a problem, we continue to address it. As long as the resident wants to work on it, we're going to work on it.'

Quote
"I will be a thorn in their side." – Ombudsman representative referring to the importance of follow-ups when she is worried about retaliation against a resident

One representative shared how she utilizes volunteer Ombudsman to address this issue, 'We have volunteer advocates in some of our nursing homes…they only go in nursing homes and most of the time, having an advocate in the building, we will reach out to that advocate and ask them to check on this resident if they don't already. Most times the volunteer advocate…they're assigned to a building. We are not. We don't have a specific building. We'll ask them, 'Listen, we have this concern. This is how we've addressed it. Would you mind following up with them and or the family member?' Just to make sure that things are going in the direction we want them to go into. Or we'll touch base with the family member afterwards just to see that things were corrected.'

Her colleague added that they hand out a large print Resident Rights card that has 'the contact information for our hotline on it and we make sure everybody understands, 'You can call anonymously. We will have no idea who you are and if you're having issues or

concerns, this is a safe space for you to call.' My staff also…we all give out our contact information and we'll largely do some counseling if residents need to talk to us because we're trained in it.' The first representative said, 'We also talk to staff and educate them that they could come forward anonymously.'

One representative said, 'I will sometimes go to the Administrator on the way out and mention some positive things about what I've witnessed…even if it's squinting my eyes to find something positive. She gave an example, 'That stake looked really appetizing. Your dietary staff are doing a great job' and added, 'I am probably biting my tongue…but I always try to leave it so if staff go running to the Administrator, then the Administrator can say, '[De-identified representative's name] seemed like in a really good mood when she left. What were you talking about?' I don't know if it completely works but I heard it has.'

When asked about strategies she uses to reduce the likelihood that staff will retaliate against residents after she visits them and leaves the building, a representative from another state said, 'I try to visit with several residents so that I am not singling out a resident.' She then added, 'I make eye contact with the staff, 'Hey, how is your day?' 'Oh, you're doing a great job, I really like what you're doing here.' Trying to make a connection with staff as well…because if they know that somebody is watching them maybe or genuinely interested in them, you know, I want them to be good staff because I want residents to have good care… And just letting them know, 'Hey, I'll be back' like introduce myself…this is who I am, I visit frequently…often…so the staff know that I'll be back…just so that there is another set of eyes out there.'

When asked the same question, a representative from another state said, 'I read that question and I asked someone, 'How would you respond to that?' Unfortunately, I can't control if someone is going to retaliate. I can't say whatever I do or whatever I say, 'I know that they are not going to receive retaliation.' If it's going to happen, it is going to happen. The only thing that I could do is to assure the resident that if he or she suspects that that they are being retaliated against, is to report it. When they report that person to the appropriate individual…administration, then that can be dealt with because if that person is going to retaliate against that resident for making a complaint, needless to say, I am thinking that they are going to do it to the next individual with us.'

She added, 'I always tell the resident, 'Look at yourself as someone that is protecting other residents for potentially experiencing the same thing.' If there is a particular staff member that had been known to retaliate, I empower them to do their due diligence, 'You can speak up and say something. You can know that you have an advocate so if you experience that'…after of course, my involvement, 'know that I will always be your advocate. You can contact me…that we *will* deal with that situation.'' She concluded, 'Again, I can't control if

that staff is going to retaliate but just to educate their family member or the resident that there is an outlet. You can contact the advocate and we will *deal* with that.'

Trusting Your Gut and Instincts

Three representatives said that it is important that they and their colleagues will trust their gut and instincts. One of them said, 'You've got to go with your gut sometimes.' Another representative said, 'A lot of times we'll go into the homes and we'll be like, '*Something* is not right. Something is going on…I really can't put my finger on it.''

She went on to describe what she does in those situations, 'I will pull up a chair if people are in activities or if there's a table and people are playing cards or checkers or something. I will ask, of course, if I can sit down. I am surprised that just by doing that or playing or helping to put a puzzle together, the residents will start, 'Oh, are you here to see Mary?' [and I'll say], 'Well, no. I am here to see all of you guys,' and they'll say, 'Well, maybe someone should go see Mary.' Just relating to them and I have been shocked at the information…right down to a level of abuse.' When asked what would happen if she didn't pull up a chair and sit with the residents, she said, 'I would have walked away.'

The same representative described the importance she sees in following her instincts when she senses that something is not right but she can't put her finger on it: 'I go by my instincts. I am a firm believer in that.' As described earlier in this chapter, she said, 'I would try to stay longer or I've even left for an hour and come back again.' She explained that doing it 'reassures residents, 'Oh, she does know something that's going on' or by the second or third time or even the next day, I will generally get a resident to go [said in a quiet voice], 'Hey, can I talk to you?' and that would open that door.'

Quote
"If something feels wrong, it probably is wrong." – Ronnie, nursing home resident Source: Educational video Voices Speak out Against Retaliation

Another representative said, 'Another thing that's kind of very skeptical and cynical of me is everybody lies. I mean, everybody does. The resident not giving you the truth because…I mean, manipulation but it's also a 'Pay attention to me' type of thing or they'll exaggerate and certainly the administration and certainly the staff and certainly everybody along the path. Lie is such a horrible word but it's true. So trust your instincts. Like Judge Judy says, 'If what you see doesn't make sense, it's probably not true.' You have to figure out what is true.'

Working Collaboratively with the Care Home

Many representatives emphasized the importance of working collaboratively with the care home including with direct care staff, managers, and Administrators. Several of them spoke about the importance of building rapport with Administrators. This practice was perceived by several representatives as an asset in their resident-directed advocacy.

That said, representatives also said that there are times when they need to assertively and professionally confront Administrators that are not responsive to residents' care concerns and/or when they cause them to fear retaliation, threaten them with retaliation, and actually retaliate against them. This scenario is addressed towards the end of this chapter under the segment titled *Directly Confronting Administrators*.

One representative said, 'You're not going to get a lot accomplished if you're always butting heads.' Another recommended, 'Work collaboratively rather than just bringing concerns and blaming them' and added, 'We should all be focusing on the same things.'

A representative from another state said, 'We absolutely will work with Administrators and leadership to try and collaborate with them…let's see what we can do.'

When asked about what she sees as effective strategies in addressing residents' fear of retaliation, an experienced representative said, 'I think mine is more of explaining. One…retaliation is never acceptable and understanding that that is a huge thing. It is never acceptable. I want to support the resident in filing a complaint with management. Helping them follow through. Often what I do when a resident does have a fear of, 'I am scared. I don't want them to know I am actually complaining'…if they go with me to the administrative office, I'll explain, 'We're not necessarily filing a complaint. We just want to share a concern and how can we work *together* to resolve this issue.' I am not coming in pointing fingers. They don't feel like they stand behind me…that we are standing together to say, 'Can we look at a solution. This is what I am feeling. This is what happened. How can we solve this together?''

When asked about a collaborative approach but also what she does when this approach 'hits a wall,' she said, 'Being collaborative. We're working together. My goal was for them not to see the resident as a complainer, which is often what they are labeled as. To say, 'Hey they called me, they just needed someone to come in and help them with the words to explain what they're feeling and explain the process.' We want to come in together.'

She added, 'If they're not willing to cooperate with our agency, then of course, 'This is unacceptable. This is what our expectations are. If this continues, we're moving it up to a higher level.' But most of the time, we don't have to get to that point because if we're coming in with a positive attitude, 'We're going to work on this together. This is a team

approach,' then it really kind of puts down the defenses of the facility staff and then also the resident to where they can feel comfortable…so next time they can go without me if they have a concern. That door is an open-door policy where, 'Okay, you listened to my concern, now I can freely go in myself if I have an issue and then I'm empowered.''

When asked how she and her LTCOP would like to be perceived by Administrators of care homes, one representative said, 'I know how I want to be perceived. I am not the enemy [that wants] to get them in trouble. I am here to work *with* them to better the life of the residents or the situation of the residents. Because I think a lot of times we walk into buildings and they're like, 'Great, the Ombudsman is here. What did we do wrong?' and that's not what it is, that's not what it should be. Sometimes that happens…sometimes residents give us complaints and concerns that we need to take to the Administrator and that's just the 'nature of the beast' but we're not the enemy. We're not there to report them to the regulators. We're here to work with them to better the life of the residents.'

Good Relationship with Staff and Managers

When asked about effective practices and strategies for alleviating or resolving residents' fear of retaliation, a very experienced representative said (after she spoke about the importance of 'safety in numbers'), 'It is about having relationships with the facility staff too. We walk this line. We have to have a good relationship with the facility too…not inappropriate…but we walk this line. We have to have that relationship with administration so they trust us too that we can get this stuff resolved and there hopefully isn't going to be that retaliation because that is part of the relationship building too. That if we have that relationship with the facility as well, we'll cut down on their [missing word] complaints.'

She added, 'You want to deal with me versus the Health Department down the road. Let's get this thing taken care of…and it is that kind of attitude. We're here to work together even though we are not with them…we're over here [said while making a hand gestures to her side]. It is this balancing act game that we have to play to get stuff done.'

One very experienced representative spoke about the importance she sees in developing good working relationships with care staff members, 'I've had the opportunity to develop relationships with staff and if there's a way that I can bring up a topic to a staff person that I trust that I know is honest and gives me kind of some inside insights at the functionality of the facility…I might use that relationship that I've developed to try to gain more insights about maybe a strategy about some particular topic. I often think a key to my approaches has been very relationship-based so there's also the relationship that you develop with the staff. I've always tried to have a very respectful teamwork approach and that has served me well over the years.'

Giving Positive Feedback to Staff

One representative spoke about the importance of providing positive feedback to care staff members, 'Comments even with the staff about the positive things that they do bring to the facility. The negatives I can talk about and positives…there are positives in facilities…I try to be commenting on that as well when I am asking for change too.'

Informing Providers About a Problem (After Resident's Consent, with Exceptions)

One representative spoke about a strategy she uses when she informs the provider about a problem with one or more staff members. She said, 'By letting the provider know they can also prevent it from happening again.' Sometimes the more people you tell, more people might be aware but that's not always the case because sometimes residents don't want a lot of people to know but the providers can be on the *lookout* for maybe if it's a certain CNA or maybe two CNAs, they can be checked, they could be checking in with other residents, 'Hey are you being put to bed at 7:00 PM?' or 'Are you staying up as late as you want?' That's how you give them the lookout of here's what's happening.'

She clarified that she'll only do it with consent from the resident unless it is 'a systems issue.' In the latter case, she said, 'I can also go and say, 'As a systems' issue, I have talked to numerous residents and what I'm hearing is there is a CNA' I might give a description 'who is very sharp, very rude.' I might give some examples of course without any resident etcetera. When it comes to a systems' issue, I don't know it's a systems' issue until I start talking to more residents. Do I go back and get their permission? I don't have to if it's a system issue, but I won't give any information that might lead to them identifying a resident.'

Another representative said, 'We work directly with the management as well as the facility to let them know in general about retaliation so that they can be aware of it and try to combat it if they see an issue.'

Being Forthcoming with the Care Home / 'Not beating around the bush'

When asked about effective practices and strategies in addressing residents' fear of retaliation or actual retaliation, one representative said, 'I think being forthcoming with the nursing home because, again, that word 'retaliatory,' no one wants to hear it. I think just putting it out there, not beating around the bush, 'This appears to be retaliatory.' Even when it's not said, I'll say it. Especially when you just start picking on a resident for no reason like you're trying to get them out the nursing home because we get that a lot. A lot of residents…they're trying to discharge them or they don't like the resident because the resident speaks up.'

Quote
"This appears to be retaliatory." – Ombudsman representative telling care homes when she notices it

She added, 'Even when the resident doesn't understand it's retaliatory, we as Ombudsman can see that it's retaliatory and we just bring it right to the light, 'This appears to be retaliatory.' I've written emails on it and all. 'This appears to be retaliatory. I am hoping it's not but it appears to be from the type of language you're using, the constant back and forth, your actions.' And they back right off. So bringing it to the forefront…to the Administrator, to the staff and using that language, it helps to dampen whatever they were trying to do.'

Identifying an 'Internal Advocate'

Representatives spoke about the importance of identifying an 'internal advocate.' That is, encouraging and/or assisting residents in identifying a trusted person whether it is another resident (e.g., a roommate), a care staff member, an indirect care staff member (e.g., housekeeping, dietary, maintenance), a nurse, a social worker, a manager, or clergy.

One representative said, 'We will say, 'Do you like somebody here? Like this person? Why don't you talk to them and see. Talk to that person first, if you're comfortable and maybe start there. If you don't want us because you're afraid, go to that person, that lovely aide that is taking care of you and maybe talk to her first and then we'll see.''

A very experienced representative said, 'As a whole, I try to find who it is in the facility the person has a trusting relationship with. Oftentimes, it might be the social worker, the admission coordinator…the first person they met there. It could be a staff person. I had people tell me many times, 'When Joanne [pseudonym] is in the building, I *know* I am going to have a good day.' So I might say, 'What about Joanne? Can I get Joanne to check in on you and talk with you about some things? What if we get Joanne involved?' Or, as I said, departments' heads, social work or somebody who…say…'Let's build some rapport with them' with their permission. But I do try to name a staff that they might have trusting relationships with.'

When asked about an instance in which she was successful in addressing a resident's fear of retaliation, a representative from another state said, 'I think sometimes its finding out from them…learning who they've spoken with because you may have a different result with a different individual. Knowing that we have staff turnover and in some instances you're

kind of labeled as a resident or maybe you've spoken with somebody in the past and that wasn't…I hate to say that wasn't a wise choice…but just like in general relationships you have staff that you're closer with and not closer with…so choosing who…maybe if you're not going to share it with the Ombudsman program or if you have previously shared it with a staff member, maybe that was not the best staff member to share it with…maybe you should have shared it with this or that person.'

The representative added, 'I've had some instances where we kind of talked through the different options of, 'Maybe you should go to the charge nurse or the CNA or maybe you really like that med tech at night.' We've had some success with choosing who…if you're not going to have me address it, let's make a game plan for that particular person that really is in your corner that is already on the staff.'

She said, 'Depending upon that resident, they may not have the understanding or the foresight or the ability to kind of contain that until that appropriate person…or maybe that person works there three days so they may not be back for a couple of days. So sometimes it is not going to work out but in the instances where they know that they have that relationship with that individual, maybe it is better to wait. I've had a couple of instances where it was successful based upon using that confidant.'

When asked about advice for residents fearing retaliation, her colleague said, 'Just to kind of build off of what [de-identified name of her colleague] said with that trust, finding a trusted person cause most of them have at least one in the building that they are comfortable telling things to and they have a relationship with…someone who is their internal advocate even if that is not their official role in the building…'

When asked what advice she has for residents fearing retaliation, another representative said, 'Trust and believe. It's I guess like in any part of our world…I am [missed word] here but I really believe it. We have to find our angel…that person that will always be there for us, our 'ride or die' type of person. I think residents have to try to seek that person out. An aide that will listen, a social worker that is responsive.' She added, 'I try to ask them if there's somebody that is in that facility that they do have a good relationship with and to try to foster that and rely on that.'

Quote
"*We have to find our angel…that person that will always be there for us, our 'ride or die' type of person*." – Ombudsman representative

The representative added, ‘And of course, *us*. We are here for you, we’re here for you but we have to be there for them, be there for them, be there for them. It all comes down to resources. Up until 2 years ago, we only had [de-identified number] staff members. We were maybe getting into half of our facilities only on a regular basis. Now, it’s our third quarter in a row, we hit 100% of facilities and that’s broad…I am not guaranteeing depth. We’re seeing depth too in terms of making sure particularly to be in really poorly-rated nursing homes…to be in there consistently. We can’t do that without staff. We can’t ask our volunteers to be that kind of dedicated.’

When asked about her general process in addressing residents’ fear of retaliation once she becomes aware of it, a very experienced representative said, ‘I try to talk to the individual about maybe what they might have done already to try to express this to staff or I try to have them identify to me what staff they do trust and what staff they don't trust.’

Another representative shared what she tells residents, ‘I might say, ‘Have you talked about this to someone you trust?’ ‘Can this person help you?’ ‘Can I help you bring it up? I can be with you or I can bring it up’ etcetera, etcetera.’

Another representative explained, ‘Can we bring on board some type of a collateral…a form of informal support mechanism? …a family member, a friend. Is there someone that they can feel they can trust, they can confide in? That person might see things a little bit with more clarity and less emotion. That's one way. Another way is to try to find out if they have someone that they really respect and have some confidence in from the provider’s side, for example, the social worker, if they have a good relationship with a social worker or someone within the provider. Sometimes we surrogate that role. Sometimes we become that confidant. Giving them someone that they know is not going to abandon them and just *leave* them, you know, come in create a bunch of complaints and noise and then just *leave* them there. I think that’s one of their concerns…a lot of that other peripheral stuff kinds of comes and goes.’

The representative added, ‘And then also a third-party provider can be really really valuable. The one that comes to mind the most is the Hospice providers and then mental health practitioners. A lot of times they corroborate and really help understand…they help provide understanding, ultimately amplifying the voice of the resident in partnership with us.’

The representative explained the rationale for the strategy of onboarding these individuals and supports, ‘Because we’re in and out. We can’t provide that ongoing sense of support…that’s where we’re gapping. And so, is there a way for me to fill up that gap with someone in coordination and collaboration as I am doing my work?’

Identifying a Trusted Manager

One representative said that identifying a trusted manager could be key to resolving residents' fear of retaliation. She said, 'Sometimes, obviously, speaking directly with upper management…Administrators depending on who they are and what building it is but identifying a manager that is known to have been helpful in the past obviously is pretty huge in resolving a lot of retaliation or fear of retaliation.'

When asked about an instance in which he was successful in alleviating a resident's fear of retaliation or actual retaliation, one representative shared this **story**, 'There was one with an effective approach. This one concern was that staff was making fun of him. He felt like they were talking about him behind his back and ridiculing him and he didn't know why. He didn't think they had a reason to be doing so. He felt like they were just gossiping about him when they left his room and got into the hall. I met him and I asked him if he would like to report that to the management and have them investigate it. He was concerned about that thinking it's going to sort of make matters worse. Then I mentioned the name of the Administrator to him and he said, 'Yeah, he seems kind of nice. I met him once.' And I said, 'Well, would you like to have a conversation with him about that?' And he said, 'Yeah, I would be open to that.' And I said, 'Well, would you like to see him right now? Maybe I can go find out if he is available and he can meet with us.' And he said, 'That would be great.' I went and I found him and he came over.'

He explained, 'I did this knowing that this is a resident-centered Administrator and I knew his administrating style. I wouldn't do that without knowing all of that. So I connected them and the Administrator listened to him very intently and gave him his cell [phone] number and said, 'At any time, if you're feeling this way, give me a call and we will investigate this to the best of our ability and see what we can do to improve things for you.''

When asked about the end outcome for the resident, he said, 'I know that he felt better…more comfortable with his fear and felt like he had someone to talk to. It did come up again where he felt like it was happening again and he felt like the Administrator wasn't quite responding quickly enough as he should be…in his mind…but ultimately the Administrator did connect with him and I don't know if it was ever a fully solvable problem maybe because his fears weren't accurate…I don't know, maybe they were but it was a hard one to investigate…the Administrator, I don't know if he ever found…he said he was going to do an In-Service training with staff about resident rights and not doing what he said that they were doing.'

He confirmed that initially (prior to his intervention) the resident was fearful of speaking up about his concerns and added, 'I believe it improved because of this process…because he felt like it was less of an issue than it was when he was first talking about it.'

When asked what could have happened if he would have connected the resident with an Administrator who is not resident-centered, he said, 'If an Administrator is not resident-friendly, does not spend time on the floor, does not interact with residents, does not have good rapport in way of good interpersonal communication to residents, if they're just involved with day-to-day business operations and staffing issues and things like that, then that's not really be connecting them with an ally they can go to and trust and feel like they can open up to. It has to be someone with those characteristics that can really have that relationship with the resident that they are needing.'

For representatives' views about the role of social workers and nurses in addressing residents' fear of retaliation, see the segment titled *Social Workers – Potential Conflict of Interest* and the segment titled *A Word About the Role of the Nurse* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

Resident-Driven Advocacy / 'I work for you'

Strictly adhering to resident-driven advocacy was highlighted by many representatives as a core principle in their work with residents.

One representative spoke about the importance of visiting residents first, 'As Ombudsmen, the first thing when we get a concern, no matter what the concern is, we're always going to go and we're always going to visit that resident first because we want to make sure that no matter what the concern is, that we are representing and advocating for the resident as the resident wants us to and is comfortable with. I think comfort of the advocacy plan is one of the most important things that we do because, obviously, we might be helping them advocate for a certain situation, but it all comes back to the resident.'

Another representative said, 'I let them know, 'I am there for you. You can call me. I am your advocate. I work for the state. I do not work for these facilities. I work for you.'

Another representative said that she tells residents, 'We don't work for the facility, we don't represent the facility…that the state pays us to represent *them*.'

A representative from another state said, 'I always tell them, 'You are my boss and I won't do it unless you tell me what you want me to do. I am bound by that.' Later, she added, 'I was often thinking…a customer is one thing but a boss is another thing too. I like to go with…they are really my boss. I want to put them in a level of a higher control than just a customer as well.'

Another representative said, ‘We follow their direction, we take their direction, and we follow what they want us to do…and we strategize with them and we often go back to them and we give them an update and say, ‘What would you like us to do next? What are your thoughts about that? Here's what I am thinking.’’

A SLTCO said, ‘I would say…as it relates to the work of the Ombudsman, you cannot put a finer point on the fact that we follow the resident’s direction.’

Quote
“*You cannot put a finer point on the fact that we follow the resident’s direction*.” – State Long-Term Care Ombudsman

Referring to an incident about a resident who in retaliation was not allowed to go on an outing to a Thai restaurant (details about this incident will be described later in this chapter under a segment titled *Assisting the Resident to Move to a Different Care Home*), she said, ‘That’s exactly what I did**.** I *followed their direction* because they know, they know what their experiences, *they* know when they are not safe and when they are. It does have a lot of overlap and it reminds me of the Domestic Violence Cycle of Abuse. That’s exactly what was happening for that resident. It’s the whole build up and then the pop and then ‘Oh, let me give you flowers, and let’s make up’ and that’s what I saw over and over. I think that we need to continue to make sure that our state-wide representatives *really fully* understand the importance of following the resident’s direction. Not only it is federal law, it is everything to the program and it is everything to the resident.’

Another SLTCO addressed situations where a family and a resident want different things, ‘Ensure that they know what the resident wants…because some family members want things to go a certain way and the resident has a different idea…so ensuring that it is about the person who is there and not the outcome that the family member wants.’

‘Best Interest’ versus ‘Interest’

One representative highlighted the important distinction between ‘best interest’ and ‘interest.’ She said, ‘Developing a plan that they are comfortable with is super super important because I might see a situation as like, ‘Let’s go down this path, this is the easiest, this is the smartest path’ but just because I see that as the right path doesn’t mean that that’s what he resident is comfortable with and that’s the important part…is they need

to be comfortable, they need to be comfortable with what's going on…for us to be successful in our advocacy.'

The issue of 'best interest' versus 'interest' is addressed in detail in Trainee manual: Initial Certification Training Curriculum for Long-Term Care Ombudsman Programs (2022).

Cultivating and Preserving Trust with Residents / 'There is no other shortcut'

Several representatives highlighted the importance of thoughtfully, diligently, and sensitively building and nurturing trust with residents. One SLTCO said, 'Everything starts with the relationship…the relationship that you establish, the rapport that you build.'

When asked what stands out to her as helpful in addressing residents' fear of retaliation and actual retaliation against them, one representative said, 'Trust. You must gain trust. That's of value to a resident and for us. To gain our trust.' When asked the same question, another representative said, 'Building trust, building relationships…we try really hard.'

When asked the same question, a representative from another state said, 'This is why it was so important that we've increased our funding to the Ombudsman program and been able to add staff because we just have to get in there and create trust amongst the residents. There is no other shortcut that I've been able to figure out.'

She added, 'If the person is prone to complain, it doesn't matter if we are once or 15 times. For those majority of people who are afraid, we just have to go in there and go in there and talk to them and not even about their complaints…just establish a trust between ourselves and them. There really is no other shortcut that I've found.'

A representative from another state said, 'Having trust and good rapport with their local Ombudsman is crucial in effective advocacy…absolutely crucial because if they're not confident in what I am doing, they don't trust that I am going to do what I said that I am going to do…the plan that we come up with together…if they don't trust that I am going to execute it the way that we discussed…that they're comfortable with, it just doesn't work.'

A very experienced representative (who was quoted earlier saying that 'most of the time people are just comfortable telling' her that they fear retaliation; she attributed it to the many years in which she cultivated trusting relationships with them) spoke about the value she sees in representatives cultivating trust with residents with regards to their willingness to share care concerns with her. She said, 'I think I've had an intent and a focus on trying to cultivate that trust. Making sure we're meeting in a private space, making sure that they're comfortable where we are and what we're talking about, knowing if I know that someone's particularly more expressive in the morning and maybe more tired in the afternoon, if

there's ways I can coordinate connecting with those people when they're feeling more available for talking. I certainly would do all those things to maximize our connection.'

Quote
"*It is important to remember…at the end of the day, we leave…we go home and the residents stay there. So we need to do everything we can to ensure that they believe in what's happening, believing in our ability to help them, believing in our ability to reduce their fear or their hesitation as much as possible and to advocate to the best of our abilities*." – Ombudsman representative

Being Honest with Residents / 'Never make a promise that you cannot keep'

Many representatives spoke about the importance of being honest with residents and not making promises one cannot keep. One very experienced representative said, 'The other thing that I have brought to this particular topic when I've been working with residents is honesty in that I have never promised them that I would make sure that this didn't happen or make sure that they wouldn't experience retaliation.'

She added, 'I would probably do almost the opposite to say, 'I will never be able to ensure that someone won't treat you differently because you spoke to me or you told me about this particular incident. I just want to make sure that you're 100% sure you want me to share your name or share this incident.' She explained, 'Because I know…at the end of the day, I'm going to go home and they're going to be there and I can't prevent or stop this particular possibility from occurring. I think I've probably just gone the distance to explain to them that I'm unable to protect them around this completely and can't guarantee that they won't have an experience like they're telling me about again.'

When asked about things that *don't* work in her experience, another representative said, 'What doesn't work is promising that retaliation will never happen. You can't do that because you don't know. It could. That's why I say I can't promise.'

When asked about what advice she has for residents fearful of retaliation, the same representative said, 'I always tell them that it's *wrong*, that they have *rights* that are supposed to protect them from that but I never promise them that because there's a right written down on a piece of paper, that it means it won't happen or can't happen again. I try to explain that they do have a right but it's something that we can't *guarantee*. We can educate staff, we can educate residents about it, but it doesn't mean it's going to *completely* protect them.'

Another representative said, ‘If someone gives me that complaint about retaliation and they want me to work on it but they don’t want their name revealed and it could be something very specific…if the person is alert and oriented to understand obviously, I tell them, ‘Listen, I will do this.’ I will tell them, ‘I can get into a lot of trouble if I reveal your name and you don’t want me to but you need to understand that the nature of your complaint is somewhat specific. They can figure out who you are. I want to help you but I do want you to understand…we need to see the big picture.’’

When a very experienced representative was asked whether it is realistic to promise confidentiality – without it backfire – such as in situations where the nature of the complaint is unique to one resident (I gave the example of staff playing with the light switch at night by one resident’s bedroom), she said, ‘We talk about it with the resident because that one would be tough to bring to the management as a general issue, ‘Hey, this is impacting your whole building’ when you know it’s not so we can’t bring it as a ‘safety in numbers’ issue. We can talk to other residents to see if they are experiencing something similar or they want to bring up something similar and we can get it to the resident council or ‘Yeah, this is happening in a certain hallway in the building with a number of residents.’ That’s great but oftentimes that’s not the case. So residents need to know that if we bring it to the administration and it is specific like that, they are going *to know.’*

A representative from another state said, ‘Being real with them and helping them to understand, you know, we have smaller facilities and we have larger facilities…so let’s just say you are in a small facility and you are the only one in a wheelchair or the only one who is using the oxygen or on dialysis what have you…letting them know that depending on the circumstances, that ‘your identity may be more easy to uncover.’’

She went on to say, ‘While it is a confidential program and while their identity does not need to be disclosed, helping them to understand that in certain circumstances, you know, complaint dependent…if they are talking about transportation to dialysis, then they are the only ones who have those appointments and then if they have a specific complaint versus a broad complaint…that they may be the only ones impacted, maybe they are the only ones that are on a modified diet.’

One representative said, ‘When I'm addressing residents’ fear of retaliation, I always tell them that should never happen…we’re here to support you should it happen, but I never make a promise that it’s not going to happen. I am very mindful of not making that promise. I recognize it very much could happen regardless of what I say.’

Another representative said, ‘If you continually hang people out…say, ‘I am going to work on this’ but you never do, they’re not going to trust you. It’s all about trust. Don’t make promises you can’t keep and I believe in being *very* honest with them.’

A representative from another state said, ‘Always keep your word with a resident. If you said you’re coming back to follow up, then come back to follow up.’

Building Trust with Families

One representative said, ‘If you get to know their families, if their families have that trust in you, the families behind the scenes can say, ‘Listen, I think you should listen to the Ombudsman. They’re trying to help you.’ The representative added, ‘That’s a huge piece’ and ‘90% of the calls I get are from families. Residents don’t call me. It’s rare that a resident calls me.’

Exercising Patience

Several representatives spoke about the importance of patience and respecting the resident’s pace and level of readiness to give permission to the representative to pursue a complaint. Certain representatives also spoke about not applying excessive pressure on residents to given consent to intervene.

When asked about effective practices and strategies for addressing residents’ fear of retaliation, one experienced representative said, ‘Handling the concerns the way the resident wants them to be handled. You know, very specific advocacy.’ She added, ‘Offering suggestions in a way that’s not coercive. If the resident says, ‘No. I don’t want you to do anything,’ but you want to help that person, trying to talk with them about it but not badgering them. I think that sometimes…especially with really serious things…you know, Ombudsmen aren’t mandatory reporters, so this often comes up around abuse or the potential for abuse or waiting. Our big concern right now has to do with call bells waiting forever and things that happen as a result. And then the residents are like, ‘Well, I don’t want you to do anything because she’ll be upset with me and it’s not going to make a difference anyway’ and we’re like, ‘We want to help you’ and they’ll, ‘No. I don’t want…’ So *not* having this argument with the resident.’

She went on to say, ‘But also then figuring out…is there somebody else I can talk to about this concern…about the fear of the staff member, about the fear that it’s going to come back to. Because by the way, sometimes with retaliation, nothing has happened yet but there’s a fear it is going to happen. There has been nothing said by the facility, there hasn’t been a “mean” staff person but there’s a fear that retaliation is going to happen…so sometimes addressing that fear of…to say, ‘Can we give this a shot?’ But, again, I am not the one in the bed…so I understand. I don’t want to make the situation worse. I’d much

rather not do something for the resident and the resident keep talking to me than the resident say, ‘You’re driving me nuts. Leave me alone. I don’t want to talk to you anymore.’’

She said, ‘Some of the Ombudsmen can’t get that conversation started with the resident and I am pretty good at getting people to talk to me but there are some people that I am *completely* unsuccessful with. It also depends on that rapport that the Ombudsman has with the resident and that often is the key to actually anything. It’s the key to any kind of advocacy…is getting the resident to open up. Because if you can get the resident to open up, they will allow you to do something for them and with them.’

After speaking about the importance of making residents feel comfortable sharing care concerns, one representative spoke about the importance he sees in patience when working with residents, ‘That’s what we teach here. We teach them not to pressure residents to receive help and to give them a lot of space and sometimes time to think about things and that’s an important part. We do also realize that it takes time to build rapport with a resident and that they sometime will not open up immediately but that if you stay in touch with them and do regular check-ins that they will sometimes open up and ask for your help for something. And sometimes they just like to talk about it and feel better about having someone to talk to about and even that can be helpful.’

When asked about effective practices and strategies for addressing residents’ fear of retaliation, the same representative reiterated his earlier words, ‘Really, it’s just what I said. Go slowly, give the resident time to come around to the idea of taking steps to resolve the problem. Don’t pressure them. Listening is the first step to gaining someone’s confidence and trust. And then really work on empowering them by giving them information about what their options are moving forward. That’s really what we’re there to do. It’s core of our work. So sometimes having all that information. So there’s the trust part and then there’s the information component where you really empower them with all the what ifs and let them decide for themselves what to do.’

Another said, ‘Here in this office we are very conscientious to make people know that whatever you tell us is private and confidential unless we have your permission to share it…to try and open up that line of communication and really get them talking so that maybe further down the road as we establish a rapport, we can gain some trust so that they will…it’s the only way you can change it…but I also recognize it's *so hard* for residents.’

A representative from another state said, ‘If they don’t let me do anything, I’ll leave them with my card and my information and I tell them, ‘You can call me if you change your mind and I will be back to check on you.’

Another representative said, ‘I always give them my card and tell them they can always call us later. You don’t have to decide right now. If you’ll want to pursue it, we’ll be around.’

One representative said, ‘Some of it is building trust with the resident. If they know we’re coming back and they know we’re going to be a support, that may push them in the direction that will allow us to help them.’

Another representative shared this **story**: ‘I have worked with a resident for several years. Each time I’d visit, she would have something that she was upset about but she would never want to address, she didn’t want me to address it, she was just upset about it. And then, one day after literally several years…four or five years, she called and said, ‘I need you to set up a meeting with staff and the Administrator and can you be there?’ I said, ‘absolutely.’ I think I even moved up stuff in my schedule that day because she never wanted to do that. So we had the meeting and there was something about her different that day too…she was sitting up higher…it was really cool to see. She was able to address the Administrator and the Director of Nursing with her concerns about staffing. It was staffing concerns that she was tired of…having to “train” new staff all the time because they had such a turnover. She finally said something about it where before she thought that if she said anything that they would for sure never give her consistent staff…that it would just get worse. I don’t know what made her finally want to address it but I can just imagine the trust through the years that I am going to keep coming back and someone is going to be there for her. I can only imagine that part I guess.’

A representative from another state shared this **story**: ‘There was one person I remember in particular. It just took time. Like *multiple* visits and then the person finally allowed us to do something, to have the concern addressed, and then things were fine.’

She added, ‘She didn’t want to be a burden and she was also afraid that there will be retaliation against her but also against the staff member and she didn’t want the staff member to be fired. Finally, she was willing to…I can’t remember which staff member it was…I think it was a nursing issue. I asked her, ‘Which staff member do you like? I can go get them.’ We got the staff member she liked and we were able to bring the concern and then have it addressed. But it wasn’t something that happened over night.’

Quote
“*You want to do well. You want to put your Ombudsman cape on. You want to run in there to save the day but she wasn’t ready for that*.” – Ombudsman representative

One representative gave this advice to other representatives, 'I would say, 'Don't give up.' Her very experienced colleague nodded in agreement. The first representative added, 'Just because the resident doesn't want anything done right then because they are afraid of retaliation, don't give up. Continue to visit with that resident…when you're there, if they feel differently…anything changed? Follow up, continue, even if you closed your case, visit, build that trust because I've seen where they don't want to have me advocate because of retaliation and fear of continued retaliation and I've seen where they've finally, 'Okay, I am ready, I am ready for something to be said or something to be done.' I would say, 'Don't give up.' Just continue that relationship…building that relationship with the resident…that you're someone that they can trust…is not just going to go away. That's what I would say.'

The Potential Value of Persistence

An experienced representative shared the following **story** which illustrates the value of representatives' persistence: 'There was a specific incident where the resident had just endured ridicule and abuse…not of a physical nature but deep emotional nature by staff in regard to some care needs that she had in her calling and different things. It was retaliatory for her requesting the care that she needed. It took five visits to a very rural area…greater than an hour travel distance but I couldn't let it go, I couldn't let it go. This person was very debilitated in many ways and was *so* hopeless…it was like…this was part of life now…this was just to be expected, 'I'm here. This is to be expected.' It just broke my heart so I was *so* persistent. I was there every week and on that fifth visit, they said, 'I'm scared but I'm gonna trust you. And I said, 'I am going to do all I can' and I remind everyone and myself daily, 'Never make a promise that you cannot keep.' Sometimes the words get away from us. I said to her, 'I cannot guarantee your safety but I can guarantee you that I'll be back and I will be following the situation with your Administrator *until* you feel safe.''

The outcome of her intervention was, 'The staff person was terminated almost immediately…suspended and terminated.' When asked about the outcome for the resident in terms of well-being and emotional security, she said, 'I think this person is forever scarred. That is a part of who they are now.' She confirmed that this resident is experiencing long-term trauma and added, 'When these people are so helpless…I hate to use this word because I feel like my role is to empower them…but when *physically* they are helpless in their daily needs and have disabilities that are huge…I don't think after being treated that way, they ever feel truly safe again. But this has been more than a year ago and when I see this individual, it still comes up.' She said, 'I wouldn't say fear but what I would say is that memory, that memory, that memory' referring to the retaliatory abuse.

She added, ‘She feels safe now and the Administrator has done remarkably well by putting her on departments’ heads list so that they’ll go in and check every morning because it was an evening issue…so they go in and say, ‘Hey, how are you doing?’ and this continues after a year…to give her some emotional support.’

When asked about the value of persistence, she said, ‘We do discuss that during our Orientation to our new Ombudsmen in our region and we talk about that because it’s real…and especially when you have a new face and you don’t know them…you’re not going to tell them your darkest secrets usually. We talk about persistence and though we are mindful of budgetary restrictions and millage and all these things…but we know that our role is to meet the needs of these folks. If it requires more than one visit, then more than one visit we make. We enlist the help of our other team members as Ombudsmen to help and again and use our volunteers in that area if we have them available. We know and train on the importance of establishing rapport and trust. We cannot do our job without it. We cannot do our job without it.’

‘Follow-up is super important’

One SLTCO said, ‘Once they know we’re watching them, the homes don’t usually do anything. They won’t pick on the resident anymore.’ She shared a **story** about a resident living in a nursing home who she and her colleagues advocated for. She said, ‘A man went to a hospital. He was there only for an overnight procedure. He is blind. He has been in the room for 8 years. They packed his stuff up and they put somebody else in. They were going to put him in a different room. But when you’re blind and you are acclimated to a room where you’ve been all that time, you can’t just move people around.’

She added, ‘We got an anonymous call and we got out there. We told the Administrator ‘Absolutely not,’ they can’t do it, and they also didn’t [missing word] a bed-hold request. So he is back in his room now. We gave the card to him. We also let the Administrator know we *will* be doing visits. Then we reported them to the Department of Health.’

She quoted the Administrator saying, ‘I’m going to do what I want.’ You know, to make money. ‘I need that room and yada, yada, yada.’ It was probably private pay. It’s a [missed word] because, ‘Right now waiting in the wings is the [Center focusing on Disability Law; name de-identified] who would come in. I’d also let the Mental Health Advocate who will advocate for people with disabilities. I have no problem calling every agency I can to fix you good.’’ She said, ‘I called [Center focusing on Disability Law] and said, ‘If I can’t get this accomplished, can you?’ The man that I reported it to is just as bad as I am. He’ll go in and he’ll cause more trouble than they want. So they listen. I don’t care who I have to call to get it for the resident. And I can get into trouble sometimes.’

She added, ‘As far as the resident permission, I get that or the family permission. And the blind man, he didn’t want his room moved. So yes, he did give us permission.’

When asked about effective practices and strategies for alleviating residents’ fear of retaliation, she said, ‘Just what I said. Giving the card to the resident and letting the Administrator know that if they think they’re going to retaliate or do something…and then stay in constant communication with the resident either by visiting or by phone to make sure nothing is happening.’

Another representative said, ‘If you’ve got a resident that has that fear, just always be in there to talk to them when we’re going into the facility.’ A representative from another state said, ‘Continue to visit them. Know that we’re there. Like whenever we’re out there, try to at least touch base…I know we’ve got a lot of other…especially our bigger facilities…a lot of other residents but just always, if you’ve got a resident that has that fear, just always be in there to talk to them when we’re going into the facility.’

Another representative said, ‘They also know that I will follow up with them and I do. A couple weeks or whatever later, I’ll say, ‘You were thinking about bringing something up…we talked about it. Has that happened? How did it go? They might say, ‘Well, I was going to’ and I said, ‘Okay, what will get you there? Is there something that is stopping you?’ Just giving that reassurance. ‘You’ve done it before. You can do it again.’

When asked what *doesn’t* work in her experience, the same representative said, ‘The other ‘what doesn't work’ is at some point…you can encourage a resident etcetera etcetera and that fear is so huge that you have to let it go, you have to let it go and follow up etcetera. You can't beg, you can't promise anything, you cannot divulge information period without the resident’s permission…and I stick by that.’

Active Listening

Representatives spoke about the importance they see in actively listening to residents.

One of them said, ‘Active listening shows that you care. You’re actively listening.’ She gave the example of ‘nodding your head’ and added, ‘The resident knows that you’re listening. You have to affirm and acknowledge the meaning. You understand that that is difficult to talk about…fear…when it’s about them. So that is something that we do. You acknowledge the feelings and needs behind what is being said. Then the Ombudsman empowers the resident to self-advocate. And we do drive home, ‘This is your home. Not theirs. It is yours.’ This is the system that I use that’s very effective. Active listening and communication skills are valuable in your work. Residents trust you when they know you are listening and the staff are not. That’s something that I do that really is effective for us.’

When asked about lessons learned in her work to address residents' fear of retaliation, a representative from another state said, 'I learned that if you show residents that you care and you have the time to sit and discuss the issues with them without rushing, they feel more comfortable providing consent.'

Another representative said, 'I think it's important that the resident knows that we're here to help and even if it doesn't go any further than them confiding in us and us being a sounding board and providing them with sentiments to try and empower them and let them know what their rights are, sometimes that's the best we can do. But just letting them know, 'You are valued. We care about what's happening with you, and we're here to help you if you decide that you want to go that route.''

Detection – Potential Signs of Fear of Retaliation

The question presented to representatives was: If a resident does not mention that they fear retaliation, are there signs you look for that indicate to you that they are fearful?

A series of signs were described by representatives as ones indicating that residents may be fearful of retaliation when they do *not* verbally state that they are fearful of retaliation.

It is important to recognize, however, that in some cases residents do explicitly say that they are fearful of retaliation when speaking up about care concerns, rights violations, and mistreatment. For dozens of examples, see the report 'They make you pay': *How fear of retaliation silences residents in America's nursing homes*, which is based on my study that focused on residents' lived experience of fear of retaliation – in their own words.

Examples from the current project: One representative said, 'In my experience, I don't have to look for body language a lot. My residents just *tell* me, they just *tell* me.'

A very experienced representative said, 'Most of the time people are just comfortable telling me. Because I've worked for so many years and covered some of the homes, I knew residents very well and I think we established a rapport to the degree that they were mostly comfortable telling me about it.' She added, 'So I don't I think I really maybe developed the skills where someone wasn't being very specific about it other than they might tell me a story…they may not label it, 'I'm fearful' but maybe the description and how they *describe* the behavior, *somehow* indicates to me of fear…but most of the time I feel like residents have been very honest with me about it.'

Another representative said, 'I've been in my role for a while and then I've gotten to know some of the residents that have been in the nursing homes for quite some time so they have been quite comfortable in reaching out to me and just that confidence to know that, 'Hey, I have someone that is there to advocate for me if I should need it.''

Red Flags

Representatives gave examples of red flags they are on the lookout for when trying to determine whether a resident is fearful of retaliation.

One representative said, 'If no one ever talks about what's wrong, something's wrong.'

A representative from another state said, 'If no one has any complaints or concerns, then you should be *concerned*. Something is going on and you're afraid to say anything.' She added, 'Or if you get answers like, 'Oh, everything is wonderful. Susie Q is doing a great job and the Administration is great.' That's probably not happening. Susie Q is right around the corner and the Administrator just now walked by their room and they just saw them…they're not telling you anything.'

Representatives said that residents will say things that indicate to them that they are fearful of staff retaliation (again, without them explicitly saying that they are fearful).

One of them said that some residents tell him, 'I am not interested in pursuing it any further.' He added, 'Rarely is somebody saying, 'I am worried about' or even that they said they've experienced retaliation. I can maybe think about one scenario in the past year where they said, 'Yeah, I would like you to follow up on that."

Another said, 'When you're visiting with them right there, they may just back up or [say], 'No. I don't want to be part of this. I like it here. I don't want to cause any issues.'

A representative from another state shared a conversation she had with a resident 'regarding staff attitudes and I had asked if the resident would like to tell me who the staff were and they said, 'No, I prefer not to say who it is.'' The representative explained, 'Because they didn't want any ill effects…they didn't want any blow back from it. They didn't want that staff to find out that they said anything even though the interview was confidential…I was talking to many other residents. But they still didn't want to take that chance that it could get back that they were the person that mentioned that particular staff person was inappropriate.'

Another representative shared that when a resident tells her that 'this situation is going on but I don't want you to do anything about it,' especially if it's something that I know is important for them, that's going to spark a red flag for me. They're bringing this up but yet they don't want any help, they don't want assistance…what's going on there…so that I'm definitely going to have in the back of my mind.'

Another representative said, 'They don't want us involved is a big red flag especially if we can identify that there is an issue.'

One representative said, ‘Sometimes we get stiffed armed. Sometimes they know who we are and they’re like, ‘I am not getting involved in this. You do your own thing. I am not saying a word.’’

Another representative said, ‘Another indicator might be a phone call and they say, ‘Hey, I live at this facility’ but they don't want to leave a name and just are kind of cagey about, ‘Don't say anything about it, don't look at my number, don't call my number back. I don't want anybody to know that I called you.’ So sometimes even on our voicemails we can pick up that there might be some retaliation that might be going on.’

When asked what the resident is trying to accomplish by leaving this voice message, she said, ‘It might be more of a general complaint and hopefully they will leave that in a message too like, ‘We’re not receiving our baths’ or ‘We hadn’t have hot water for a week’ or ‘Call lights aren’t being answered because they don’t have enough staff’ or ‘We’re running out of supplies because the facility can’t pay their bills.” Her colleague explained, ‘I am using this term lightly but they might threaten the facility and say, ‘I am going to call the state’ or ‘I am going to call the Ombudsman and then you’re going to have to deal with that’ but then they don’t tell us who they really are so they sometimes call us at a point where they haven’t gotten something they want and they’re angry with the facility, yet they are not giving us any direction to help them.’

Body Language and Facial Expressions

Several representatives identified residents’ body language and facial expressions as signs that they may be fearful of retaliation. One of them said, ‘I think that part of our job is always trying to read body signals and to read expressions and moods. That is part of what we’re trained to do…so of course it is something that we’ll look for and I can get a real good reading, I think, kind of out of the gate when I am talking to somebody whether they want to move forward and obviously, some people will just say, ‘No. Because I am scared.’’

Another representative said, ‘Their overall demeanor. You can tell a lot of someone by their facial expressions. They brought it up. Did they look scared? Are they stuttering all of a sudden? What does their voice sound like when they’re talking to me? Do they sound calm? Do they sound fearful? Do they sound really nervous? Are they fidgety or antsy? Do they sound angry? Those are all things that I am going to look at.’

She added, ‘Topic avoidance is definitely something I would look at’ and ‘I am also gonna look at what they’re saying…how they’re wording what they’re saying because I want to be looking for…Do they feel helpless in this situation? It would be things if they feel helpless and feel like there’s no way out. Those are things that I would be looking at. But I would also

try and engage the resident in conversation to see if I could pull some of that information out to better help guide me.'

A representative from another state said, 'I look at body language and this might seem obvious that they might want the door shut but I have noticed the way that request is put sometimes is *different*…where they'll say 'Please shut the door' because we do ask that, you know, but sometimes they look like they are looking around [said while looking to her sides] and say, 'Please shut the door. I don't want anyone know we're talking.' Things like that are big triggers that they are fearful of being seen talking to us.' She added, 'I've had staff outside of the door listening…so it is a valid fear.'

When asked if she witnessed it, she said, 'The instance that I actually caught the staff member because they weren't very stealthy and they bumped the door. I went to open it and there were two staff members right there.'

Another representative said, 'Their bodies become smaller. They fold in. It's very typical body language. Their body is speaking, they're watching the door. They are *very* aware who is around. That's why I always ask, 'Would you like me to close the door?' but there again, some of them are so scared that's gonna bring attention itself if we close the door.'

Quote
"*Their body is speaking*." – Ombudsman representative

Another representative said, 'They try and hide in the corner so that they can't be seen from the doorway.' One representative said, 'I find that when I am talking to them, I catch them looking out the door…seeing who is listening or is anybody walking by. You can see them fidgeting. There's just an uncomfortable feeling when you're looking at their body language. When they're uncomfortable, I know something is not right in that situation and it's really looking at how they're talking or who they're looking for [said while looking upward and sideways]. That's what I observe when I think there's definitely a problem.'

Another representative said, 'Trying to look at the door to see who might be eavesdropping.'

One representative described situations where residents will say things that suggest they are fearful of retaliation: 'We do our visits. We walk up and down the hallways, we're passing out our brochures, and the residents ask, 'Hey, who are you?' or if they know us…I've had residents literally look at me and they'll look around…they don't want me coming in like, 'Don't come in my room' and they'll make eye movements or a head nod

[said with a hand gesture indicating ‘go away’] in that ‘I know that there must be a staff person on’ and they do not want to…even though I could have just been talking about, ‘How are you?’ that type of thing. They are *terribly* fearful of me walking into the room because they know and I’ve been told that, ‘Oh, I saw you with the Ombudsman. You better not have said anything,’ that type of thing.’ Her colleague added, ‘They whisper, ‘Call me later. Don’t talk to me now.’ Her colleague added, ‘That happens a lot.’

A representative from another state said, ‘I think during a visit, we might see or hear something they whisper and they ask for their door to be closed. They fear that staff might be behind a bathroom door because sometimes they share a bathroom with another room or they're fearful that staff might be listening right outside their room.’

Several representatives said that a sudden change in the residents’ body language when they notice a staff member around could be a sign that they are fearful of retaliation.

One representative said that a lot of her residents ‘are not looking at my eyes though I am the only one there. They are looking around to see if someone’s by the door or anywhere else where someone could possibly be hearing what they’re trying to say. It’s like it’s you and me, it’s you and me but they are all over the place looking around. A certain staff member walks by and their whole demeanor changes.’

Quote
“*How they act when a certain staff member walks by or comes into the room…speaks volumes*.” – Ombudsman representative

A representative from another state said, ‘Body language. A resident may shut down as soon as the caregiver enters the room.'

Her colleague added, ‘You could be sitting there having a conversation with a resident and a staff member that they do not get along with walks in or if they feel like they don't get along with that staff member, they just freeze. It's a *whole* different body language, a whole different demeanor. They all of a sudden don’t want to talk to you any longer because they’re afraid of what that staff member might tell somebody else later or what have you.’

When asked about signs indicating fear of retaliation, one representative said, ‘They’re very quiet. They are not very engaging. You’re not able to engage.’ She added, ‘It’s the shift in their eyes and the feeling with the hands. They just shut down and say, ‘Well, I don’t have any complaints.”

Another representative said, ‘I’ve seen them being quiet when someone walks into their room…and you can see them [said while making a facial expression indicating fear] almost like an abused person where they shy away from them or they become very quiet. When the door is closed, they are very vocal and talking and when that person comes in, they just kind of clam up. So yes, in that nonverbal sense, they remain quiet.’

One representative said that when residents capable of speaking are not saying anything when receiving disrespectful treatment from staff, it might be a sign that they are fearful. She shared this **story**: ‘I was in a home and the aide came in and took a person's tray…I mean he had the fork and he was eating…a very slow eater and she came in and gathered up his tray and his plate and everything. He was eating from the plate. She grabbed that all up and took his dessert and put it in front of him, which he was not eating, and took his tray and left. I followed her out into the hallway and asked her, ‘Did you not see him eating the peas?’ Because he was eating peas.’ And she said, ‘I thought he was done.’ I said, ‘He had his fork in his hand.’ And ‘Did you notice you don't have his fork on the tray? He was eating.’ She said, ‘Oh, I'm sorry.’ I said, ‘You don't need to apologize to me, but I think you need to get him a new plate.’ She did get him a new plate but that was just blatant.’ She added, ‘The aide took his meal tray before he finished his meal’ and ‘the resident didn’t say a word. The representative said that it was a sign that ‘he is afraid to speak up about it.’ She added, ‘When she was gathering up his things, he could have said, ‘I am still eating’ and he wasn’t speaking. She said that this resident is ‘absolutely’ capable of understanding and speaking. He even told the Ombudsman representative, ‘Thank you’ when she intervened.’

When asked about signs that indicate to her that a resident fears retaliation, one representative said, ‘For me, if they don’t immediately want advocacy or if there’s repetition, if a resident is complaining multiple times and then we will also watch interactions. We'll watch the resident…how their interactions with certain staff. We kind of have to be mindful of all of that so yeah, I look for repetition and then if there's a reason they don't want advocacy, we always want to know why. Is there anything we can do or we do ask questions but yeah, repetition, I guess would be one I’d look for.’

Another said, ‘I think if they are often fearful to share their identity or say [quietly], ‘Well, I'm going to tell you but please don't tell anybody’ you know, they'll let me know they're scared or if they are trying to share concern and they're looking around to see if anybody is looking, listening to them, watching them, I know that they're fearful of speaking to me.’

One representative said, ‘Sometimes they will put their hand over their mouth, they will wring their hands like this [illustrated wringing her hands] kind of a sign of anxiety. They'll fidget. They’ll fidget a little bit when they're saying it.’

A very experienced representative said, ‘Many times it is just signs of anxiety…rapid eye movement…clutching their hands…looking at the door as if afraid…whispers even if you’re in a closed room. Just body language.’ She added, ‘I’ve been told so many times, ‘You won’t be here tonight. You’re not here every day’ and I say, ‘You’re absolutely right. I want to help you, not hurt you, and I am going to do what you’ll tell me to do.’’

One representative said, ‘The minute I walk in if they're looking over my shoulder, you know, who's there who's behind me. They've seen me before, I identify myself but you can see the caution in their eyes. Sometimes they'll talk and talk and talk to us about everything but anything that touches on a complaint or if they do, they get extremely nervous and [digest] not to say anything.’ When asked to elaborate on non-verbal signs, she said, ‘Not looking at us or looking wildly around…like looking for danger kind of thing. They’re hearing what we’re saying but they want to be sure that…it’s mostly with the eyes that I notice things.’

She added, ‘They refer us to their family. That’s seems to be a default thing. ‘I have some problems but talk to Jimmy or talk to my daughter’ or whomever. And we do but it’s like, ‘If it didn’t come from me, it’s not going to be as bad.’ They’re just afraid.’

Another representative said that ‘Tears, exhibiting anxiety’ is a sign that they fear retaliation. She added, ‘I see a lot of tears, a lot of anxiety.’

A representative from another state said that in some situations crying and yelling – such as when residents are otherwise calm at baseline – could be signs of fear of retaliation or actual retaliation. She said, ‘Crying, yelling…things that you hear down the hall or residents yelling and you’ve never experienced that before. You know you never witnessed that. This resident is normally calm.’

Hesitation and Reluctance

Representatives talked about residents’ hesitation and reluctance to voice care concerns or file a complaint as a potential sign of fear of retaliation. One of them said, ‘I could spend my entire shift with them but at the end of the day, I get to go home and they’re the ones that are there. There’s a lot of emotion behind what the residents are thinking and feeling and experiencing. Sure, they may want things to get better but if it’s a long bumpy road to get better, I could see how a resident would be hesitant to go down a long bumpy road.’

When asked about signs of fear of retaliation, another representative said, ‘The hesitation. They’re not sharing freely with us what’s happening in the facility.’

Another representative said, ‘I wouldn’t say that they actually come out and say retaliation but they’re reluctant filing complaints with us due to the staff is their family now…they don’t want to get them in *trouble*. That’s how I feel. I always encourage them to speak up and I do education and In-Service and let the staff know what the feelings are and that they have a role in making them feel comfortable to speak up. That’s kind of how I see it.’

A representative from another state said, ‘I watch for signs of hesitation. Some residents are just going to tell you and they go straight through without any pausing but some would be more hesitant or they’ll pause before they tell you something so you can tell they’re thinking about how they want to word it because maybe they don’t want to be offensive…where that might lead to something else.’

When asked about signs indicating that a resident is fearful of retaliation, one representative said, ‘Facial. They might be quiet. Their eyes might be looking to the hall to see if staff members are going. Just hesitancy…even when I am asking a question, I am assuming they are processing it and they are like [said with a hesitant tone of voice], ‘No, I think everything is okay.’ You know, just that hesitancy.’

When asked the same question, another said, ‘A lot of times when I get a complaint from a resident and they express that complaint to me and at the end…we ask, ‘Okay, do you want us to follow up? Do you want us to open any investigation?’ Sometimes they sort of ‘beat around the bush’ and say, ‘Well, no’ and it could be a really egregious complaint and so I will say to them, ‘Hey, as your advocate, my role is to work with you to resolve this so that we can make sure not only that this doesn’t happen to you but also for other residents.’ So I put it out there, ‘It's not only just for you’ so a lot of times when I explain that to them, then they're relieved so they'll scurry around and say, ‘Well, no. I think that this is not going to happen again’ instead of just admitting that they actually fear saying something or having someone advocate and speak up because they may receive some type of retaliation. So they'll give another explanation, ‘No, let's just wait a while’ or ‘I've heard even some family members say if they complain, they may discharge them and my mom is comfortable here or my dad is comfortable here so I don't want to ‘rock the boat.’ These are some of the telltale signs that I see…okay, they are fearing some type of retaliation.

She added, ‘Sometimes I'll just be bold and say, ‘Can I ask are you uncomfortable with telling me? Have you ever experienced staff retaliating? If so, can you share that with me?’ Sometimes they will share it with me and sometimes they won’t.’

Another representative said, ‘It's mostly nonverbal stuff so if they feel comfortable or kind of fidgeting in their seat [or] an open area kind of looking around. When they tell me about a concern and I ask, ‘Can I talk to so and so?’ like the administrator or something about this

concern and they hesitate and they're like [with a hesitant tone of voice], ‘Heee, well, I don't know,’ you know, kind of talking through that because normally there's a reason for the hesitation so that's kind of what I look for.’

Another representative said, ‘When we’re doing just your commonsense motivational interviewing through the process of engagement, someone's reluctance to share information for example could very well be just that. Sometimes there's a sense of reluctance of even engagement like I might be on a non-complaint visit and asking some questions, ‘How are things going here?’ ‘How's the care?’ those types of things and all of a sudden, I can just sense that I struck a chord, and their boundaries go up and they don't want to cross that line because if they do actually share what's going on, it could lead to them having a sense of some type of negative retaliation from staff or leadership.’

When asked about signs that residents are fearful of retaliation, one representative said, ‘Well, if they are not forthcoming, you know, they seem to be holding back on expressing a concern that maybe we already know about…could be a sign that they are a little hesitant to speak to us for possibly fear of retaliation. Or they inform us of an issue but they may come right out and say they don’t want us to do anything about it but don’t specifically say why. We might be able to assume that could be a potential fear of retaliation. Maybe someone that really doesn’t want to be seen with you coming into their room and kind of would rather you leave. Who knows if that could be a sign or not. But also acting differently if a staff person comes into the room or goes by the doorway of the room and there’s a change in how they’re interacting with us…might give us an idea that they have a concern.’

One representative spoke about a mismatch between words and intonation, ‘When it doesn’t match up. The resident will say, ‘Everything is good’ but you can just see the stress and expression on their face that there’s something majorly not right…is one of the things that I see.’

A representative from another state said that the way residents tell their story including missing details in their accounts might be signs that they are fearful of retaliation. She said, ‘You can tell by how they tell you their story. How they explain the situation that happened. You can tell that there are missing details in their story. They may not say that they are afraid of retaliation but you’ll ask them, ‘Do you know who the aide was?’ and they’re like, ‘No.’ Do you know what they look like? ‘Oh, I don’t remember’ when in reality they do. They don’t want to tell you these fine details because they know it’s going to come…in their words…’bite them’ at the end of the day.’

Retracting Complaints / 'I changed my mind'

Several representatives said that sometimes when residents change their mind or retract complaints it might be a sign of fear of retaliation. One of them said, 'That's common.'

When asked about signs she looks for that indicate to her that a resident is fearful of retaliation, a very experienced representative said, 'They may back out of a plan that we'd agreed upon. They call you up and say, 'Let's not do this. I changed my mind.' Whether or not they're really saying, 'I am afraid of this, this, and that' or 'I am afraid of…' They don't use that word… They kind of get into thinking about it or other residents said, 'I should just be quiet' or those scenarios.'

Another representative said, 'Let's say that they were very vocal with us the first time we go in… they're telling us things that are going on and it's very important to us too if the resident does not want us to share their name, we will *not* share their name and we just talk in general. But you can see the next time we go in, they won't say a word, they won't say anything, they're just disconnected.'

A representative from another state said, 'Sometimes I will talk to a resident and then the next day they might call and say, 'Well I changed my mind. I don't want you involved' or 'I can work this out myself.' She added, 'If they give me permission if I say, 'Are you okay with me speaking with staff or the administrator?' and they say, 'Yes' and then I think they changed their mind because they don't want to get in trouble.'

She added, 'I've had residents say, 'Well, why don't you just go meet with the administrator or social worker and represent me in a meeting.' I think they feel like if it's coming from me, it won't seem like they're complaining and I think residents sometimes feel, 'Everyone's just going to think I'm lying but if you say it they'll believe you."

Change from Baseline or Withdrawal

One representative identified the following signs that may potentially indicate that a resident is fearful of retaliation, 'Change in their attitude, eating, behavior, if they're withdrawn.' She added, 'Sometimes the roommate may call in a case or call us to come out and investigate because there's a change in their roommate.' She shared a **story**, 'I've had a case where a roommate called for their roommate…for the other resident in the room and let us know, 'I know something happened' but they won't tell me what happened or the roommate will say, 'I don't know what happened but I feel like something has happened because now they won't come to activities, they won't do anything or participate in anything anymore…so I know something happened but I don't exactly know what it is.'

When the representative went to speak with the resident, ‘The resident didn’t provide consent to advocate. They said there weren’t any issues. They were having family problems but that was it for that one.’ The representative said, ‘I feel like it was more like they didn’t want fear of retaliation. They just gave an excuse that it was something else.’

A representative from another state identified withdrawal as a sign that a resident may be fearful of retaliation. She said, ‘If they're alert and oriented and have most of their cognitive awareness, a lot of times you’ll just see them withdraw, you just see them just stay in their room. Let’s say they are incontinent, they may not venture out past their room because the fear of having incontinency in the common area and staff making a big deal of it or staff being, ‘Well, I’ll get you later’ and they are in soiled clothing. That can be a motivator for them to feel like, ‘Okay, I am not going to venture far from my room’ because maybe they can provide some care for themselves or attempt to provide care for themselves. We see that a lot when a resident isn’t coming out of their room or there’s a change in that…they were doing it before but now they’re not and there hasn’t been a decline in a disease process, an injury or a [missing word].’

She went on to describe what may occur when a resident is experiencing an incontinence episode in a common area. She said that she has seen residents in ‘an activity in a common area and they have had unfortunate incontinent episode and staff either notices it or they alert someone to it… sometimes the residents are not aware…but then they have to remove them from the activity or the common area to go back to the room and then we'll make comments like, ‘Well, now you're gonna miss bingo because we gotta go back and change you’ or ‘Well, now you're going to miss this’ or ‘You know what, we just got you dressed half an hour ago. Why is this happening?’ That demeaning tone like somehow they are being *punished* because of an unfortunate accident or their body working in a way that caused this and kind of implying to the resident that they have some control over it. I think that’s the retaliation part is. For the most part, I've never met a resident who intentionally has incontinence or retention and so for them to imply or denote somehow that you're doing this or you're having this incontinent episode and therefore ‘making my job harder, making it more work for me,’ and making it so that now you're missing out on maybe something fun or something beneficial, that is the retaliation and residents don't want to hear it, they just don't want to hear that anymore so they'll just stay in their room, they'll kind of seclude themselves. That way, if the incontinent episode happens in their room, they're closer to the bathroom, they could push the call button, and staff will come in and close the door so nobody else is hearing it with the exception maybe of a roommate… but nobody else in the common area is hearing it. So that's kind of what I see.’

She added that sometimes a decline and deterioration in residents' condition (e.g., 'You just start to see that decline') and 'failure to thrive' could be signs of fear of retaliation. She emphasized the importance of 'being able to identify that and ask the question why?' Her colleague attributed the resident's 'failure to thrive' to 'feeling of hopelessness.' The first representative said, 'Let's say that they yell all day long and they are tired of them. They don't want to work. They're retaliating. They are "problem" residents [said the word problem with quotation marks]. 'That's what they do all day long. Just ignore them. That's normal.' In reality, it's not normal. They're there for a *reason*.'

Her colleague described the pathway of 'failure to thrive' due to fear of retaliation, 'They're hopeless because nothing can be done. They're experiencing this. They can't act upon it because it will get worse so they start to get depressed and pull away. Then you just kind of start, 'I don't wanna eat anymore, I don't wanna do anything anymore.' The first representative added, 'I want to die.' Her colleague added, 'It's that process.'

The first representative added, 'My thing would be if their 'failure to thrive' is due to hopelessness, I want to know what they've done to change that around. Have they talked to the doctor? Have they ordered a psychologist to go in there and talk to them? Their spiritual needs…is there a Church going in? What do they believe in? What's their religion? Have they had Church come and maybe do communion with them? I want to know what they are doing to *help* change that.'

Resource Box
"Failure to Thrive"
For a critique of the term 'failure to thrive' and the need for thorough investigations of root causes (underlying conditions, diseases, and contributing factors), see *The New York Times* article: 'Failure to thrive,' or a failure to investigate? (May 13, 2024).

The latter representative added that residents isolating themselves in their bedrooms may be a sign of fear of retaliation, 'Sometimes a resident stays in their room all the time, they don't come out for activities, they don't go out for meals and they might tell you they're comfortable just staying in their room all the time but it might be because they fear that the facility doesn't like them and so they're more maybe depressed or isolating themselves because of what they fear they might hear from the staff.'

Acknowledging Residents' Fears

Representatives spoke about the importance of acknowledging residents' fears. One of them said, 'Validation, acknowledging, believing them that it could happen or it had happened. And then…a lot of it is providing that education, which helps provide support. I feel like the more supported they feel, the less fearful they feel because they do have somebody in their corner and, 'You know we're going to be checking in on the process.' So just elaborating for them on that process so they'll understand exactly what our involvement is, how they can reach us if something happens.'

When asked if there is something she thinks is important when addressing residents' fear of retaliation, a very experienced representative said, 'I think it is important to talk about it and talk about it with the resident…that this is real, 'This is a real fear and I understand that. I understand where you're coming from' and, 'I get to leave and they are here and 'You depend on the staff and I understand your fear.' We talk about the law and the protections that they have…their right. We talk about their rights and their right to complain and that there shouldn't be any form of retaliation, but I understand their fear. 'I am here to support you and help you to do what you want in this situation.''

When asked what stands out to him as important when addressing residents' fear or retaliation, another representative said, 'For me, it's to acknowledge them. I'd reiterate to them…like when they say, 'Oh God, I don't want you to say anything…that's going to make things 10 times worse,' I acknowledge their fear and reiterate what they're saying so they know I am listening and I understand what they're getting at. That's kind of the start of it.' He added, 'My second thing is I tell them, 'This is 100% confidentiality. This is up to you. Whatever you want to tell me that you want to remain confidential, we're not going to go through. I have to have *your* permission to do anything. Without your permission, I only go as far as you want me to.'

When another representative was asked what he finds as of value when helping residents alleviate or intervene with fear of retaliation and actual retaliation, he said, 'For me it's really about *acknowledging* to them and expressing understanding of their concerns about fear of retaliation. It's really about building a rapport and trust with them…ourselves…that makes them comfortable in order to speak to us about things that they might be concerned others hearing about. Really, just developing that trust and letting them know that everything with us is confidential and just creating a space for them to be able to talk about it with us regardless of what we do with that information together or separately. We just want them to feel comfortable talking to us about it. Then we see where it goes from there. We can let them know what their options are and different ways of dealing with different issues either on their own or with our help or in other ways.'

One representative described how she talks with residents through their concerns and fears, 'At least with the fear of retaliation, telling them…kind of reinforcing what their rights are, talking through what the concern is, what the fear is, why do you have that fear? Did it happen to you already? Did it happen to you in the past? Has it happened to your roommate or someone you know here? And just reinforcing that if something happens, saying that's not right, this is what should have happened, this is what that person could have done or you could have done in the past, this is what I can do to help you go through this process of trying to resolve an issue without receiving retaliation or if you do, kind of nipping it in the bud with myself and the facility or, if needed, [Department of] Public Health.' She added, 'Arming them with confidence and knowing, 'No, I could push back. This is my right. I can do this. They shouldn't be retaliating. If I complain about the staff, they shouldn't just come back and talk to me about it…that's awkward, that's confrontational, and uncomfortable. Telling them, 'That shouldn't happen. That's retaliatory. If it happens, let someone know' and just kind of talking them through that process.'

Providing Emotional Support

When asked about the extent to which they provide emotional support to residents, one representative said, 'All the time.' Her colleague agreed. The first representative added, 'All the time. I am a big hugger. I give hugs too. Sometimes people just need a hug.' She added, 'It's just being a human being and wanting to connect with people that you just listen and kind of pick up on…Oh, they need someone to hold their hand or they need a hug or we just need to let them process whatever it is that's going through their mind in order to make a connection and figure out how we might be able to help make things better for them.'

Providing General Reassurance

Representatives spoke about the importance of providing residents with reassurance that they will do everything they can to assist them if they choose to receive it. One said, 'We assure them that we will be there…we will be there to support you, to advocate for you.'

Another representative said, 'Being present, letting them know that it's illegal, that we're there for them, that just because we may not be in the building at that moment does not mean that we're not going to follow through and continue to monitor the situation and be there for them and be present for them.'

Providing Reassurance Based on Past Experience

The latter representative spoke about how she tries to provide reassurance to residents, 'Really just kind of trying to educate them with knowledge and just kind of assuring them that you don't know until you try. If it hasn't happened to them at that building, you don't

know until you try and also with my familiarity and my buildings and the same with my colleagues in theirs, 'Well, in the past I've brought concerns to this manager and I haven't had residents that there were any problems afterwards or any change in care in response to this.' So also giving them that context that I am familiar with this building, this is what I've seen, if that helps your fear at all.'

She added, 'Usually, having to go through a process once along with us. We make a complaint or we bring up an issue to someone and it then gets fixed. They see these little bits of things where it's like, 'Oh, okay. It does work and no one comes and yells at me or doesn't answer my call lights'…stuff like that. Sometimes 'the best way is just going through it…kind of powering through and do the process and…because you don't know. Sometimes it is just the fear of and it's not based on anything other than stories they've heard.'

A representative from another state said, 'I have told people and my staff have too that this is not something that we commonly hear from people at this facility…if that's true…to encourage them.'

One representative said, 'I will share with that resident that has that fear of retaliation that is considering whether or not to work with us…I'll share some general examples… without using resident's identifiers… about how we've been successful in the past in helping residents that had that fear…that we were able to be successful with them and addressing their care issue without them being retaliated against.'

This representative shared that she also provides reassurance to the resident, 'I'll talk about that we are very familiar with our facilities and that the facility management knows the Ombudsman and that they know we're going to continue to come back until the issue is resolved. It's the empowerment piece and just reassuring them that they have the right to voice a concern and this is what they should expect…things like that.'

A representative from another state said, 'We always reassure and try let the resident know that you are there for them, we support what they decide but then we also try to educate them and let them know, 'Hey, this has worked before and we can't promise that if we say something you're not going to be retaliated against…we can't promise that but we have seen this work in this scenario. We do provide them with some information from our previous [advocacy] and history that has worked before in other scenarios. We try to reassure them, 'You know, we can go with you' or we try to empower them if they don't feel comfortable by themselves or with us doing it. We offer multiple outcomes for them or multiple solutions for them and let them decide.'

Empowerment

Many representatives highlighted empowerment as a central practice when working to address resident's fear of retaliation and actual staff retaliation against them. Empowering residents was an integral component in many representatives' strategies for addressing residents' care concerns, fear of retaliation, and actual retaliation against them.

Quotes
Fear of retaliation is a barrier that "may influence a resident's sense of empowerment." Source of latter quote: Module 3 (page 26) in The National Long-Term Care Ombudsman Resource Center (2022). Trainee manual: Initial certification training curriculum for Long-Term Care Ombudsman Programs. "*The most common way people give up their power is by thinking they don't have any.*" – Alice Walker

When asked about lessons learned in addressing the issue of residents' fear of retaliation, one representative said, 'I think one thing that is very important is you have to empower your residents. Everybody has to be on board with these residents run the show here. Well, within reason, but they retain all their rights and you have to get everybody on board that residents are to be treated, truly treated with the respect that they deserve and that anything less, they're not going to stand for it. So empower your residents and there are ways to do that. I think that is one of the most important things that I can think of.'

Another representative said, 'It's the empowerment. That's where I've had the most success in my experience because most folks are, in my experience, interested in chasing the actual complaints in a formal manner so the best thing that we can give them is tools to recognize and manage it and help them know where to go with it…including calling us if they want to but [also the] Department of Health, filing formal grievances, and Resident Councils and things of that nature. It's the empowerment…just by the sheer numbers.'

Quote
"*It's the empowerment. That's where I've had the most success*." "*It's the empowerment…just by the sheer numbers*." – Ombudsman representative

One representative said, ‘I think that we can educate the residents and show them how to advocate for themselves…do some educational sessions…teaching and training and letting them know the residents rights, letting them know that whenever they come to us, everything is confidential and we’re not going to share it with anyone and prove to them that that is the case and to trust us to take care of it.’

One representative shared a **story** illustrating how the education and encouragement she provided to a resident resulted in a successful outcome, ‘With the residents, just kind of standing their ground and exerting their rights and saying, ‘No. I know that you know this is my right.’ Having a resident that feels empowered is really what has helped with any kind of fear of retaliation. Again, not actual retaliation necessarily but fear of it like, ‘I'm afraid that he'll be mean to me if I say I don't want a guy to shower me…that I want a female.’ So this resident was informed of her rights, encouraged to say, ‘No, I want a female to shower me’ and she did it and it worked out just fine. He was a little pushy but eventually in the end she got a female CNA to shower her. So it does work…it doesn't work all the time.’

When asked how the male CNA was pushy, she said, ‘He was irritated that he had to go, ‘No, I'm your CNA. I have to give you your shower’ and she's like, ‘Well, no. I want a female’ and it was a preference that was *known* to management, it all been talked about. She just kind of stood her ground and exerted her right and said, ‘No. I know I have this right’ and he did go and get a female CNA to shower her.’

She added, ‘We had talked to her before and she mentioned this problem but she said, ‘I am kind of afraid to upset the “apple cart” is what she would say. By “apple cart,” she meant the male CNA. She was afraid to really do it but through us encouraging her and saying, ‘No, but you really *can*. Here watch.’ The managers were literally telling you, ‘You can have a female shower you. It’s okay. That’s your right. We’ll put it down that it’s a preference.’ Before, staff didn’t listen to that but after she asked and then insisted, he did go and get one and she didn’t report that he was cranky or did anything to her after that.’

One representative shared a **story** illustrating how with her help, violations of residents’ rights and their fear of retaliation not only were resolved but eventually led to starting a Resident Council in the care home. The representative said, ‘With one of the facilities that I was visiting, I was able to see the outcome of *empowering* the residents.’ She said that the residents ‘weren’t getting fed the food that was shown on the menu, you know, alternative…and they were hungry.’ She clarified, ‘The food portions…so normally you have alternatives and normally if you don’t like something that’s on the menu, you have that alternative. Well, some of these companies are trying to save money and don’t have alternatives. So a few of the residents were going to bed hungry. And so when they would call me, I went down there, talked to them but they were scared, again, retaliation…they’re

scared to say anything. So when I brought it up without bringing anybody's name up, I addressed the situation…they saw a resolution, they saw things changing, they saw the alternatives coming back, the options, they saw the portion of the food, you saw them start to shine, they became a powerful group of residents that help each other now…speak up.'

She went on to say, 'They actually started a Resident Council because they didn't have a Resident Council. The lady that had called me, I encouraged her to be the President of the Resident Council and start these monthly meetings with residents. To see them go from feeling like they didn't have a voice and now being able to speak and have a voice and bring up these issues without being retaliated against was a success.'

The representative described what she saw as key to the successful intervention, 'I think networking together…the bridge…we're not against the facilities, we're not against the Administrators and every time I go into a nursing facility, I make it very clear, 'In order to make the quality of life of each resident better, we have to work together. We can agree to disagree and that's fine but at the end of the day, it's those grandpas and grandmas that are in there that matter the most.' When asked how the residents overcame their fear of retaliation, she said, 'I think by overcoming and by being that bridge and seeing the Administrator actually take action…not against the residents…start ordering food…start putting the menu back into place for them.'

After using the word 'bridge' twice, I asked what does the 'bridge' represent in her eyes and she said, 'For me, I visually I see…we have this company…we have nurses, Administrators, we have these people…normally, when they see the car of the state driving up to the building, they panic…we're the bad people, we're the bad guys…so I want to see that bridge come together to say, 'Hey, we're here to help you. We're here to help you work together to make their life better.''

Another representative described how she uses role play to empower residents, 'To me, this is one of the most important things is back in [de-identified year] one of my goals for Ombudsmen was empowering residents so they get that sense of their power back because oftentimes they feel like they don't have that. Trying to restore that their sense of self again…empowerment means to them, etcetera. That was a focus so I learned lots of different techniques on how to empower. We probably don't need to go through all of those but here's another technique I use. I will say because I encouraged self-advocacy first and so I will say, 'Tell me about a time that you spoke up for yourself and you were *proud*.' They'll tell me something and I'll say, 'How is it different now? You used your voice before. Tell me how it's different.' 'Well, it's different because I'm reliant on someone's care.' I got that so then I'll say, 'Tell me what would happen if you gave me permission to advocate for you or if you did for yourself? Tell me what would happen?' 'Well, I might miss a meal. I don't *know*

what might happen. I don't even wanna *think* about what might happen.' Okay, so then I might say, 'Well, let's do a role play.' Really big on role play. I'll first role play where they are the resident and I'm the CNA or something to that effect and then we will be where *I* am the resident asserting my rights and *they* are the CNA and the difference. And they'd go, 'Oh, I never even thought about that. I didn't even think about saying it that way.' Just changing the dynamic where of course if you say to a CNA, 'You always…', well, that's where the CNA might be defensive…'You'…'always.' if you switch it to, 'I want my care this way.' It's very flat out there. 'Here's what I would like. Here's what I want. Here's how I want you to care for me' is a different dynamic than having someone go on the defensive. It's just changing the words.' She added, 'That's something that I do. Yes, this takes time but it is very important. What I have found is I think the role play helps and giving back that power of self-advocacy to the residents.'

When asked to elaborate on what she meant by restoring the resident's sense of self, the representative said, 'Restore their sense of self by *empowering* them. Because obviously they *were* empowered and they still can be empowered because they have had power throughout their whole life probably where they spoke up something about this. It could be as somebody got a spanking and that resident spoke up and said, 'That is not discipline. That is beating your child' and felt good about saying something or they found a huge mistake in the budget and they brought it up and they felt empowered by the recognition that you have just saved us $10,000. It could be things like that that gives that resident, 'Hey, I have done this before. I was successful. I can do this again.' So bringing back that voice of that resident that I am still powerful.'

The representative added, 'I also say, 'When people speak up, that gives them more confidence, more power, which encourages them to continue using their voice.' She went on to say that 'when I am talking about retaliation,' that it's important for her to have a connection with residents, *acknowledging* them, establish that trust with them, listen to them, telling them that she can't share it without their permission, telling them, 'You have federal rights…you have protections' etcetera, and that there could be consequences for a staff member. I also say, 'I can't promise you that retaliation won't happen but what I can tell you is…if you say nothing, nothing will change.'

Resource Box
Quotes
"*I can't promise you that retaliation won't happen but what I can tell you is…if you say nothing, nothing will change*." – Ombudsman representative *"It's not going to stop unless you say something."* – Ombudsman representative

Educating Residents About Their Rights

Many representatives said that a central part of their role is educating residents about their rights whether it is their right to receive respectful, dignified, and safe care or their right to complain about the care they receive without fear of retaliation and without retaliation.

One of them said, 'Making sure that they know their rights is super important.'

Another representative said, 'I always tell them that it is their right to address a problem without fear of retaliation. I always tell the residents that it's a federal regulation…it's in the regulations that they have a right to complain and file grievances without any retaliation coming back to them.' He added that he does it 'to calm their fears.'

A representative from another state said, 'What we could do to help is empower them with the resident rights. I think the more familiar the residents are with what their rights are, the more empowered they become, the more they are going to know what they can and cannot do and not just take the staff members' word for it.'

Another representative said, 'Just educating them that this is their home, they should feel safe in their home, they should not feel afraid of staff members…that they have a right to feel safe currently with where they live.'

One representative spoke about the importance of 'Not only hearing their resident rights because, you know, I hear things all the time but understanding it, really absorbing those resident rights.'

Demonstrating to Residents How Their Rights Can Be Realized

Representatives spoke about the difference between telling residents they have rights and *demonstrating* to them how these rights can be realized. One SLTCO said, 'Explaining to them that those are their rights but then showing them. It's one thing to tell people they have rights. It is another to demonstrate that you respect those rights. Knocking on the door and waiting for an answer…that's one of the biggest cues that you are respecting someone's right to privacy. Saying, 'How do you want me to care for you this morning?' You know, giving a person a say versus, 'All right, we're going to get you up now.' We're doing something to you versus we are listening to you, we are caring for you, 'What do you want?' You have a say. It's your right to tell us how to care for you and what to do.'

When asked about the distinction between educating residents about their rights and demonstrating to them how their rights could be realized, she said, 'I think it's one thing to know that you have a right of choice. Okay, you're telling me I have the right of choice but to take a situation and to look at their menu so you don't like lasagna and you want to have beef Stew. This is a choice that you have and if you don't want this, you need to know and

be comfortable that the facility is going to honor your choice of beef Stew because this is also another option.'

Representatives spoke about the importance of telling residents that what the staff member has done or said to them is wrong and that they have a right to be treated with dignity and respect. One of them shared this **story** about a nurse who expressed demeaning and degrading words to a resident: The resident was bariatric (obese) and lived in a skilled nursing home. She had 'a rancid smell about her.' A nurse was 'just terrible to her.' The representative said, 'She needed help getting up to walk to the bathroom, she needed help getting dressed and some basic ADL's, putting her shoes on was difficult for her and this nurse was just constantly, 'If you lost a little bit of weight, you would be able to put your own shoes on,' 'If you lost a little bit of weight, you'd be able to walk yourself to the bathroom,' 'If you weren't so lazy, maybe you wouldn't smell this way.' Just nasty nasty comments. Through the years of visiting that facility, I knew this resident and I could just tell by looking at her after this nurse walked out of the room that she was uncomfortable. So I sat with her. We talked not even about that at first. We were talking about [de-identified name of college] football and what the activities were for the day and the holidays coming up and things like that. I wanted to go about it that way because I wanted her to be comfortable. I wanted her to not just jump right into 'I saw your face when that nurse left. Tell me what's going on how can I help?' So through some conversation, she eventually did tell me what was going on. She's like, 'Listen, they're short staffed. I don't want you to do anything because she's right.' She said to me she thinks she's right, 'I know I smell and I am fat.' It was heartbreaking to hear that and you can see how degraded she was so we kind of let it go, I mean, not let it go but like we just continued on the conversation and I continued to bring up, 'Listen, you have a right to be treated with dignity and respect. I think she should not be saying these things even if you believe them to be true. Those are not words that should come out of her mouth.''

She went on to say, 'I continued to just kind of reiterate that to her…that she's a person, she has feelings and through three or four visits she's like, 'No, I don't want to do anything.' And then, the one visit we were sitting there talking and I had said to her, 'You know what, if she's saying these things to you, she's probably saying them to other residents, she's probably saying them to residents that might not have the ability to say something' and I'm like, 'It's it just shouldn't be happening' and that comment after a couple of visits, she was like, 'Oh, you're right if she is saying this to me, she's probably saying it to someone else.' With that then, she allowed me to talk to the Director of Nursing and with her permission, the Director of Nursing came down to her room on a day that that nurse was off so the other nurse didn't know that she was saying something to her and the Director of Nursing was *horrified* that this was happening absolutely *horrified* that this was happening. What they

ended up doing is they brought in people to talk about treating people with dignity and respect, they brought in someone to talk about sensitivity training with those who are overweight.' The obesity awareness training was provided to staff 'because of the retaliation that the resident was getting.' She added, 'Then they ended up moving that nurse off of her schedule. That nurse no longer cared for her and that nurse did eventually come back and apologize to this resident.'

When asked how it made her feel that she was able to resolve this situation, she said, 'Oh, you feel like you're the queen of the world, you feel amazing but on the flip side, those couple of visits where I was just hitting a wall…I wasn't doing anything…we were just visiting. I was reassuring her and making her comfortable. Those visits break your heart. You want to do well. You want to put your ombudsman Cape on you, you want to run in there, you want to save the day but she wasn't ready for that.'

Addressing The Name Tag Game

Representatives reported on a practice where care staff members do not wear their name tags or that they wear it but in a way that residents can't see their name on it (such as when the name tag is flipped intentionally or unintentionally (i.e., only the back of the name tag can be seen) or when the name tags are not elder-friendly when the font used is too small (ideally, it should be 14 point) and/or when the name is displayed on a background with weak contrast or when the name on the tag does not use dementia-friendly font type while caring for people with dementia. The DEEP Guide titled *Writing Dementia-Friendly Information*, recommends using 'an uncluttered font without serifs or 'curly bits' (for example, the guide suggests using Arial font type rather than Times New Roman).

In addition, in some cases, residents may ask a staff member for their name, but they refuse to give it to them. Just as we'd expect it in our homes in the community, people living in LTC homes have a right to know who is caring for them.

One representative said, 'They refuse to tell you what's their name is even if you proactively inquire.' The representative quoted a resident saying, 'I asked their name and they wouldn't tell me' or telling a resident with dementia, 'You remember me.''

It is important to ensure that staff wear their name badges and that they will wear them in a way that residents can actually see their name on it (as one representative said, 'They're putting it around' i.e., facing back) and seeing that nursing homes, Ombudsman representatives, and SSAs work to enforce this federal nursing home requirement.

Another representative said, 'If there is a situation where there is a specific staff member, getting the name of the staff member is the biggest tool because figuring out who is creating the problem…is there a problem just against this resident? Against multiple

residents?' She went on to say that it is sometimes challenging for residents to know the names of staff members because many don't wear name tags. She added, 'That's the biggest thing. If they can get the name of that staff member, *then* you can go to the administration and say, 'I think there's a problem here with this staff member.''

One SLTCO described how she handles these situations where staff do not wear name tags. She said that she sends a Zoom mail to the Administrator saying: 'It has come to my attention that your staff are not wearing name badges. I am letting you know right now that if I come in and somebody doesn't have a name tag on, I am going to report it to the Health Department. I don't want to do it but I will.'

She went on to describe how in one case she even involved the union to help resolve a situation where staff do not wear tags, 'I've been around long enough…and I have a good relationship with the nursing home…and they know that if I ask them something, they'll generally respond to it. And the ones that don't, we kind of know the homes that we're going to go in and keep [she didn't complete the sentence].'

She added that she and her colleagues are currently working on a situation in a particular care home where staff members do not wear name tags. She said that she told the Administrator, 'You know, your staff are not wearing name tags. They're refusing to put them on. Your staff are intimidating residents and not answering call lights. Let's work together to see how we can fix that.' She said that when the Administrator told her, 'Well, if you can think of what to do,' that's when I called the Union in and asked for a meeting and, 'I feel that getting together we can probably try to solve some of these problems.' She added that the federal nursing home regulations require staff to wear name tags.

Empowerment Through the Grievance Process

One representative spoke about the importance of empowering residents through education about the grievances process. She said, 'One thing that we've been trying to do here is, you know, we talk a lot about empowerment because that's what pro-seniors is all about…is empowering the residents…putting tools in their hands is the best way for them to protect themselves. One of the things that we've really been trying to educate residents on is filing formal grievances because it's not a complaint box, it's not just telling somebody, the social worker or somebody. You're filing a formal grievance and that means that the facility has to do an investigation on it but whether that helps with retaliation or not, it at least will alert the Department of Health. When the Department of Health comes in, they have to see the complaints…the formal grievances that have been put in place. That hopefully will stop further retaliations or things that are going on if there are truly issues going on but if the facility does their job and follows up on these grievances, then

hopefully it will resolve the issue and the residents feeling empowered and knowing they took care of the issue themselves. Those are tools they have access to but they don't always know about them.'

Another representative said, 'Grievances are very important. If a grievance has been filed, then there was a problem for that resident.' The representative also identified a concern, 'If they [surveyors] don't look at the grievance and they go by record of what's recorded in the resident's medical records or in the social services notes, they're not going to capture what you need. It's just my experience about it.'

A representative from another state spoke about the value she sees in using the Complaint Form / Grievance Form. She said, 'One of the things that I think is successful in dealing with this is having residents put down on a complaint form. Every facility is required to have a complaint, grievance, concern…whatever they can call it…form. When I talk to residents and I hear about this, I encourage them to try to write that down because a lot of times if it's happening to them, it's probably happening to other people on their hall or unit and I say this all the time, 'Not everybody's meant to be working in healthcare.' It is a tough job. You have to have the right temperament and the type of patience to work in that environment so using the complaint form or grievance form is a really great tool that we use or we try to empower residents to use because they could fill it out themselves to denote, 'Hey, on this shift a staff member blah blah blah treated me rudely by saying, 'I'm tired of taking her to the bathroom four times in a shift' or 'I'm tired of doing that.'' By writing that down, it does two things. One, it requires the facility to investigate. Any grievances or concerns filled out and turned in, it's the Executive Director's responsibility to investigate the situation and then provide some intervention whether that be retraining that staff…there's lots of interventions. That's one positive. It holds them accountable.'

She added, 'The flip side of that is that if they say, 'CNA Jones did this' and they investigate and then they address that with CNA Jones and ask her not to do that anymore and she finds out that that resident is the one that complained, then it kind of sets up a paradigm a little bit that, 'Well, then now I'm not going to take care of you because you complained to my boss' or whatever. It would not be uncommon that that a CNA would be relocated to a different hallway just to diminish that animosity between the caregiver and the resident.'

She then described the second value she sees in filling out a complaint form, 'The other thing it does is…the surveys when they come in and they survey the facility. One of the things they will look at or ask for the facility is those concern or grievance forms and they will look at them to see patterns…for lack of a better word…of where there are lots of complaints about staff being dismissive, inattentive…those kind of things because if there is a systemic issue or are they not getting that training at the beginning of their employment

and what they need to do or what is the best approach to things. Are they seeing it not just with this one CNA that the resident complained about…maybe there's two or three and they were all hired at the same time so the survey team can look at that more as a systemic issue to see where the patterns that you're seeing and what is the facility doing about it to try to improve that. I really like that form as a means of twofold.'

She added, 'But I also feel like that paper somehow symbolically gives the residents some empowerment and it allows them…or with the help of another writing it…to put down in words what they really feel is so egregious. Everybody's perception is their reality. How a resident perceived something may not be how the staff perceives it and can that [i.e., filled up complaint form] be used as an educational piece to get the staff to see it from the resident perspective. When you're a nurse and call lights are going off and you're trying to pass meds and this person needs this and whatever and Mrs. Jones wheels up and says, 'Hey, my stomach is upset. Can I get something for nausea?' And she just dismisses her or says, 'You're gonna have to wait with the other ones.' And not mean to be mean but she's overwhelmed and again…does that help the facility understand, 'Hey, we need to do a better job with staffing. Do we need to do a better job of in-servicing our staff? Do we need to have the Zofran which is what you get for nausea…do we need to have that not just 'as needed' but every day for this resident? We need to have it like a morning med every day for her.' Those are the things that that form *really* can lead to. I always say there's *endless* interventions that can happen when you fill out a complaint or grievance form and *that* to me is the *powerful* part of it. There are endless interventions that can come from that.'

Quote
"*There's endless interventions that can happen when you fill out a complaint or grievance form and that to me is the powerful part of it*." – Ombudsman representative

When asked whether in her experience Administrators see the Grievance Form as a friend or a foe, she said, 'It depends on the Administrators themselves. I always say, 'People's moral compasses are not always pointed in the right direction or the *same* direction.' I think a lot of it depends on that and I also think sometimes the corporation or the management company who manages or employs people for the facility….what is their bigger focus? Is it dollars or is it resident satisfaction or employee satisfaction? I think those agendas really determine whether the complaint form is used as a quality assurance or is it used as, 'Well,

another thing we've got to fix.' Again, that varies amongst…there's seems to be no 'tried and true' for that, for me, as far as this person does it this way and that person does it that way.'

As recognized by another representative earlier, a representative from another state said that depending on the nature of the complaint, pursuing a grievance can sometimes identify a resident when they don't want to be identified. The representative said, 'It depends…sometimes it can if it's very specific. If you're filing a grievance because of your diet, that's something that's very specific to you but if you're filing a grievance because the heat isn't working in this side of the building, that could be a bunch of people…so that could be a way to do it so it's really going to depend on the situation.'

Advice for Residents Fearing Retaliation

Representatives were asked whether they have any words of advice to residents fearing staff retaliation when voicing care concerns. They responses are presented here:

One SLTCO spoke about the value she sees in peer support, 'Residents can support each other in de-stigmatizing the coming forward. People are stronger together. Saying, 'I heard [de-identified name of care employee] spoke to you that way. I will go with you to talk to the Administrator, to talk to the Director of Nursing Services. I heard it. That's not okay. That's not acceptable. We don't have to accept that here.''

After speaking about the importance of finding a care employee the resident trusts and getting them involved, a very experienced representative said, 'Encourage people to talk to the Resident Council President because that person can bring a generalized complaint to the council or to the departments' heads without identifying anyone.' When asked if she has anything else to add in terms of advice for residents, she said, 'No. I talk about rights and empowerment but as far as *actual action* right now, is usually the connecting the people to people…the support system in the facility.'

When asked what advice she has for residents fearing staff retaliation, a representative from another state said, 'I think talking to somebody they trust…again…speak with other residents, 'Hey, are you experiencing this too?' and reviewing the residents' rights for abuse, neglect, and exploitation…those things.' Her colleague added, 'Sometimes depending on the circumstances, I might make sure that the person is aware that they do have the right to have a camera in their room…that would be something that might help them feel more secure and safe.'

Representatives spoke about how they encourage residents to speak up. One of them said, 'Part of my role is to make sure residents are getting quality of care, good quality of life and that there's no violation of their rights. So really just getting them comfortable with me and letting them know that it's not okay. If you are living in an apartment and you felt your

landlord was retaliating against you, you'd want to say something because this is their home. This is likely where they're going to spend the rest of their life.'

Another representative said, 'Get the Ombudsman involved.' Her colleague added, 'Because we go a long way....we can do a lot for those residents....I always tell them, 'It's your right to complain. This is your home.' I always tell them they have the same rights I have in *my* home. And having been left soiled for two hours, is just not acceptable.' The first representative added, 'We always tell the residents, 'We are not here because we want the facility to get in *trouble* and to call state regulatory and get fines. That's *not* our goal. Our goal is to get a resolution for *your* problem...right here, right now.' Her colleague added, 'And have the best quality of care and quality of life that they deserve.'

Quote
"I always tell them, 'It's your right to complain. This is your home.' I always tell them they have the same rights I have in my home." – Ombudsman representative

Another representative said, 'I just let them know what their rights are...that they really need to be treated with dignity and respect and to have a say about all things with their lives while they're living there. And just to let them know that there's support available to them should they feel like they ever need it or want it...whether that's through regulation or licensing or Ombudsman or maybe getting better connected with somebody in the facility management who can be an ally for them. And just let them know that they do have some choice. That that's really the goal here...that they have choice and even if that means that they want to have a different caregiver, that they do have that option in some situations most of the time. And then, just let them know that they can bring up these issues also just not as a stand-alone but during established care meeting or something like that...could be a great time to do that [missing word] on their own.'

A very experienced representative from another state said, 'Residents are in their homes. We are guests in their home. Residents are able to remind staff that, 'This is our home and you're a guest here so you're going to treat us with dignity and respect in our home.' And staff back off if you are very vocal...residents really drive it home that, 'We've got somebody outside of this door that can help us if things don't go the way they should.' They are referencing their advocate. Because I am a very *strong* devout advocate. Nursing facilities

are going to respect the residents in the facility as long as I have breath in my body to make certain that their rights are being protected.'

In the last minute of the interview, this representative referred to a campaign called 'Speak Up' (developed by the Joint Commission) and added, 'My last words to encourage residents to speak up on behalf of themselves and have them understand, 'If there's difficulty for you, you've got a buffer outside those doors and you've got resources.''

She explained, 'We are the buffer for the residents. We consider ourselves as a *resource* outside of those double doors that they have *complete* access to. So we want them to utilize their autonomy. We don't want them to be thinking, 'We're not going to call Mrs. [de-identified name of representative].' Mrs. [de-identified name of representative] does not mind you calling her. Because if you're calling me, there's a problem. So we are the buffer for them and we encourage them to call us.'

Another representative said, 'Know your rights. That's really important. Gather support from other residents so you're not alone in this. If it's happening to you, it's likely happening to other people. So let's gather support because while they might not listen to one person, they're going to listen to 10. Have the support of your Ombudsman. We are here to help, we are here to support, we are here to advocate for you so have the support of your Ombudsman. Be vocal if you're comfortable with that. Be vocal. Bring it up at Resident Council. Those are other avenues when you don't want to be the person at the podium talking.'

One representative advised, 'File complaints. I always tell residents and families, 'Hey, if you don't talk about it, it is not going to go away. You know, Just because you don't talk about it, it doesn't mean it's going to go away. You have to file a complaint with the state. You have to keep talking about it. I think it's important that people talk about it. They need to tell somebody about it. When something is happening, you have to tell *somebody* about it. If you don't tell the Ombudsman, tell your family, tell somebody what's going on.'

Quote
"*If you don't talk about it, it is not going to go away*." – Ombudsman representative

An experienced representative said, 'I often encourage them to report incidents immediately. If you wait, then it's less likely to be handled. But if you go ahead and address the situation…and that's part of that communication…'It bothered me. I've experienced this.' So addressing it as quickly as possible.' She added, 'I also encourage residents to be kind to their staff, to thank them for a good job, to encourage behaviors that they want to see in staff as well as themselves. That it can go both ways. But to make sure that when they are experiencing retaliation, that they are reporting it to the appropriate staff.'

Another representative shared that as part of The Peer Program, they teach residents what they call 'The Ladder of Resolution.' We tell them, 'Start at the bottom of the ladder. You don't want to miss any steps going up there. Start low. Start with the people that can actually help you…if it's a CNA that can help you.' We don't want to run to the Director of Nursing if the CNA can help you.' She explained, 'If you continue to work your way up the ladder, by the time you get to the top of the ladder, then most times the situation that was not ideal to start with, you're able to resolve it.'

Taking One Concern at a Time

While this may depend on the circumstances, one representative said that at times it's helpful to address one care concern at a time rather than many simultaneously.

The representative said, 'I think it is effective sometimes to…and again, this is specific to…is the resident able to do this in that situation safely and or is the staff responsive, addressing one concern at a time. If you are really hot and come out at them with 20,000 things that the staff have done wrong and this and that and the other, and it's awful…and I am not saying it is great because we know it is not great in many facilities. If you work on one thing at a time versus 17 things are wrong and now you're labeled as that resident who is never happy. So if we can address the most critical safety-related or care-related concern and, you know, it is all in that approach. I've seen that being successful.'

When asked about what may be the downside of voicing 10 complaints at once, she said, 'They may not all be heard…unless you've written these 10 complaints at once, the note taker or the recipient of that message is not going to fully address or be able to pass those along and/or depending upon who you've chosen to share that with, maybe that is not their role in the facility, maybe you've told the custodian that you want your medicine at a different time and they're not able to effectively advocate for you in that role.'

Coaching Residents on How to Communicate Their Care Concerns

Representatives spoke about how they guide and coach residents in conveying their care concerns and complaints in ways that may increase the likelihood that staff and managers will be more receptive to listening and addressing them.

One of them said, ‘We tell them to be assertive and not aggressive. Everyone is going to respond better to someone that is sure of what they want, is positive about how they’re going about it versus someone that’s yelling and screaming. That they continue to nicely but assertively ask for what they’re wanting…what the issue is.’

An experienced representative said, ‘Encourage what they’re doing right. When you go in and you have some issues, you can say, ‘Look, you’re doing so good in this area. This is just one thing that I have an issue with it.’’ She explained, ‘It almost lessens the blow of a bad thing when you kind of coat it with a bunch of great things that the staff are doing and share, ‘You know, this is an issue that I had today.’’

Another representative shared a **story** about a physically disabled resident who was fearful of retaliation related to her wish to have the staff use a stand lift and not a full body lift for transfers. She said, ‘I’ve been working with her on how to get that across to staff and finally she goes, ‘I told that aide, ‘I know my body better than you and you need to do it my way’ and she seems to be getting things better. They are not pushing the full body lift anymore but it took her standing up and saying, ‘I am done. You gotta do it my way.’’

When asked if there was a thread of retaliation in this incident, she said, ‘I'm sorry, that was kind of the point…the staff were like, ‘No, you need to be in a [full body] lift. You cannot do a stand lift safety. You have to do it.’ And she's like, ‘No, I don't. You're not listening to me.’ She had been fighting with the retaliation of *threat*. They were threatening her nonstop about, ‘You can't do this. This is not safe.’ And she said, ‘But it would be if you did it my way.’’

Residents’ Approaches

When asked about residents’ approaches that are effective in addressing their fear of retaliation when voicing care concerns, an very experienced representative responded at a general level, ‘There are some people whose natural personality is little more outspoken and bold and they are just willing to take the risks or they got to the point with a particular problem where they almost felt like it couldn't get worse so that they were willing to step up but I do think it takes a very particular kind of bold personality that is willing to kind of confront the situation without fear or with an expectation that they could have an experience that could be adverse around it but they were willing to step forward.’

Another representative spoke about residents who take a business-like approach to addressing their care concerns. These individuals systematically document their concerns and then use the information in support of their advocacy. She said, ‘I’ve had a few residents who have treated it almost like a business plan. These residents write everything down, they take notes, they take names…so the resident, ‘These are the facts. I wrote them all down. This is what happened, and this is what I want to see done.’’

She added, ‘It is that resident with that feisty approach. They just take matters into their own hands, but they might need someone there…maybe me or one of the staff to help them along. So when you tell a resident, ‘How about you take a few notes about what you see happening and then we can sit down with the staff here and talk about it?’ And they are like, ‘I’m in.’’

That said, a representative from another state said that this business-like approach can sometimes result in a negative response. She said, ‘We get that quite often where they document day to day, time, people, what they’ve done and unfortunately what happens is for those persons, they then get *labeled*. Meaning they’re labeled as somebody who is a chronic complainer, they’re labeled as somebody who is looking to get staff into trouble and it becomes a head butting type of situation where the facility staff don’t want to change and the resident keeps pushing on trying to get their point across. We’ve had many cases like that where we’ve mediated…that we have had staff in the room, the resident, family members, and let’s talk this out and how can we resolve this so that we can all move forward from what has happened. Sometimes we are successful and other times neither side wants to budge. Yeah, we’ve gotten that more times than I’d like to count that we’ve gotten reports, you know, this date, this time that so and so said this or did this and they continue to send this to us even after issues have been resolved. They’ll go back years and years they’ll be sending us either text messages or emails or written information that they felt. It’s unfortunate but those residents get labeled as ‘very difficult’ or ‘challenging’ and, ‘They’re looking to get everybody fired.’’

The representative went on to share a **story** about another resident who she described as ‘very challenging’ and who had ‘a litany of complaints’ and ‘she was a person that wrote down everything’ and ‘there was always a little bit of truth’ in the care concerns she expressed. She said that ‘it got to a point that she felt like nobody was listening to her.’ She even ‘started having other residents call with complaints with her standing there of course coaching them.’ The representative said that ‘we opened an investigation and we went back out there and investigated those concerns.’ She described how she approached the situation, ‘Now, when we have something like that, then we kind of do a more of a broad scope within the facility, then we're looking it up, we're talking to other residents, we're talking to the President of the Resident Council, we're talking to other units, family members if they're there, we're kind of interviewing them randomly and privately to kind of see again is this an isolated or is it a pattern.’

Another representative shared this **story**, 'I know one resident that had a lot of grievances. He didn't hear about the Resident Council. I am not sure if people were intentionally not having him on the Resident Council but he became the President of the Resident Council and even the facility gave him a little tag as 'President' and they gave a little tag for the 'Vice President of the Resident Council' with their names. It was a source of leadership and it was a source of outlet and not to say that his grievances were not true but it gave him an outlet. I would hear *less* of the complaints because they were dealing with them in the Resident Council. It empowered him. I admired him for, 'I am gonna go' and he on his own was able to win the crowd and became the President and all that good stuff.'

When asked about effective residents' approaches, another representative shared the following **story**: 'I think just a resident beginning to be part of a Resident Council. Stepping in to be the President of a Resident Council to advocate for everyone else in the building. This resident experienced retaliation…it came from management and management was let go and after that, with a new management, she became a Resident Council President. It just gave her an opportunity to be a voice for others and encourage others in the facility to stand up and voice their concerns.'

A representative from another state shared a **story** about a resident who was very physically dependent on care staff for meeting her daily care needs. The story describes her transformation from being labeled 'the complainer' (her complaints revolved around 'long call light waits') to becoming the President of the Resident Council. Beyond her other advocacy efforts, this resident also invited a legislator to visit the care home. The representative said, 'I have a resident who had a lot of challenges and barriers ahead of her because she was kind of known as "the complainer" so she already was kind of pigeonholed with that label. That made it harder for me to help her address issues.'

She went on to say, 'She was a great advocate. In fact, she became the President of the Resident Council and implemented closed door meetings where they would all meet together and then eventually invite the staff in and kind of go through the complaints which really helped with anonymity on the other residents side…that kind of gave them comfort to voice a concern and know that it would be kind of voiced as a general resident concern with no names attached so that was nice. She just had issue after issue and eventually kind of went invited a legislator to come and visit the facility, which he did…talked to a couple people in the media who wrote some articles and made visits and kind of brought a different kind of a spotlight to the issues there…in addition to obviously working with the state inspectors and working with our office…they worked with our [Personal Needs Allowance] group [and] Disability Rights [de-Identified state]. She was shaking every tree that she could. I don't know that things were ever really resolved to her satisfaction. I think

things did get better for a while but then it seemed like they always kind of slipped back into bad patterns. She wasn't afraid though to continue to advocate for herself.'

She added, 'She had certain times of the day where she wanted to sit down on the commode and she would sit there for a long period of time but she kind of had it timed so that it worked with her schedule and her body. It was a challenge, I mean, it's not like they can be there right there at 2 o'clock on the dot…so kind of managing expectations is the part of the conversations that I became involved with too with the resident, with the staff…and 'Let's talk about realistic expectations and put together a plan and what that might look like' and there might be days where there's some emergency or somebody fell or somebody went to the hospital where right at 2 o'clock or between 2 and 2:15 it's not going to happen.'

This representative added that key to her intervention was her involvement of a person from the corporate office after the Administrator was not cooperative. She said, 'I went up the corporate chain and I said, 'Okay fine, this person is not working with me,' I found who that corporate person was, I pulled that person in, they got involved…they started sitting on in our meetings. They seemed to be helpful [moved head slightly from side to side indicating more or less] and that person started working with that person as her person to let them know, 'Hey, this isn't [getting] resolved' because it was kind of a hamster wheel of issues…like things were getting better for a while and then they'd slid back. So, anyway, then she had that lifeline to connect with that corporate person. It did seem as though things got better once we involved corporate.'

For other examples of representative's strategy of involving corporate office in efforts to resolve care problems, see segment titled *Involving Corporate Office* later in this chapter.

A colleague of the latter representative shared a **story** about another resident who advocated for himself after his power chair was taken away from him in a residential care home. She said, 'I'll throw an example for a resident's approach that was effective. Once in a while, we get calls from individuals who have lost use of their power chair…motorized wheelchair. Facility staff might take it away…maybe they were "unsafe" [said the word unsafe with hands' gesture indicating quotation marks] for some reason. I had a resident who was fairly independent living in a residential care facility level of care…so little less than a nursing home…different than assisted living but that resident knew why he needed that chair back and was ready to fight for getting that chair back but was also fearful that if he got three strikes, he wouldn't ever get that chair back again and so didn't want that because he had multiple disabilities that just strength wise couldn't use a manual chair to get around the facility. And this person through advocacy with myself involved, looking into the facility policies and procedures, and after he had worked with going to the

administrative staff versus the therapy staff who had taken the wheelchair away, the administrative staff actually saw a different perspective and we were able to build our case as to why this person needed this back, why the previous incident took place, and that person has their power chair back…and fearful of maybe losing it in the long term but knowing that they shouldn't have lost it in the first place and so speaking up about that.'

She explained why they took his power chair away, 'I think it was that the speed was too high traveling in the hallways with other people. Meaning, they thought it needed to go slower…he was going too fast. I think one time he had been outside and gotten off the sidewalk onto the grass and that was another reason that a staff person had reported that he lost it for. So this resident was able to say, 'I am going to explain to you why I did that that day' or 'My chair does have a governor on it and it doesn't have to go that fast and I am willing for it to go that fast so could you meet me in the middle? Could we have a compromise?' And they were able to come up with one.'

A representative from another state shared a **story** about a resident in 'early signs of dementia' on a 'memory care unit' in an assisted living. She said, 'She was a complainer. She would always make complaints.' She complained 'that they weren't helping her enough' but 'they didn't believe her complaints.' The family called the Ombudsman program because it was getting worse. She said that her complaints were getting worse and she was not happy anymore and she doesn't want to live there anymore.

She added, 'So she quietly put multiple cameras in her bedroom. She said that she discussed it with the resident and then the resident asked her family to place the cameras the bedroom. The family sent the video clips to the Ombudsman representative who watched them. She said, 'It showed that some staff needed additional training in dementia care.' She explained, 'Because they would try to get her out of bed when she didn't want to get out of bed and then she would throw things at them but from the footage that I saw, she started throwing things after *three* staff members came at her to try to get her out of bed after she said she didn't want to get out.' She added that the staff members wanted her to get out of bed in the morning, get dressed, and go to breakfast.

The footage also showed that 'other staff retaliated against her by eating her food ('they were eating her strawberries') and wiping their hands on the couch. It was caught on camera.' She said that on the footage 'you see staff members going to her refrigerator, sitting on her couch while she is laying right there on the bed, eating the food in front of her, and then wiping their hands on the couch…from the strawberries. I feel like they're instigating and making the resident angrier by going into her refrigerator and eating her food and taunting her more.'

Another approach used by residents and considered by representatives as effective included residents texting or emailing their concerns to the Administrator and 'they cc me on it.' One representative shared her thoughts about this strategy, 'You'd be *amazed* at how much stuff gets done because they don't want us coming into their building.' She added, 'All they need is our email and text and things will get resolved.'

She said, 'Those Administrators, Social Workers, and Directors of Nursing, they get the texts and I've even have them text, 'Who is that third number?' or 'Who is that fourth number?' and then I will text back, 'It's me [de-identified name] the Ombudsman.' I am *amazed* at how much stuff [gets done], 'Well, fine we'll go give them a shower' or 'We'll do this.' I think I have about 20 residents that I will get random text messages and I have discussed it with these residents, 'Do you want me to ever intervene?' and they'll reply, 'No, this is good' and 'I think it's going to get resolved.' They'll call or text 'if we need to see you' but I've been amazed…all they need is our email and text and things will get resolved.' She added that 'families will do that a lot too. Families will send out an email and they'll put us on it and that's very effective too.' Representatives from other states also shared that residents email their Administrators with care concerns and cc'd them.

One SLTCO described what she sees as the value of this strategy, 'I think it's good because it could help guide the response because the Administrator knows someone else is watching. I receive some of those emails.' She shared her belief that Administrators take care concerns more seriously when an Ombudsman representative is cc'd on the email.

Other representatives reported that some residents try to advocate for themselves by calling the media (e.g., 'We've had residents that have reached out to the media'). In a recent case in Connecticut, a nursing home with a troubled regulatory history neglected the care of many residents. The representative worked closely with the President of the Resident Council (documenting care concerns and putting things in place) but the care home was 'not listening' and the care didn't improve. The representative asked the President whether they wanted to speak with the media. They agreed. Along with a state investigation that confirmed many of the allegations, the newspaper article resulted in some improvements in residents' care (Altimari, 2023).

Another resident's approach was described by a representative from a different state. A physically disabled resident started a TikTok channel after experiencing neglect and staff cruelty. This is how she told the **story**: 'There are residents that are *very very* vocal and unafraid. When someone is threatening to them, they don't mind telling *everyone*. Well, I did have a little situation. It was in our very urban area…we had a younger gentleman that was very disabled by an accident and he had very limited use of his body without assistance. However, he felt and was not receiving the treatment he needed. Staff

members were *very very* cruel to him verbally. They felt he was demanding and different things. He started his own TikTok network and he would film them when they came. He has his own TikTok *channel* that he posted life in a nursing home…and I thought Oh my Gosh. He was not afraid…let me tell you that and he was bringing it to light and he would say, 'If you continue to do this, you're going to be on screen' and they were.'

She said that he used his cell phone to film staff abuse and retaliation against him and then he would upload it to TikTok. She added, 'He had very limited use of his body' so 'he had it all set up with these devices to hold his camera so he just had to touch it, but in retaliation, they would take his phone. They eventually discharged him.'

She said that the reason for the discharge had to do with him using TikTok to film staff members, 'That's my take on it. They discharged him and the reason was…the health, safety and welfare of the residents in the facility was [missed word] and they said…it was an elaborate story…that he was [de-identified personal background information] and staff was afraid to go to the parking lot…he was having people come up there…and actually, I think people [the public] that were so *enraged* by what he was showing, did make calls to the facility and staff but he actually moved to another facility outside of our area.'

It is important to recognize that in some cases this or similar actions by residents may result in threats of retaliation or actual retaliation against the residents such as in the form of involuntary discharges. While residents' frustration about their care and mistreatment is fully understandable (residents' may suffer tremendously from neglect and abuse, become desperate, and reach a breaking point), it is important to take into consideration the potential consequences of taking photos and filming people in the care home and posting them on social media platforms (examples of issues include informed consent, privacy, confidentiality, and dignity issues). This issue is recognized here given that this segment primarily focuses on residents' approaches representatives consider as effective.

The example that follows may or may not illustrate an effective approach and in some cases it could be harmful to residents. Working closely with an Ombudsman representative in these situations may assist residents in making good decisions that will increase the likelihood that their voice will be heard, their concerns will be adequately addressed, their care needs will be met, and they and other residents will remain safe.

One representative shared, 'I am seeing something relatively new in the last couple of years since COVID…is a handful of people every week where the pendulum is way on the other side where they are using their cell phone video capabilities…going out and taking videos of what's going on in the facilities, what's going on in the hallways but particularly on the

weekends when there's no one around. They'll take a view of everything and then they'll post it on the Facebook page or on TikTok or what have you.'

She added, 'Not everyone in the facilities is old, not computer savvy. Some people get really desperate to get attention to the situation. So we're called in usually by the facility and say, 'Stop that person' basically or 'talk to that person because that's not appropriate.' There's pictures of residents who haven't gave approval to be in that video.' That type of thing. And I like to say, 'The squeaky wheel gets the grease' but they're also the first ones to be replaced. So we have to tamper down a little bit some of the over enthusiasm. It's almost a fearless type thing. They're fearless.'

Quote
"I like to say, "*The squeaky wheel gets the grease" but they're also the first ones to be replaced*." – Ombudsman representative

She said, 'Tying it back to the phenomenon is that they hit the threshold. I am tying it back because they in essence trigger some type of retaliation for their actions.

She added, 'I understand their frustration and their aggravation and it mostly has to do with showing empty hallways, nurses' desks that have nobody, things that indicate that. They'll say something like, '2 o'clock in the afternoon on Sunday. Here is what I am finding in the facility.' Going through…either walking or in their wheelchair and taking pictures of no staff anywhere, that type of thing. And they do get caught and then we have to deal with the retaliation of that…taking that down and usually the Administrators are very angry at that point…for their PR purposes or whatever.' She said that some of these videos are still out there on the internet (such as You Tube) as 'the facility has not caught up with yet.' She went on to say, 'They're trying to get the power back. Some kind of leverage. You can say all you want but a picture…that whole thing is worth a thousand words.' She added, 'And as you know, we as Ombudsman are not allowed to do any kind of photography…kind of videoing in the facility.'

When asked whether some residents experience retaliation in response to posting these videos on social media, she said, 'I do. I think the people that are doing it have nothing to lose by it. I think they hit a wall. Oftentimes they are definitely not the private pay residents that are doing it. They're on Medicaid, they tend to be younger, M.S. patients, long-term chronic patients. They just say, 'I can't live with this the next 5, 10, 15 years.' They put

themselves as risk for being moved into another facility potentially and that's something we have to be very mindful of. I just wanted to indicate that there's a new trend out there. They're mad and not going to take it anymore kind of thing.'

Resident-specific versus General Complaint

In general, representatives spoke about the distinction between two types of complaints and how each may sometimes lend itself to a different approach. One very experienced representative explained, 'I try to explore different ways of addressing the topic or the problem that might not have to involve individual identification of them if that's possible. We all know that some complaints lend themselves more to that type of approach than others.'

She gave an example, 'If somebody had a medication complaint that they were supposed to get a medication at a specific time and it was a specific type of medication, if we're going to bring that forward, that isn't something that we can kind of lose in some kind of an anonymous report. That's going to be very specific to that individual and very specific to a time and a date and maybe even something that can then be connected to who that individual was that did or didn't do what they were supposed to. That's something I can't guarantee a resident that I could dilute in sort of a bigger general report but if they're talking to me about maybe a food complaint that…maybe some specifics are that it's breakfast, I can probably try to figure out a way to report or get some attention toward that complaint without identifying that individual because everybody eats breakfast and generally there could be a wide range of people that would have the same concern or problem related to breakfast. So those are the two things. If there's a way that I can generalize and work on a problem without identifying the person, I would try to do that to alleviate their concerns about fear of retaliation and if I can't, I will be very honest with them that this situation, if we were to take it forward, it is gonna identify you and the very specifics of your concern.'

General Complaint. Several representatives said when a resident does not give them permission to intervene or when the resident gives them permission but without permission to use their name, they will try to find out whether other residents have similar concerns. If they do, they may decide to pursue it as a General Complaint (also referred to by some representatives as a Group Complaint).

One representative said, 'The first thing I would do is I would try to find other residents who may be having that issue…because at that point [i.e. if other residents have similar concerns], I could address that myself as a Group Complaint.' The representative emphasized, however, that 'you have to learn how to do this without walking into a room and say, 'Hey, somebody down the hall said that they're scared that so and so staff

members are retaliating against everybody. Have you been retaliated against?' You can't do that. You have to be more gentle. You have to work your way into it.'

She added, 'Technically, at that point, you're advocating on behalf of that group and you don't have to reveal any information. If I didn't get other people, then I would go to whomever I am going to talk to…the Administrator, the Director of Nursing…whatever and I would say, 'Listen, I have received a complaint about retaliation by staff members in general. You might want to do some staff training. Maybe, if I felt comfortable, I would say, 'Especially on B Hallway or East Wing.' Something that gives them a little something to go on. If I am comfortable that that won't give it away.' The representative recognized that 'it's very much' a fine line because if the complaint is unique enough, staff could figure it out.

Another representative said, 'It's case by case situation….but if we do have something and the resident is fearful of retaliation, we can see if it's something we can address for *all* residents. Is it something that's happening to all residents that we can look into where this particular resident's name would not need to be used so they didn't have to fear retaliation?' Her colleague added that they can then pursue it as a General Complaint 'and see if this is a systemic issue that we can deal with it that way. We do that a lot so that the resident doesn't have to give that.'

A representative from another state said that when a resident tells her that they don't receive the care they need but they don't give her permission to use her name, she uses a Geneal Complaint. She'll do it 'especially if it's about care, we can address it. It can affect all residents…care can affect all residents…and if this resident is being affected this way, more than likely there's more than one resident being affected. Just because they don't want to speak up, doesn't mean it's not going on…so we do try to address it.'

Quote
"*If this resident is being affected this way, more than likely there's more than one resident being affected*." – Ombudsman representative referring to lack of provision of care to a resident

When speaking about the importance of anonymous complaints, another representative spoke about using a General Complaint. She said, 'If a resident is afraid to say, 'I am not getting my showers. I am only getting showers once a week and I am on hall 400. If you mention my name, maybe I won't be getting showers at all.' Or maybe it's been two weeks. I

can say, ‘I don’t have to mention your name.’ Again, ‘You’re my boss. But what I can say is…as I am walking through…I am not only going to go into your room. I am going scattered through this whole facility and I’ll bring information back to leadership, ‘400 hall…I am hearing that showers are not happening at least twice a week.’ Maybe your corporation is offering it three times a week but I am hearing maybe only getting them once a week. I am suggesting you’d do an In-Service education to make sure you’re doing what federally or state you’re supposed to be doing but also to make sure that the residents are getting the best care because I know that this is what the staff is called to do and that’s what you’re here to do. I appreciate what you do.’ I always try to do ‘positive, negative, positive.’ But I want the staff to do an In-Service about showers, better care. That’s what we want.’

A representative from another state spoke about her efforts to identify if there’s a pattern of similar care concerns experienced by different residents. She said, ‘What I’ve done in all my years in investigative work…when we get either a family member that fears retaliation or we have residents who are very fearful, what we do is when I go into the facility, I interview *several* residents and I just randomly pick persons to talk to usually if it's the family member that fears retaliation, they'll give me the room number so that I can at some point get to that room so that I can interview that resident particularly and what I tend to look for when it is a fear of retaliation and they don't want their name mentioned, I'm kind of looking for a pattern whatever the concern is. For example, ‘The overnight shift…my call light doesn't get answered at all. They don't answer me at all.’ Then what I would do is I pick that unit, interview those persons, kind of find out the response time, how they feel it, are they having issues on a particular shift and kind of walk each person until I can get to the overnight shift to find out if it is a problem for them, if it's a problem for more than one resident or if it seems to be an isolated issue occurring for that resident.’ She explained that she can then pursue it as a General Complaint without singling out particular residents, ‘Because then if I see a pattern, what I can report back to the facility is, ‘You have a problem on this unit with your overnight shift not responding to call lights.’’ She added, ‘Then they’ll say, ‘Well, we’ll do in-servicing on that shift or we’ll pull call light bell report to see how long it has taken them to answer call lights and then what I would do is I would circle back to the family member and or to the resident depending if I can get them directly without having to go through either the receptionist or the nursing staff and I’ll find out, ‘Hey, did it improve?’ If it didn’t, then it’s another conversation to have and or we make a referral to the licensing agency that this is happening and this is the impact it’s having.’

Another representative said, ‘One thing that we focus on is our scope work which means we have to talk to other residents too and by doing that, it gives us more power…more information and ammunition as we go and talk to administration, ‘Listen, there’s a problem here because I’ve got four or five residents that are not getting their shower, they’re afraid to

speak up…we've got an issue going on here.' We can even give like a certain part of the building…saying, 'There is an issue because there's a certain aide that is creating this problem.' By having that extra bit of information, it does take the pressure off of one resident feeling like they're being retaliated against. Saying, 'We've got a concern here. There is a problem because this whole area is not getting their showers and they don't speak up about it.''

Another representative described how she handles situations where residents seek her assistance but ask not to be named. She referred to situations where the resident has dementia and they or their family request not to be identified. She said, 'When I am aware that somebody has those fears, there will be times where I will say, 'Okay, I am not going to use your name.' I may be going to the Administrator and say, 'I spoke with a couple of different residents who have expressed this concern' or I'll call and say, 'We received a number of calls regarding this going on in the facility' so that they really can't pinpoint it to one resident or a family member.'

Telling Residents That Other Residents May Experience Similar Issues

One representative said that she sometimes tells residents who are reluctant to pursue a complaint against a staff member that other residents may experience similar issues and/or mistreatment from the same employee. She shared what she told one resident, 'You know what, if she is saying these things to you, she'd probably saying them to other residents. She is probably saying them to residents that might not have the ability to say something.' She said that her statement has led to a positive breakthrough in her advocacy for this resident.

Another representative said that she typically doesn't feel comfortable telling residents who are reluctant to give her permission to intervene that giving permission may assist other residents. She said that it may unfairly exert excessive pressure on the resident and added that she gives a lot of thought before using it and that she doesn't use it often.

She shared this **story**: 'A resident voices a concern to me and is fearful of a staff member and that staff member provides care and the resident might tell me, 'You know, she almost dropped me when she was helping me do A, B, or C. Well, she's fairly new. She probably hasn't had a lot of training' etcetera…are very willing to dismiss it. Well, then I do get permission and it's a matter of sometimes…and I hate to use this one but maybe her training is not where it should be and other residents could be affected…I hate to use that…but sometimes you have to and they'll think, 'Why…I wouldn't want anybody else to get word.' It's not what you want to use but sometimes it's a matter of going to the Director

of Nursing and saying, 'This resident does not want this CNA working with her for these reasons and that CNA will get reassigned and that's a very simple one.'

The representative said that she doesn't like to tell residents, 'By you reporting could help other residents' so they are not affected by someone who maybe doesn't have enough training. It's almost like a guilt and I don't want residents to feel it.'

She added, 'I don't use it very often. It's like a last last resort that you might be protecting others…and that's something they had not even thought about, 'Oh, I guess. I have not even thought about that' (referring to other residents who might be negatively affected by the same staff member). She said that when residents respond to her statement by saying, 'I never even thought about that,' it is 'because they are so wrapped up in their own possibility of retaliation.' She reiterated, 'It just doesn't feel good' and, 'There is another way that I could be doing it. It could be without using any resident information. Like I could go to the Director of Nursing and say, 'I just want you to be aware that there is a concern about a CNA who may not be fully trained. There may have been an incident that you may not be aware of that the resident is not willing to share. Maybe that person needs a little bit more training.' I could also do it that way, which I have also done.'

Harnessing the Power of Individualized Care Plan Meetings

Many representatives spoke about the importance of Care Plan meetings as a vehicle for change in addressing residents' care concerns, fear of retaliation, and actual retaliation. In addition, several quotes illustrate some of the ways in which representatives' presence in Care Plan meetings may change the dynamic in the room and the outcomes (though variation and exceptions on the latter issue were also conveyed by certain representatives).

Resource Box
What is a Person-Centered Care Plan Meeting and Why Are They Important? Educational video developed by Connecticut Long-Term Care Ombudsman Program

One very experienced representative said that using a group complaint works 'really well' when 'it is an across-the-board issue…when it impacts large numbers of people but when it is a real specific issue for one person, that's impossible to do, care planning is huge for residents. This is a normal thing that we do in facilities all the time…it is not asking them to do anything crazy, 'We can all get together with you and the team here and I'll be there. We

can bring the family or whomever you want there and have this normal process in the facility to try to talk about what is happening so that we can bring some resolution.' So if we can normalize some of these processes that are used in long-term care, that can work.'

She explained, 'We try to develop interventions that normalize things like having a care planning meeting at the facility with the resident. This is something that happens every day here in the building…so maybe that's a tool we can use to get this issue resolved for you…where it is not just me going into the Administrator…this, that, and the other thing but we can do this *together* and talk about these issues and put a plan in place.'

She added, 'It is a normal process that happens all the time in facilities but I am not always there at those meetings…so that changes the *dynamic* sometime.' She went on to say, 'I've had enough people say that those meetings are different when I am there or when the Ombudsman staff is there. You know how people act differently when they are being watched?' She said, 'It helps so that the resident is heard in that meeting and has a voice. Facility staff are more willing to listen when we are there because someone from the outside is present. And they know because we use our presence as our superpower…that we are not going away…we're going to come back and we're going to check to see how it is going. And maybe we need to have a follow up meeting.'

When asked whether when they sit in Care Plan meetings the dynamic in the room and/or outcome change, a representative from another state said, 'One hundred present.' Her colleague gave an example, 'We're always present in them but sometimes I've been in these care plan meetings and there's a Director of Nursing which is the problem and she will pretty much come across the table at some of these residents and I'm just like, '*Lord*' that this just happened.' We're there and we need to de-escalate the situation sometimes. I've even had to say, 'This is *not* acceptable behavior *at all*.' It's crazy but yeah, it definitely does have some barrier when we're there…no doubt about it.'

When asked what could happen when representatives are not present in Care Plan meetings, the first representative said that they'll talk about discharge, 'We might not be able to meet your needs,' they'll say that stuff to them. Or 'If you don't like it here, you may need to find you another place to go' instead of, 'Let's work on the problem.' They're real good about that.' The representative considered these statements as threats.

Her colleague added, 'That's their go to, 'We can't meet your needs any longer' is what they always allude to…always, 'We can no longer meet your needs.' And, 'If you don't like it, then basically there's the door.' And, 'You can go someplace else if you think the care is going to be better.' They'll say it in these terms in these words too.'

A representative from another state shared a **story** about a family who believed staff retaliated against their loved one because the family complained about her care and how Care Planning helped improve things though only temporarily. She said, 'I was working with a family that had very involved siblings and the resident can communicate her needs but often chooses not to. There was the family…very active and had a lot of demands when they put their sister in a nursing home and felt that staff were punishing the resident because she'd ring the bell or if she needed something so they ended up putting the resident in briefs so they wouldn't have to toilet her as often. The family felt they were doing things to retaliate against them. So I came up with a suggestion of having it in her [Care] Plan that they do a toileting plan every two hours because basically they just thought if we put this on the resident, the family will be happy the resident won't have any trouble so we'll alleviate this. I think coming up with plans for their family concerns or resident concerns rather than just assuming that things are going to change. And always having some sort of follow-up.'

When asked about the outcome of the intervention, she said, 'They started this and it was great for two to three weeks as I remained involved. Then it stopped and then I got back involved. It's one of those things that I think when families do say often, 'When you leave or you no longer go monitor, things go back to the way it was before.'' Unfortunately, in this situation that's happening but as long as I'm involved and go randomly and sort of check on the resident…but I think it's really important to come up with a plan then and follow through. Sometimes I'll recommend checking in weekly, we can do a quick Zoom or phone call so we'll bring up these concerns and if there's retaliation there's retaliation so just close monitoring.' She added, 'Follow up is super important. I go in-person in any case with the resident, I'm there in-person, I do random visits to facilities. I'm very much present. I'm grateful that I have the ability to be there, to be able to have enough time to do that because it's very important.'

Quote
"*There's so much variability from one meeting to the next….It's from we might not have even needed to be there to thank the Lord we're there*." – Ombudsman representative about his presence in Care Plan meetings

When asked about the effect of his presence in Care Plan meeting on residents who are fearful of speaking up, the representative whose quote is displayed in the quote highlighted on the last page said, 'There is an empowerment component that we provide residents because they know and feel as though they have someone who is *on* their side, that

understands their vantage point on things, supports in their independence and their self-determination and all their rights, and also won't abandon them.'

When asked if the dynamic, process, and outcome changes when he is present in Care Plan Meetings, another representative said, 'Yes. I feel like any meeting that we're there whether it is a Care Plan or Discharge Planning meeting or even just to address concerns, I think our presence as Ombudsmen makes a big difference. I feel like the building is more careful about what they say, how they say it, and what their plan is to address the situation.'

Her colleague added, 'Because we're Centralized and we work for the State of [de-identified state] and we're Regional Ombudsmen, as Ombudsmen, our role holds a little bit more weight. If we were De-centralized in different agencies…we're Regional, we come out of the state so we collaborate with the Department of Mental Health and different services…so our role holds a little bit more weight. Coming into the buildings and having those meetings, they mean something. I think because we're Centralized, that's why our program is a little bit different. I just want to express that because you're not going to get that with people where a lot of the state are localized and their access agencies and only their State Ombudsman is in the state but we are Centralized and we all come…and we're regional so it holds more weight.'

The first representative chimed in, 'I have to agree with [de-identified name of representative]. Especially someone who worked at the Access Agency level and had to collaborate with a lot of these nursing homes, I will tell you that working as Access Agency, they'll dismiss me a lot quicker and then working from the State Centralized level…knowing that we have more access to [the State Survey Agency], the State Ombudsman, our state representatives, I think that's what holds our position a lot stronger when we attend these meetings, when we come to the building, when we address situations. I think if it wasn't that, I don't think we would be heard or even taken seriously in certain situations.'

When asked 'What happens to the dynamic in the room when they sit in Care Plan meeting, one representative said, 'I can only go by what residents tell me because when I am not there, I don't know. I've had multiple, multiple residents tell me, 'Everything is different. They listen to the resident. When they have an advocate in those care plan meetings, everything changes. It is the single most powerful tool we have.'

Quote
"*I've had multiple, multiple residents tell me, 'Everything is different. They listen to the resident. When they have an advocate in those care plan meetings, everything changes. It is the single most powerful tool we have*." – Ombudsman representative

The same representative said, 'One of the big education pushes that I try to make…of course, it only works with residents who are alert and oriented…they've never been educated on their right to attend their own Care Plan. Facilities do a *terrible* job of making sure residents attend their own Care Plan [meetings] if they want to. On a weekly basis, I have someone say when I ask, 'Well, did you go to your last Care Plan meeting?' and they're like, 'What's that?' So one of the big things I educate residents and their families is attending their own Care Plan meetings. Because if solutions are to be found, in my experience, that's where they're found.' The representative explained, 'Because if you get these things in their Care Plan…it's written…everything comes from that Care Plan. I had someone from the state survey agency tell me one time, 'If you want to be able to bring accountability, it has to be something that is in the Care Plan.''

Quote
"*If solutions are to be found, in my experience, that's where they're found*." – Ombudsman representative referring to Care Plan meetings

When asked about effective practices and strategies for addressing residents' fear of retaliation, another representative said briefly, 'Having Care Plan meetings to address some of the concerns and making sure that it's documented.'

A representative from another state said, 'We're big on Care Planning meetings as many as we can. It is so time consuming but sometimes…particularly if it's disjointed within the staff. If we're getting different stories…PT [Physical Therapy] is telling me one thing, the social worker is telling me something, everybody has got a different point of view, I stick them all in a room together…it's more important to get them all on board on the same page, than even the resident. But again, that's very time consuming. I don't care about the time consuming-ness of the facility. It's for us…because none of them go less than an hour. That's not even with prep time.' She added, 'We get them all in the room together. Sometimes I am not even pro having the resident in there unless they're really on top of their game because it's really hard for the resident to hear about themselves in the third person…like, 'She said this' and 'She said that' but I am always very encouraging to have a family member in there that will advocate besides me. But I think so many problems have been resolved because the facility…their oars are in the water and not rowing in the same direction. And if we can just play it out and let them fight amongst themselves, we usually come to a better conclusion. And then we have documented care notes and documented

care plans and we can work with that. But if I am going room to room and getting different stories…anyways.'

When asked what advice she has for residents experiencing fear of retaliation, another representative suggested, 'When voicing mistreatment or concerns, I would address the caregiver and the Administrator at the same time or join like a care plan meeting when family members are present…discuss their concerns of retaliation…not just mistreatment, request regular monitoring or follow-up from the Director of Nursing and the Administrator.' She added, 'If they don't want the Ombudsman to advocate on their behalf with their consent, then they can…if they are ready to make their own complaint, do it in front of a crowd, do it in your care plan meeting when you have the Director of Nursing, the Administrator, Office personnel…when you have everybody there, let everybody know what happens to you.' She explained, 'I don't think that everybody is on board with retaliation or mistreatment. So if you let it out and everybody is appalled at the same time and then it's all hands on deck, 'Who did this? What do they look like?' Later in the interview when she was asked about lessons learned in her efforts to address residents' fear of retaliation, she added, 'Discussing retaliation in the community with the resident and staff member and the Administrator at the same time is proving to be more effective in my cases.'

One representative described a strategy he often uses at the beginning of Care Plan meetings he attends, 'Well, it usually starts at almost every one that I'm at…when I ask the resident if this is the group of people that they want at their care planning meeting. That usually puts people on their heels before we even get started.' He explained his strategy, 'I am sending a message to everyone around the table. And what that message is is that this is their meeting and we're guests.'

Another representative spoke about the importance of educating residents about their right to receive an updated version of their Care Plan., 'It's my habit. The last thing I'll do at the end of a Care Plan meeting is I look at whoever is leading the meeting and I'll say, 'How long it will take you to get this updated so that the resident' of course, their family if they're there 'can get an updated copy of their Care Plan?' The family and the resident will say [in a surprised tone of voice], 'You mean we get a copy of this?'' She added, 'I had an Administrator…it was the first care plan I had done with them and they actually called me out and said, 'They don't get a copy of their Care Plan.' That's what they do' even though nursing home residents have a right to receive a copy of their care plan.

One representative described how Care Plan meetings can be helpful, 'Almost always…if I call a care plan for someone, it's usually because it's a complaint that's going on and there's *always* that fear of retaliation. *Always*. We have to tell the resident, 'Hey, we can do a care plan, we can all talk about it as adults and get everything on the table, you'll give

them your expectations, they'll give you their expectations. We'll come together. We will figure this out.' And, 'If we do it that way, you're going to have less retaliation around you because everybody is going to know what everybody is thinking.' A lot of times, *just that* in general, *that's* your resolution. She added, 'When everybody gets in there, they'll start sitting there and they start talking about their call lights turned off, instead of that resident pointing fingers at that one person, it is a problem that needs to be addressed. And at that time, they'll usually come back and say, 'Well, we're going to do an in-service' or they'll ask me to come back and do an in-service with their staff.' This representative and her colleague confirmed that they use Care Plan meetings to proactively address residents' care concerns, fear of retaliation, threats of retaliation, and actual retaliation against them.

A representative from another state shared a **story** illustrating how a Care Plan meeting has helped shift from an institution-centered care to a resident-directed care for one resident. She said, 'A resident who contacted me and he had worked third shift for [several decades; number de-identified] years. He was working 11:00 PM to 7:00 AM and he worked at a factory. Unfortunately, he retired and had a pretty massive stroke and was placed in a facility because he couldn't care for himself. But he was never able to reset his internal clock as far as his sleeping pattern and so he would want to be up from 11:00 PM to 7:00 AM and that's when he would want his shower and eat his meal and then he would want to sleep from like 8:00 AM to 4:00 PM or 5:00 PM. Well, in a typical long-term care facility, that's the busiest time, there's more staff, there's more management and so what was happening was they would want to give him a shower at 10:00 AM while he had just gone to sleep he was in deep R.E.M. and he was knocked out so he would refuse and so then they would mark it as, 'He was refusing' and so then he wasn't getting showers for a week on end…that kind of paradigm.'

She added, 'So he calls me…of course he calls me at 10:00 at night and leaves a message…I tried to call back first thing in the morning before he goes to sleep because he was worried of explaining that on the message. I talked to him and I said, 'You know, you have the right to choose when you want these things and I *completely* understand your schedule not being able to flip' and so I said, 'Here's what I think you could do. Here are some interventions that you can try to get them to realize your preferences or how you would want that.' He went to a Care Plan meeting…he made some copious notes, went into that meeting. I ended up going with him to the care plan because he was so intimidated by those people that he couldn't say, 'I don't want to be interrupted between 8:00 AM and 5:00 PM.' I don't know that I conveyed anything different than he did, it was the support of me sitting by his side and making sure that every item on our agenda was all checked out.'

During the meeting, the resident said, ‘Look, I want my shower at 10:00 at night’ or ‘I want this’ and the facility did some pushback because again, they have limited or lower staffing at the hours that he wanted them…but he was able to compromise with that and when I say compromise, the facility saying, ‘Look, we don't have that much staff to do this but how about we move it up till at 9:00 o’clock…did your shower at 9:00 because we have staff here till 10’ and so that makes it and he's like, ‘Yeah, I can do that.’ So he was realistic about his wants if you will…atypical from everyone else…not wrong just atypical. He met with the kitchen staff about getting a meal that wasn't just a peanut butter and Jelly sandwich from the pantry and a banana for his meal every night he wanted what was served 6:00 o’clock or whatever time. I saw lots of positive come from that by him empowering…but it started with that complaint form, having him write it down so that it is very clear, not a subjective statement and then him working with that but also having staff finally acknowledging this is a man who's never going to sleep at night. He's just not going to. Again, their perception was, ‘Well, he is here now. He should be awake all day like every other resident and sleep all night’ to the point that they wanted to give him a sleeping pill so that he would sleep at night. He was like, ‘I don’t want a sleeping pill.’ Again, he has that right to refuse but by refusing that sleeping pill, then he was categorized as being difficult or refusing care because he wouldn’t take the shower at 10:00 AM or he wouldn’t take the sleeping pill. So again, he is categorized [said with hands gesture indicating quotation marks] as a “difficult” resident and a result staff don’t want to deal with him. Well, it is not that he was being difficult. He just had requests that were a little atypical than the traditional working world.’

She added, ‘When I first talked to him, he was *so* angry, he was *so* frustrated that he couldn't get…in his mind…a good night's sleep because they were coming in to clean his room and he was just so angry and so I said, ‘Look, you have got to lay out for them your schedule.’ He said, ‘Well, they are not going to listen. I am afraid that they are just going to wake me up. They’re going to drug me out with a sleeping pill.’ He had this fear of retaliation that even though he’d express these things, they weren’t going to listen.’ They were to continue to come in when it was convenient for *them* versus when *he* wanted it. It probably took us about 3 phone calls really help him build his confidence…to be able to go and fill out the form, go and talk to staff in the kitchen or wherever because he felt like he had to be *compliant* with them and that was the retaliation part for me was that he was being I guess conditioned or to think that he had to adapt to them when it really was not the case.’

She described the outcome of the intervention, ‘It took about two months for them to get things switched and get more routine with him where he was getting a shower at night, he was getting a meal tray…what I call a true meal tray at night to eat his meal and they have made up some signage to put on his door to not disturb him between about 8:00 AM to 4:00 PM every day. So no housekeeping coming in, making sure he got his meds before he went

to sleep…those kinds of systems…but it took about two months to get that outcome where it was really flowing well, where his complaints were pretty minimal.' She said that the situation was resolved to the resident's satisfaction.

Resource Box
Night Program
Hebrew Riverdale All Night Program for people living with dementia.

Conducting Thorough Investigations

Several representatives spoke about the importance of them conducting thorough investigations of residents' care concerns and mistreatment complaints (after meeting consent requirements). One SLTCO said, 'The instances where we were most successful is by doing a good investigation. Number one, asking a lot of good questions. We usually start with Who? What? When? Where? Why? How? and we go from there. And who else can we speak to? And then casting that net wider sometimes. If somebody will not give consent for a certain complaint, well, we're going to go and talk to other people to see if they have a similar concern that somebody else expressed…and just continue to cast that net wider and talk to as many people as possible to collect as much information as we can and or find somebody who is willing to give that consent…because then we can advocate not only on behalf of that one resident but everybody by even just speaking up.'

When asked what stands out to her as of value when working to address residents' fear of retaliation, another representative said, 'I always typically explain to them the process as far as, 'You know, once I get this information, what am I going to do' but I try to get as many details as possible before. For example, did this happen yesterday? A week ago? Was it during the week? Was it a weekend? Was it morning staff? Evening staff? Was it a male? Was it a female? I will usually follow up with somebody in upper management and a lot of it is about some education with staff and really coming together to work together but I always want to make sure that the resident is agreeable to every step that they take.'

When asked if there are things she finds valuable when she addresses residents' fear of retaliation, one representative said, 'The general process…we ask a ton of questions. If they say they don't want to say anything because they want the staff to answer the call lights or they don't want to be…obviously that's retaliation. 'Does this happen often? Is there a certain aide?' You know, we start asking questions. That's part of the process. We want to

know, ‘Are you afraid? Are you worried about one person? Are you worried about multiple people? Is there a certain shift?’ We always ask questions to get more information.’

When asked what stands out to her as valuable in addressing residents’ fear of retaliation, another representative said, ‘I think the most important thing we try to do is to empower the resident to use a facility grievance process first and Resident Council. And after assuring the resident enough where they feel secure and have the trust that I can make the retaliation stop and they consent, the first thing I always do is I try to get all the information that I can about the staff member or staff members who are being accused of retaliating or mistreating the residents…before addressing the concerns with the Administrator. I know that every case is different and I always follow the residents’ wishes but some residents don’t want to see the staff member ever again, other residents just want additional training…so that’s mainly what I do…I try to get all the documentation, all the information first before I even go in to bring it to administration.’

A representative from another state said, ‘Sometimes we can narrow it down to a shift. I recently had one facility where I had four people talk about the night shift and a specific employee that works on that shift.’

Another representative said that when she gathers evidence, she tries to identify whether it is a “bad apple” situation [i.e., an individual staff member] or ‘a systemic issue.’

Using a “Magnifying Glass” / ‘Identifying where is the heart of this issue’

Several representatives spoke about a practice that could be characterized as using a “magnifying glass” to identify root causes as the basis for resolution of care-related problems. The practice often consists of slowing down and taking a close look at the circumstances, contributing factors, and causes underlying residents’ care concerns.

One of them said, ‘It is good to be persistent but there is value in taking your time…slow down, take a breath, really observe what’s going on, and take it one tiny piece at a time because the more you tackle the small things, it’s going to lead to greater success.’

Representatives shared stories illustrating how they use the “magnifying glass” to identify root causes and resolve residents’ care concerns:

An experienced representative shared this **story**: ‘I had a resident who does have mental illness and she is known to be just kind of a negative person, complains about a lot and one of those things was not getting her medication timely. She'd be at the medication cart asking for her medicines and there would always be an argument between her and the medication staff because they would make her wait because she was aggravating them. The complaints went on and on.’

She described how she handled the situation, ‘Finally, I went in and met with her. They labeled her as a “drug seeker” and looking at her medical records, you find out she was prescribed morphine twice a day…never any more…nothing additional. There was no evidence that she went out on the street and got any more medication. She took exactly what she was prescribed by the doctor. We sat down with medication aids and explained, ‘You know, the doctor has prescribed this medication for her for whatever reason, it's not for us to determine, it is for them to follow the prescribed plan of care by the doctor.’ They really were creating drama for themselves and the stress for themselves in fighting with her. They *knew* that yes, she gets this medication…if they just go ahead and give her medication, she will go on about her business, less arguing with them, less retaliation with her and everybody kind of lives more happily.’

She added, ‘But understanding that when you make her wait to the very last minute, she begins to feel…whether it's withdrawal symptoms or beginning to feel pain and that increases her agitation…increases the likelihood of confrontation and if they want to stop it and understand what she actually is experiencing, then they can make their life less stressful as well as making sure that she's not experiencing pain.’

She said, ‘It actually worked. But helping them understand from her point of view because you just get someone that's begging for medication, ‘Oh my gosh’ but understanding that literally she's *beginning* to feel pain when the medicine is wearing off [and] what she's experiencing, and we were able to work through it. Now, there's still sometimes that there may be an issue but for the most part the staff are good *now* about giving her medication timely, but they were *absolutely* making her wait because she complained.’

When asked if she saw the delays in giving her her pain medications as retaliation, she confirmed, ‘There was indeed retaliation. She complained about the timeliness of medication and their response was to make her wait even longer. She was labeled and had to wait and begin to experience the pain from the withdrawal due to retaliation.’ The representative confirmed that the withdrawal symptoms contributed to her coming back again and again and asking, ‘What about my medications?’’

I asked: To what extent do you find that those issues have to do with a gap in understanding or gap in communication and then to what extent do you see yourself as a mediator?’ Her response was: ‘Yes. Communication is one of the biggest issues. Not being able to understand somebody's point of view until you actually see it, until you experience, until you explain that side of the story. For this situation, they did not understand how the pain started to come and how the agitation *increased* as the medication was leaving her body before a new dose would come and help maintain that pain again. So that communication and connection of understanding each side of the story makes a *huge* difference.’

Referring to her metaphorical “magnifying glasses,” she confirmed that her slowing down and looking carefully at the details of a situation helps her resolve these issues. She said, ‘Absolutely. Every time you’re looking at behaviors, what’s causing the behaviors? Let’s look closely, slow down, and see what the steps are that cause behaviors.’

Another representative shared this **story**: One resident without dementia in an assisted living received a retaliatory discharge notice for smearing feces on the sink, walls, and carpet. A representative’s investigation (in consultation with a pharmacist) found that what the resident has done had to do with a thyroid issue that was not adequately treated.

In the words of the representative, ‘The retaliation was the discharge notice instead of getting to the root cause of the problem. We had a resident that was spreading feces supposedly and the answer was a discharge like we're just going to discharge this resident instead of getting to the root cause of the problem. But then, as we started investigating and getting to the root cause, the retaliation side of it was the fact that the staff wasn't coming in to clean the room any longer since we were involved, there were multiple things that transpired for this resident because…one, because we had gotten involved in the discharge notice but we were also trying to find the root cause so we started with the root cause of the problem but because of that, this resident was retaliated against. It was during COVID…so, ‘Oh, we’re going to make you isolate because you might have COVID’ but the resident’s roommate didn’t have to isolate and we know what that looked like at that time period. So there were multiple things…they knew she liked activities [so] they would not let her go into the activities room any longer by herself where before she could go in, sit by herself, and work a puzzle. It was multiple things of retaliation for this resident.’

She added, ‘It was her medication. They were not looking at her medication and how medicated she was in the evenings. She had an adult brief and she would go in and try to take it off at night…was trying to clean herself up so there would be feces on the sink where she had tried to take it off and take care of herself. That was the picture they were trying to paint. That she had it smeared on the walls, on the carpet, and there might have been a time when some fell out of her adult brief going from the bedroom to the bathroom, but it was not done intentionally. We also have a pharmacist on our council, which is great for me, so I had her look at her medication and this resident had a thyroid issue that was not being treated, which could cause some of these issues as well.’ She added, ‘The medication they had her on was at such high doses that at night that she was just…I don’t want to use the word zombie but almost zombie-like in the evenings where she could not communicate, she could not function…she was just doing the best that she could trying to clean herself up.’

When asked about the outcome of the intervention, she said, ‘The resident at that point had decided she wanted to be relocated to another facility because of the retaliation that was going on. She did not feel comfortable. She didn't feel like it was her home any longer so we worked with her case manager to find a placement for her.’ The representative said she believes the threat of retaliation and the actual retaliation against the resident was a contributing factor in her decision to move to a different care home.

When asked how the resident has been doing in the new care home, she said, ‘She was thriving in the new place. I went to follow up with her a couple of times and she loved the staff and the staff loved her. They knew the situation and went through her medications and found that happy ground for her and she was *thriving* in that facility.’

When asked whether there were issues with smearing feces in the new care home, she said, ‘No. There was at the beginning…the facility continued to monitor and work with her to find that balance for her.’ The new care home found a resolution for her.

One representative shared this **story**: A resident received ‘a transfer and discharge pertaining to a violation of a smoking policy.’ The representative said, ‘The facility kept on saying that the resident was smoking in her room.’ A close investigation by the representative revealed that ‘the resident was not smoking in her room.’

The representative added, ‘The resident’s room was right next to the doorway to go out to the smokers patio and after some investigating and actually having a transfer and discharge hearing with the hearing officer, it was determined that the smoke smell that was in the resident’s room is because the staff were just not closing the door behind them when the residents went outside to smoke so it would come back through the door…her bedroom being right there. It just constantly smelled of smoke, so they accused her. She was a smoker…but they accused her of smoking in her room.’ She said, ‘She told me. She said, ‘I swear to you [de-identified name of representative]’ and she cried. We’ve had several very long conversations. She was like, ‘I have *not* smoked in my room.”

When asked how the situation was resolved, she said, ‘It was resolved…we finally had the hearing officer had a hearing…and the facility… in another form of retaliation…had their *lawyer* involved at the hearing, which never happens. So now the resident is automatically intimidated because now there’s a lawyer on the other side of the table. But we stayed *dead* strong and what we thought was right. We fought the good fight…it kind of got a little scary for a little bit because we didn’t think we’re going to win, but ultimately, we ended up winning and the resident was able to stay at the facility.’

The representative added, ‘With that being said, about a month after we won the case, she reached out and said, ‘The retaliation is still real and I know it is now and I just need your help to get into another building because I am just not going to deal with the nonsense.’’

When asked about the nature of the latest retaliation, she said, ‘It was basically the renewed. They refused. They were still trying to say that she was smoking in her room. They wanted her smoking materials, which she turned in her lighter every single time. They kept on saying she still has paraphernalia in her room. They would come in and do a room search whether she was in the room, whether she was not in her room…whether she did give permission…whether she didn’t give permission…they didn’t ask. It just got to be too much for her, and she said, ‘I know you worked so hard on keeping me here’ (‘she was truly grateful’) ‘but for my mental health, I have to get out of here.’ She did move to another care center and she is fine. She’ll call every once in a while, and just check in and say, ‘I just wanted to say, ‘Hi, I am doing okay.’’ When asked whether this resident has any issues with smoking in her new care home, she said, ‘Not at all. Not at all. Not at all.’

When asked about instances where she was successful in addressing a resident’s fear of retaliation, a representative from another state shared this **story**, ‘I had a resident that was on the residential care side of the building. He went into the hospital, went to the skilled [nursing home] and they wouldn't put him back with his roommate in the residential care setting. He made some complaints. I got involved and he just said, ‘They're keeping me here in this room with a bad roommate. They're punishing me. They put me in a small room. They just don't like that I speak up.’ He is a younger gentleman, and he said, ‘You know, they don't like that staff talk to me.’ He *really* was really upset about this and really believed that he was being punished.’ She said, ‘They put him in the skilled part. He wanted to go back to the residential care and they put him in a really small room with a pretty difficult resident and he just really felt that he was being punished, not allowed to go back to the other side of the building because he complained.’

When asked about the nature of his complaints, she said, ‘He was complaining about some of his care… just a variety of things.’ She went on to describe how she handled the situation: ‘We basically came all together to talk about why are you keeping him there…what's the real reason? He was able to talk about his concerns with sort of a mediator. We came together to come up with one week left in this room and then you'll get moved which he did go back to his room. I think part of it was miscommunication between staff. I think that part of it could have been a financial reason of keeping him in skilled.’ She confirmed that it had to do with Medicaid and added, ‘I think part of it was he didn't realize why he needed to be there for a short time. I think all of that could have been prevented had there just been better communication with management and him from the beginning.

Unfortunately, that didn't happen.' She clarified that there was a clinical justification for having him at the skilled part of the building 'maybe for 4 or 5 days I would say but this went on much longer. There was mis-documentation by staff that I actually proved to be true.'

Another representative shared how she reviews Call Light Logs to identify response time patterns and advocate for improvements. She said, 'Some places have Call Light Logs that you can pull from, which is really helpful for us to figure out…confirm that, 'Hey, this call light is taking much longer than what's acceptable' but being able to kind of see the progression of those logs, you know, if it was taking over 30 minutes and now we're looking at 8 to 9 or even just 15 minutes which is the regulation, that's an improvement. It's nice to kind of help residents advocate for themselves resolve these issues and for us to offer some backup too and be able to see that change too just by looking at the data in addition to getting that feedback from the resident too about, 'Yes, I'm *not* waiting as long' and 'Oh, let's talk about other ways…like you know you're going to be needing to go on the commode at certain times, let's go ahead and schedule that with the staff and your care plan so they know that you are probably gonna need to go to the bathroom at this time and this time.''

When asked about the things she has done to bring this change, she said, 'After we get permission from the resident, kind of agree with the resident on a plan. I am there, and we are right there with the resident and we are pulling the right kind of stuff and we're talking about like, 'Here are the issues' and, 'Give us the printout,' let's go through it. It looks like there are problems around those times…kind of analyzing the data, looking for trends…a lot of times we're coming as a third party looking at this information seeing it for the first time and maybe we can kind of identify trends and sometimes it is a matter of who was working that day. Is somebody slacking on their job? Asking questions that maybe the facility doesn't have time to really drill down and look at…really identifying where is the heart of this issue.' She said that she uses the Call Light Logs to advocate for an individual resident as well as for multiple residents experiencing a systemic issue.

She went on to describe what she does when her examination of the Call Light Log enables her to identify a concerning pattern, 'We have to work with management because they're the people who manage the staff and are able to implement the changes and improvements…hopefully improvements…I mean, sometimes it happens, sometimes it doesn't but that's where our first stop. We can get up higher if we need to.'

I asked her about situations where staff members respond to a call light request, come to the resident's bedroom, turn off the call light, and leave without providing the requested care (either because they are busy providing care to other residents or in retaliation) or they turn it off remotely and this practice results in a Call Light Log that may not reflect the actual time in which care was provided to the resident. In response, she said, 'I would

throw on there that we get a lot of feedback from residents themselves so if you're there and you're just visiting with various residents, I feel like we pretty quickly pick up on, 'Well, they come in and they shut it off and they say they're coming back but they don't' so collectively, if we hear that from residents just from interviews, we take that to the staff.'

Identifying and Bridging Gaps in Communication

A pattern was identified from interviews with multiple representatives whereby a gap in communication (such as between residents and staff/managers) often contributes to conditions resulting in residents' fear of retaliation and actual retaliation against them. Identifying those gaps in communication was identified by these representatives as an important strategy for resolving care concerns, fear of retaliation, and actual retaliation.

Referring to the incident described earlier where a resident returned from the hospital and was placed in a skilled nursing home for an excessively long period of time (he wanted to return to his bedroom with his roommate in his residential care setting and felt that he was punished), one representative said, 'All of that could have been prevented had there just been better communication with management and him from the beginning.'

One SLTCO said, 'I would say that a lot of times the root cause of…I would say the majority of the concerns from my experience has been some sort of gap in communication and identifying that gap in communication and bringing clarity and highlighting how could we do something different or more next time because there was a misunderstanding or something wasn't addressed or leadership doesn't know about something.' She went on to share this **story**: A care need was expressed and 'the caregiver then becomes like rough handling of things, intolerant, intentionally leave somebody on the toilet for a long time or doesn't take them at *all* and so then you have a resident who is lying in bed all day in their own feces and urine.'

She added, 'Then with the relationship piece…the Ombudsman having a good working professional relationship with leadership and there can be this level of trust that is built with that resident that may express a concern about bringing that forward and you can talk them through that and say, 'Here's my experience so far with this Administrator, here's other examples of how I've advocated successfully for other people…this is what I know about this Administrator.' Then you take it to the top and you let them know…and I've had a couple of instances recently where we've brought it to leadership, Administrator or even corporate and they said, 'I had no idea' and they did their own investigation, and they terminated the person.' She described the role of the representative in these situations, 'Identify where did the miscommunication occur. Where the communication did *not* occur.

I mean, especially with the low staffing levels and stuff that we're seeing recently and the last couple of years…it's even more highlighted I think.'

Another representative shared this **story**: 'A family member approached the Ombudsman first with concerns regarding quality of care to their loved one where the resident was not getting their care needs for toileting according to the family.' She added, 'The family had a perceived fear of retaliation…the family was one of those families that don't want to 'rock the boat.' We hear that all day, every day, 'I don't want to rock the boat,' 'I don't want to be labeled a complainer.''

She added, 'The Ombudsman started looking into it and spoke with the resident and figured out that the resident was being left on the toilet because the resident was never taught nor learned how to do the pull cord while they're on the toilet to say that they're ready to be transferred back to bed. It was one of those situations where once we got involved, we kind of got to the root problem that nobody knew. A care conference was then held and it all got worked out. It's like, 'Ah, okay' and it held up that mirror for the facility to say, 'Ah, here's where we could do something different, better or more.'

When another representative was asked how often in his experience root causes of care-related problems comes down to gaps in communication, he said, 'More than 50% of the time.' He then added, 'Way over 50% of the time.'

Role as Mediators

Representatives spoke about their role as mediators and negotiators. At the outset of one interview, one of them said, 'As the Ombudsmen, we are considered mediators because the word Ombudsman that's a Swedish term…it means mediator.'

'Ombudsman' is "a Swedish word meaning agent, representative, or someone who speaks on behalf of another." – National Long-Term Care Ombudsman Resource Center (2019).

When discussing their role as mediators, it is worth reiterating the words of one of them, "There are always three sides to the story. Their side, the resident's side, and the truth."

Another representative spoke about his role in helping different entities see things from a different vantage point, 'One of the biggest things that we do is we try to empower the voice of the residents or we try to amplify their voice for them. A lot of the work that we do is helping other entities, residents included, seeing things from different vantage points and so helping staff on the floor, helping staff in middle management, helping leadership understand how would that make you feel? Would you start to become a bit paranoid or concerned if this happens? You bring it up, there's no change management to it, there's no

accountability to it, it continues to perpetuate itself. Is this person a "constant complainer" or are we just simply failing with any change management here? Kind of trying to help them understand that elevated voice of the resident and their perspective and trying to cultivate some empathy for what the resident experience.'

When asked about the extent to which she feels as though her role is one of a mediator that works to bridge gaps in communication related to abuse, fear of retaliation, and actual retaliation, a representative from another state said, 'Well, that's such a loaded question but I think we would say that we feel that way a *lot* and especially with the state of long-term care right now with ownership changes, with staff turnover at all levels. We find ourselves having to not only communicate but be the follow-up communicator, to be the person that makes sure the steps get put into place. So we're a mediator for those people who I think are more independent. We feel like we are more of the case manager or the facility social worker at times consistently following up on certain individual complaints that come in…it could be a Medicaid application, it could be where are we with improvements on bathing right now, it could be anything. I feel like we have to keep closer tabs on things and there are certainly not enough of us to do that.'

Advocating for Staff Reassignment

Several representatives described the strategy of advocating for reassignment of a staff member away from caring for a resident being neglected, mistreated and/or in fear of retaliation from this care employee. One of them said, 'I also remind them that, 'You can change caregivers.' If this is somebody that they're really scared of or they don't trust, we can change that. We can ask them not to come back in your room' and sometimes that's exactly what they needed to hear and that's what they want.' She added, 'Take that person off the hall. That's a really good strategy.'

Another representative said, 'At a more localized level, looking for different alternatives to rearrangement with that staff and that person. I think sometimes when we work with particular populations, we forget that there can be personality differences even amid the circumstances.' The representative added, 'While I do appreciate the fact that the staff members in a long- term care setting reasonably should maintain a level of professionalism independent of personality differences, we're also talking about a very unskilled marginally trained group of professionals. So sometimes just identifying where those lie and then gaining some rearrangement has proved to be successful.' By rearrangement, he meant, 'Retraining and then possibly moving them to a different area of the building.'

One representative shared this **story** about retaliation against a resident in reaction to her complaining or expressing care concerns: ‘There was a particular resident who felt she was being retaliated against by a certain staff member. She knew who the staff member was. There really wasn’t anything to prove how she felt or what was going on. We did advocate for her to not have that care by that particular staff member. She preferred not to be cared for by that staff member. They were moved to another hall and that resolved to the resident’s satisfaction. They were happy and in that sense it was a success for the resident.’

When asked about the nature of the retaliation, she said, ‘She wouldn’t put her call light within reach, she had an attitude, her table would be put too far, she wouldn’t ask how her day was going…just in and out, and not personable. She just felt she all of a sudden being rude to her. It wasn’t anything that she outright said. There were no words spoken. This person is obviously retaliating against me but it was her *attitude* and those non-verbal things that she would do. The resident just felt retaliated against.’

A very experienced representative from another state shared this **story**: ‘An individual had some difficult experiences with a staff member on their approach and their attitude and their tone.’ The representative described these staff actions as ‘authoritative,’ ‘almost confrontational,’ and ‘there almost been aggressiveness to her approach even to when she was assisting her to the bathroom…just the way she supported her body as they walked to the bathroom’. She added that the resident ‘felt that it was very uncomfortable, and she felt demeaned by her,’ and she ‘felt intimidated by her.’

She added that the resident ‘had talked to her daughter about it and they had met with me and then I had a discussion with the resident and the daughter about her experiences and she gave permission and I think the reason she gave permission for it to come forward was because she had a lot of family support and the family and the daughter…I think their involvement was really key in this particular situation. So we did have a meeting with the staff at this particular home, the key management staff, director of nurses, administrator and the daughter and I presented her concerns and we were able to coordinate a plan moving forward where that particular staff person would no longer serve this resident. I think part of the success of that was to kind of get away from the debate about what happened or didn't happen and to get to a maybe a more agreeable space that no matter what happened, it wasn't something that was desirable for the resident or benefited the resident and we could maybe move forward with a plan that that particular staff person wouldn't serve this resident and hopefully avoid a reoccurrence of it.’

Another representative said that sometimes residents are willing to give them permission to advocate for staff reassignment but other times residents are not willing to provide this consent because they are afraid that the co-workers of the employee removed from their

assignment will retaliate against the them. She said, ‘What I’ve shared with persons who are fearful of retaliation depending on what the concern is…for example, if they have a particular aide that they're saying is retaliating against them, then I try to explain to them that, ‘If you give me your consent to be able to do this investigation and advocate for you, we can have that person *removed* from your assignment so you don't have to see him or her again and you don't have to have that interaction.’ That's some of the support I try to provide for the resident. Sometimes they're amenable to it and sometimes they don't want to take the chance because they're fearful that the *other* employees are going to retaliate because they had them removed from the assignment.’

A representative from another state shared this **story**: ‘I had a resident who records everything. She keeps her phone on record in her drawer. Her husband is in the nursing home too. Over the weekend, an aide came in, pushed the resident…was arguing back and forth with the resident but that aide left and reported that the resident pushed her. She didn’t realize she was being recorded [It was audio recording, not video recording]. However, she swung the story. The police were called [because that is the protocol that needs to be followed ‘anytime an aide says a resident hit.’ ‘They had to call the police, get a police report’] and the resident would not report it. She had the evidence, the proof that this woman lied, and she would not report it. Again, because she is worried about this aide and like, ‘She just had a bad day.’ The aide was upset that she was telling her, ‘Hey, can you check my husband’s pad?’ because they were at the same room together and he needs more care and she didn’t want to do it so she was arguing back and forth with her and then pushed her but then reported that the resident pushed her and it was a whole big thing. And the resident would not report it. She would not tell the different story even though she had evidence, she just would not…she didn’t want ‘any smoke.’ That’s what she said, ‘She has got to be here. I don’t want any problems with none of the aides.’’

The representative shared what she heard when she listened to the audio recording, ‘You can only hear the aide screaming at the resident and telling her to get out of her way. You couldn’t hear nothing. The resident didn’t say anything. She only said, ‘Could you please check my husband? His pad needs to be changed.’’

She went on to describe how she handled the situation, ‘What we were able to do, again, they followed protocol, but the facility didn’t know that this actual aide was the culprit, it wasn’t the resident. What we were able to do is just anonymously…this is because if the resident doesn’t give us permission to report, we can’t but having an established relationship with the facility and being able to support them in other matters, I was able to say, ‘Listen, you have to pull this aide off of this resident…out of this area. You’re going to have a problem.’ They were able to listen and they were able to do it. Having established

relationships with facilities, when residents don't want to talk about retaliation, sometimes having those established relationships can help support residents because they will now listen to you say, 'Hey, you may want to pull this aide off' and they will do it without having to give the back story.'

When asked how the strategy of staff reassignment works in an era of an unprecedented workforce crisis and poor staffing levels, one representative said, 'We would never put that statement out there on its own without a lot of other information to go along with it. If they're going to bring up the idea of changing caregiver, there are a lot of things to consider. Number one, that caregiver is likely still be around and they are going to still see them in the hallway or what not…so we just want them to know that…because sometimes they have fear of them still being around…sometimes they even come into their room and work with their roommate. We want to have full disclosure about it. They just wouldn't be caring for them but they would still be around and possibly even still caring for their roommate but, if it's important for them, we will try to see if during that shift, someone else was there to help them. And that it may not be all time always thing just because of that very need of shortages of staff especially if it involves a male or a female gender preference…that can't always be met but they will certainly make an effort to try but if it was a specific personality thing, that that person could absolutely be reassigned to not care for them.' He added, 'As an Ombudsman, we want to have full disclosure and to let them provide their own informed consent as to how they want to move forward' and 'We want them to know that 'this person may still come back and care for your roommate but at least they won't be caring for you. Are you okay with that?''

Role of Resident Councils in Addressing Fear of Retaliation

Numerous statements made by Ombudsman representatives illustrate the critical role well-run Resident Councils can play in addressing residents' care concerns and their fear of retaliation when voicing these concerns.

Resource Box
What is a Resident Council and Why Are They Important? Video developed by Connecticut Long-Term Care Ombudsman Program

Resource Box
A Guide to Strengthening Resident Councils in Nursing Homes (January 2024) developed by Moving Forward Nursing Home Quality Coalition. Texas Long-Term Care Ombudsman Resident Council Toolkit (2023).

One representative said, 'Resident Councils are very powerful I have found in my area.' She added, 'I have a lot of good success with my Resident Councils.'

Another representative shared a **story** illustrating how assisting residents with the Resident Council brought a positive change. She said, 'There was a facility here that…it was a Union facility ('They don't ever terminate anybody') and we were having a lot of problems with retaliation and poor care.' She described the retaliation, 'It could be the littlest thing…a CNA or nurse didn't like that somebody rang their call light twice in one hour. It was nothing like major that we get…it was just a general attitude. Anybody who questioned a staff member was on the receiving end of that retaliation.'

She said, 'We went in there and we worked really really hard with the Resident Council and really helped them come together and get a voice in the facility. I do think that that alleviated some of the abuse…the retaliation that was going on because even the people that weren't the President, the Vice President of the Resident Council felt that they could then go to the Resident Council President or Vice President and have their ear and say, 'This is what I'm experiencing' and then have them speak without necessarily naming the resident. So that did happen in one facility and I felt like that was a really positive.'

She added, 'We worked with the Resident Council for a couple of months, and we really worked on what residents' rights are, 'This is your home. You deserve to be treated this way.' And then we do a follow up every month and lots of feedback came in that it was more positive…more positive feedback…that they weren't experiencing what they felt they were experiencing four to six months prior.'

Another representative said, 'I think Resident Council is great for residents. I know that the Health Department looks at all the minutes…if there are issues that the Administrator has to answer those issues. I think it's a good benefit for residents to join, they can have it anonymous, there doesn't have to be staff there. I always encourage individuals to join.'

That said, as will be described in detail below, representatives identified several challenges in the implementation of Resident Councils and their opinions regarding the effectiveness of the councils varied significantly.

One key factor underlying the perceived effectiveness of Resident Councils had to do with the extent to which the council is resident-run versus care home run.

One representative described how she educates staff when they interrupt, control, and try to influence Resident Council meetings, 'I'll do a lot of education like, 'You have staff meetings, you have stand up. This is their stand up time. This is their time to let it all air out and if you're not going to support them…this is *their* meeting…you shouldn't be in there.' Her colleague added, 'Let them know that it is resident-driven, not facility driven**.'**

Quote
"*Let them know that it is resident-driven, not facility driven*." – Ombudsman representative referring to Resident Councils

Another representative said, 'We have noticed that once you get it and have *residents* running the council and you have a team there, that makes a really big difference as far as the success of the council and speaking for the other residents.'

A representative from another state said, 'There is a way in which it is supposed to be run. It's supposed to be a resident who is running the council meeting. And if they want to have somebody…a staff member takes notes, that's fine. But most residents don't know that. They don't know that so it's kind of the way it is.'

One representative described two general types of Resident Councils, 'I can remember going into a skilled nursing home in [de-identified name of city]. I went in…it was during [state] survey and I was in owe at the sense of the residents having a sense of empowerment at their Resident Council to bring problems forward and source solutions rather than the council feeling like they needed to fight their way through things to get attention and leadership basically viewing the resident council for example as an adversary. So when we're talking about this fear of retaliation, I think [it is] centrally rooted in those two different types of council engagements with leadership.'

He described how Resident Councils can help when there's a problematic leadership culture, 'With the broader cultural element, that can prove to be a little bit more difficult. Where I found some success in that is bringing those issues to the Resident Council and gaining a collective voice of the residents as to help the escalation point, understand the seriousness of the cultural imposition.'

He gave an example of 'an executive director in an assisted living that's very power over orientated and so when people complain in order for them to retain their authority and their power, it becomes retaliatory in nature. Sometimes to the point which, you know, I talked about some passive ways, passive defiant ways but it could escalate to the point where that executive director is blatantly making threats to people individually in their apartments…threats of, 'I'll kick you out of here.''

He ended up resolving the situation by indicating that he plans to reach out to the chair of the board of directors. He added, 'One of the things that I found to be really really successful is…especially with culturally-infused sense of oppression, an iron fist at the top of the assisted living or skilled nursing…and utilizing the collective voice of the residents through the councils, that's where I found a lot of organizational level advocacy that's gotten good results. At a more local level, it just kind of depends on what it is but I think a lot of times once people better understand other people, I think we become human again.'

One SLTCO said, 'A nursing home that does it well gives residents a space for themselves…private time to talk and to bring things forward and then has the administration go in in a meaningful way…not rushed, not pressed by in a meaningful way to address the concerns, follows up on, gets back to, and is accountable for items that are brought forward.'

When asked about the value she sees in Resident Councils when it comes to addressing residents' fear of retaliation, a very experienced representative said, 'To some degree, it is a group of their peers so that they have peer support around a particular situation and if they have enough interest and the leadership is willing to do it, they could move a situation forward as a group. They can submit a complaint from the resident council on a particular topic that maybe two or more people are experiencing and it sort of gets away from that individual identification if the resident council is functioning that way. I think we find that resident councils vary to a large degree about how much they see themselves in this particular type of role, but if it is a council that kind of prides itself on wanting to do problem solving and collaborate on improvements, then it's one tool that a resident could use to bring their situation forward and to get some peer support.'

When asked about the role of the Resident Council in addressing residents' fear of retaliation, an experienced representative said, 'I work a lot with the Resident Councils. I encourage the Resident Councils to voice their concerns as a group. There's power in numbers. And sharing their concerns, their fear of retaliation…because it really takes that away…if you are voicing a concern that everyone is having and you're doing it, 'As a group, we're having an issue with medications not being given timely,' so it takes away that fear, it takes away that identifying them specifically, and really kind of help work with the issue without focusing on that one particular person.'

A very experienced representative shared a success **story** in a nursing home. She said, 'Having residents complain about something as a group. We were having food issues in a facility…getting that to the Resident Council so it wasn't just one or two people complaining…it was the *whole* building and we can bring the Administrator in and 'See, it is not just a couple of residents' And that cuts down on that fear of retaliation…well, you can't retaliate against the whole building. That doesn't work. It is really so…and that getting residents together to feel comfortable and safe to do that.' When asked about the outcome of her intervention, she said, 'Residents felt safe to get together as a group to make some changes in the building with things that they wanted.' She added, 'The food had changed. They brought a new company in and it was terrible and it was cheaper for the building and it just fallen off the rails.' She said that they 'felt safe and it worked out. So bringing people together is really important.'

Another representative said, 'Resident Council is one of the most important things in a facility as residents can come together. Being one person standing out alone is a super super scary thing but if you are one person surrounded by other people that are like, 'Yes, this is a problem' whatever the concern is…call bells…cold meals, when you're not standing alone, it's empowering.'

Gaining peer support and speaking up as a group is important also because in some care homes managers try to prevent residents from discussing care concerns with each other, neglect, and abuse 'to avoid creating the group effect' (Logan, 2024). In contrast, a Resource Guide used in Marin County Ombudsman Program, California (2021) states, 'Effective Resident Council meetings require the support of an Administrator who believes in residents being the center of all decisions that affect their lives.'

Quote
"Who knows the concerns and solutions better than the residents who live here 24/7?" – Courtney Broussard, Administrator, St. Jude's non-profit nursing home where the LA PEER has been implemented

Other representatives shared their views regarding what they see as the value of residents' participation in a well-run Resident Council. Examples include: 'There's power in numbers;' 'being able to come together as one…and share;' 'It's a community of peers;' 'Trying to bring the residents together so that they can have a voice together. She added, 'When residents come together and you have a strong, empowered Resident Council, then they can be the voice of all of the residents in a facility and that does make a big difference;' 'If there's a collective consensus that it is a facility-wide issue,' 'It's a leveling field when you see multiple people able to talk about grievances;' 'It's a safe place for them to share concerns,' and 'It is really a safety zone or should be for the residents.'

When asked about the role of Resident Councils in addressing residents' fear of retaliation and actual retaliation, one representative said, 'I would say that to be able to bring the information to the Administration as a whole collective and not pinpoint one person…so that way, the retaliation wouldn't be against a particular resident because it went through and was addressed through the Resident Council.'

Another representative said, 'It doesn't single one individual out.' Related to it, a representative from another state said, 'If it is not a very specific complaint, the President will just take it to the staff, take it to managers and depersonalize it and make it anonymous that way because no one knows out of the group who said what.'

Another representative said that Resident Councils are 'beneficial because there are multiple people aware of the concern….so that singled out piece. But that means that there are more eyes on the resident in the building because all these other people know that that person has made that complaint because they were in Resident Council. So it is kind of like group mentality that everybody knows so it might lessen that *fear* of someone retaliating because I brought it up but the Resident Council President knows about it and all of that…so they kind of have a built-in support system.'

When asked about her thoughts related to resident empowerment in Resident Councils, she said, 'Absolutely because they feel more confident and stronger and I think it is

common knowledge that if we're confident in what we're doing, we are going to be more comfortable and be able to communicate those things a little bit smoother.'

Several representatives said that residents participating in a Resident Council may realize that other residents share their care concerns. One of them said, 'I think most of the time residents think the problems they're having are their problem and not everyone else's. They are looking at it from a very dark point of view, you know, they've been ripped theoretically from their community…it's not a great experience but I think that hearing everyone else speak of the same problem and it could be food, which is always number one but not having linen or not getting showers. They come to the realization that it's not just them and I think there's certain peace with that in some way.'

A representative from another state said, 'I think it's really important for residents because they don't feel so alone in making a complaint or bringing up an issue because oftentimes somebody will bring something up and you have two or three people saying, 'Oh yeah, I have that concern too' or 'I have that concern' and I think it's really helpful for them and they feel more safe doing it with other residents.'

A representative from another state said, 'Not all residents come out of their room all the time…they don't always socialize with other people…so the Resident Council is a great way where they can come out at least once a month, talk to the residents, and realize that they are not the only ones going though that. And they can all collaborate together to address the building and say, 'Hey, it's not just one person. It's ten of us.''

Another said, 'Residents also can see through Council that when residents share a story about 'I complained about this and it got better' and doesn't say, 'I was retaliated against,' it shows that there was no retaliation from complaining…so they also see that.'

One representative spoke about why she encourages residents to participate in Resident Councils, 'I encourage them all to do is to go to the Resident Council. That's really important. We always try to…we have [over 100; exact number de-identified] facilities…but we try to make sure that the residents go to the majority of these. And if we know that somebody is really struggling, we make a special effort to go to their room and encourage them to come because they have to realize that they're not the only people making complaints or having issues. I think sometimes people feel like they are in a silo. And again, the people that are afraid tend to not get involved in activities, not outspoken or even amongst their peers so I just throw them into a Resident Council and say, 'Look, you're not the only one feeling that.' And they can voice something there that won't go back to…theoretically…to the facility or they can see there's common problems and that they are trying to resolve them. So I think the number one thing in all of our work is to try to give

people hope. Hope that their conditions will improve, hope that maybe you could move to a different or better facility.' The representative who spoke about the value of Resident Councils in leveling the field added, 'I also encourage them, 'This is about positives too and positives for change.'' In accordance, the Resource Guide used in Marin County Ombudsman Program, California (2021) states that the Resident Council can also serve as 'a sounding board' for new ideas on how to improve 'the quality of the workplace for staff.'

A representative from another state said, 'In my mind, it would be a good time for residents to ask how their staff are trained, 'How have you trained your staff to not put residents in a position that they feel retaliation? What kind of training does your staff have?' Where residents can ask questions about staff.'

When asked about the role of the Resident Council in addressing fear of retaliation and actual retaliation, another representative said, 'We advise people to work with Resident Councils because there's safety in numbers. And you're not alone. You're not taking on a problem yourself and you're doing it with others hopefully. That's the goal. Or at least with the support of others. It's really a way of publicly addressing an issue out in the open versus behind closed doors. In effective Resident Councils, there's a communication process between the council and the management. There should be a very clear and effective interchange of information of issues being addressed, which is different than one to one…sort of behind closed doors if you will.'

A very experienced representative said, 'I think it's just what a council is…It is a time where more than one person can come together and address needs and problems. It doesn't single *one* individual out so there is some power in that. And there are public records kept that the state regulators look at and review. I think it is a *very* powerful tool. Ombudsman attends *at least* one Resident Council and try to do many more every year so that we can remind them about the right to be free from the fear of retaliation.'

One representative said, 'Resident Council is basically to help empower the residents. They come together as a collective and they're able to learn from one another, they're able to *freely* discuss some of the concerns that they see and maybe also discuss some ways that they could provide or just some advice and some education to staff as far as their experience in dealing with retaliation or whatnot.' She added that Resident Council members can also represent the voice of other residents who are unable to express their concerns, 'I see the Resident Council especially council members I see them as advocates as well for the other residents in the facility who are not able to verbally express. They are the eyes, they are the ears, and they are the voice for other residents. They are the representatives of other residents in that facility.'

Quote
"*They are the eyes, they are the ears, and they are the voice for other residents*." – Ombudsman representative referring to Resident Council members

When asked about the role of Resident Councils in addressing fear of retaliation, one representative said, 'It's one voice. Everybody is there together. The council represents *all* residents and so the residents can be anonymous. They can say, 'The Resident Council said…' Also, if the process is done right, the facility must give a response back or attend the meeting and attend the next meeting to address the concern. I always tell people like Resident Councils, 'It's a great way to handle things anonymously' especially if there's a lot of residents that go because the staff know who goes.'

She described how Resident Councils can work to represent the voice of all the residents in the care home. She said that the Resident Council can be 'sneaky' and 'the Resident Council President is sneaky. The Resident Council will go and talk to all the residents and say, 'What do you want me to bring up at the meeting? I know you don't typically come or you don't come this time or you're afraid. What would you like me to say?' So we do have some Resident Council Presidents that are detectives too. They'll gather information from all the people that are able to communicate that weren't able to attend or don't want to attend and then they bring up the concerns for the group…collectively, the whole building.'

She added, 'Unfortunately, I don't see that as much as I'd like but…because I've done this forever…I've known some Resident Council Presidents that took their job very seriously and they were going around and talk with most of the residents and they did it over the month. They go and speak with these three on this day and these four the next day and by the time the month passes, they actually talked to all 100 people or 50% of them that could communicate. So that's a powerful thing. But again, some of the Resident Council Presidents are all gung oh and will do that, some actually don't have the ability to do that because they are in a nursing home too.' She concluded, 'But I love Resident Councils and Family Councils for the same reason. They can be very effective in addressing concerns in a way that is less likely to have consequences for a specific person, which is nice.'

Quote
"I got on the PA system three days in a row before…and I would say things like, 'This is your home and if you want changes, you should come down and talk about them.'" – Mary, nursing home resident Source: Educational video Voices Speak out Against Retaliation

One representative spoke about the critical importance of group grievances (through the use of a Grievance Form) and care home written response, 'The grievance process…is it anything more than part of your performance improvement cycle and communication? I guess that's how I try to portray it to providers. If you have a culture of excellence in your performance, you're opening up this dialogue through these processes. It's a hit and miss whether it's received well or not.' He added, 'Communication is part of your feedback loop. Your feedback loop is part of your performance improvement.'

Related to it, the Resource Guide developed by Marin County Ombudsman Program (2021) states, 'Effective Resident Council meetings have the potential to help identify problems early when they may be easier to resolve and before they become a bigger problem that may involve outside agencies like licensing to resolve them.'

Representatives spoke about the Resident Council as a place where representatives routinely educate residents about their rights (such as their right to have a private Resident Council, if that's their choice) and the grievance procedure.

They also spoke about the importance of having an effective leader in Resident Councils and the need to educate the President of the Resident Council about the council, ways to run it well, and ensure that it is operated as intended. One representative said that when she educates Presidents of Resident Councils on how to run Resident Councils and what are some of the benefits of these councils, it makes the residents 'much stronger.' She added, 'You get to see these residents especially the President be that voice, be strong, stern, and not show fear.'

A representative from another state said, 'I usually see that Resident Council Presidents have a responsibility to all the residents and they take it seriously.'

Referring to Resident Council Presidents, one representative said, 'I really encourage them to involve the Resident Council…to be brought up as a group, which is very helpful because it's an engaging conversation…that helps a lot.'

One SLTCO said, ‘My program does as much as possible and [we] give them the tools to set up the Resident Council the way that they want to run it but also give them a template on, ‘Hey, here’s a common way to run a Resident Council’ and to structure it with potentially a President or Vice President and so on and do forth.’

One very experienced representative said, ‘If you have a Resident Council chair…in some of these facilities you have very educated residents who understand what needs to be done. You empower them with information on how the system works and how the system can work for them. Then they encourage other residents…this is how we can defeat what’s going on in our home. It’s really basic knowledge, empowerment, and encouragement. And if you do it in a straight line, residents get it. They know how to take the message. And it *works* when you do it correctly. It’s not back and forth. You sit and you explain to them, ‘This is the law that protects you. This is how you can defeat what’s going on here if this is what’s happening to you.’ If you explain this to your residents in the correct manner as an advocate, residents become stronger. They are not as delicate as they were before because they have a voice. Their voice matters. And we encourage them to ‘Please use it.’’

One SLTCO said that the Ombudsman representatives’ presence in Resident Councils ‘is critical…as the desire of the residents…with the permission of the residents for us to be there. But we also say that that’s the same for the staff to be there. It's the residents’ Resident Council. They invite if they want staff to be there. They have a right to be alone with *any* of us and talk about their concerns. The Resident Council is an excellent forum to educate on all their rights and in particular talk about the fear of retaliation. I think the more that this is out in the open…and we talk about this regarding abuse…if it's not discussed, then it stays a secret…it doesn't become a thing that people are paying attention to or is on their radar. I think Resident Council is an excellent opportunity to talk about that.’

A representative from another state said, ‘If we’re going to do a recommendation to go to a Resident Council to help resolve an issue with them…giving the resident that option, I would not do that unless I knew it was an effectively run Resident Council. Just like the Administrator, I would not just have someone go to the Administrator just because they are the Administrator. I would not have someone go to a Resident Council just because there is or should be a Resident Council. It would need to be, to my knowledge, an effectively running one.’ He explained, ‘It’s not going to be helpful and it’s going to be discouraging to the person that I am referring to and I am going to lose credibility in providing them helpful advice if they get themselves into a non-helpful situation.’

Challenges Related to Resident Councils

When asked about characteristics of Resident Councils that do not work well, the latter representative said, 'One of the challenges with Resident Councils at least in nursing homes is lack of participation by residents and the abilities of residents to run the meeting by themselves so they rely on facility staff to manage and in many cases run the meeting quite frankly. So we've seen a heavy influence of facility oversight and facility presence in those meetings that keep some residents from attending, it can tamp down voices that are trying to be heard in these meetings. We've seen these meetings become more facility-centered than resident-centered.'

He added, A lot of people see these as really gripe sessions or just a place to complain and they are not really a positive meeting environment where good things can come of it. It really just a place to gripe and complain and not a place to really work on other positive aspects of one's life in the nursing home. We try to help Resident Councils work on positive things like working on Holiday menus or Holiday celebration or having sub-committees on Staff Appreciation Day, Memorials, and different things like that…really full-rounded Resident Council meetings get involved with.'

Regarding the 'gripe sessions,' he added, 'It's absolutely a negative. That's why they would not attend. When we bring up the Resident Council as a way of dealing with maybe a laundry issue or food or something like that, 'Oh, I don't want to do that. All they do is complain.' Maybe they've had an experience there where it was unpleasant because it was all just about complaints and certain people dominating the meeting with their personality types or maybe even a facility person dominating the meeting with their personality type.'

Several representatives said that Resident Councils are rarely truly resident-run. For example, one of them said that it 'is rare in our area' that Resident Council only has residents in it and is 'only resident-run.'

Another representative said, 'Resident Councils are largely not run by residents. They are run by the Recreation Director, the Social Worker…they'll bring all of the heads of the disciplines in the building to the Resident Council meeting and they'll go, 'Alright, dining services, what are your issues with dining services?' while the dietary manager is in the room. 'Nursing, okay, what are your nursing issues? This is when you'll get your one or two strong residents that will say, 'You know what, the other night food was cold, we didn't get any milk with our meal' and that is not something that happens often so Resident Councils are great on paper. I don't think that they're largely effective.'

One representative identified a challenge that may occur when residents do not back each other up during Resident Council meetings, and how staff presence could influence residents' willingness to speak up about their care concerns. She said, 'When I go to a Resident Council, I am right there encouraging residents to speak up because either you have a great Resident Council or you have some where the residents don't say a word and then afterwards, 'Well, so and so said they'd bring it up.' 'Well, I brought something up last time and you didn't back me' so there's part of that. My impression about Resident Councils is that you can have a great Resident Council if you have an effective leader in it ('whether it's a resident or a great activities leader'). Great if you have a Resident Council that is actually led by the residents. I think they are more willing to speak up. But if you have a bunch of staff in there, I think residents aren't going to say much. They're not.' She explained, 'I think it is intimidating' when a bunch of staff are present in Resident Councils' and 'I don't think residents are going to speak up with an Administrator or the Director of Nursing there. They will with the dietary [staff] but they are not going to with them there. I think that's important.'

She added that one staff member 'could be there to take the notes because you do have Resident Councils where there are Presidents and I think those are the ones where you're more likely to get a response where's there's a staff member taking notes or if you have your own secretary and a resident-led council might say, 'John, you told me the other day that your hamburger is like a hockey puck.' And then another resident will say, 'Yeah, it was.' But if there's a bunch of staff in there, nothing.' That's the difference. And if I am there, I will give my piece and then I will ask questions, I'll say, 'Well, how was it that way? Tell me more about that.' Residents need to have some follow-up questions to get them more engaged.'

She shared that in her experience some of the most effective Resident Councils are run by social workers, 'I have seen some great Resident Councils where you have a great social worker who leads it and is the only one there or it's truly resident-run. Those are the most effective because you have a social worker who says, 'I want to hear your concerns. This is *your* meeting. *Yours* alone.' And for some reason, the residents are speaking. They're encouraged. If you say, 'Okay residents, this is your place to whatever,' that's nothing. They hear that every time.'

Another representative spoke about the difference between staff-run and resident-run Resident Councils. She started by describing what she sees as the value of Resident Councils, 'I think they are very powerful in the ability for them to be a good voice for the group, not just one individual. The concern I have is that a lot of Resident Councils are not run by the residents. Staff…and I get it, staff maybe have to put it on the calendar and find a room, there's some orchestration by the staff to get it organized…but it should be run

exclusively by the residents and staff should be invited to attend if so needed. What we see is that a lot of facility staff want to run the meeting and when I say run the meeting, they have the agenda, they have the topics, they are the ones taking the minutes of the meeting so they are in control and if they are in control, then they have the ability to convey to someone, 'Hey, you know, resident X complained about you at Resident Council. They said you did X.' What that does is set up this little paradigm where residents are somewhat targeted because of speaking up at the council.'

She added, 'When it is truly run by residents and staff are *invited* in to participate or to discuss an issue or a topic with the residents, there is more positive outcome that come from the council. I feel like it can be a powerful way to almost mitigate retaliation versus if it's run by staff, you see more retaliation, 'This resident complained about me so therefore they don't like me and therefore I don't like them. I am not going to care for them.' Residents are fearful to speak up when staff are in the room for the duration of the Resident Council.'

She said, 'It has been my experience that staff feel obligated to be there and run the meeting because they perceive that the residents can't do it for themselves.' She added that this may be the case in a 'memory care' home 'but for a traditional facility who has alert and oriented residents who know what's going on, there should be no reason why somebody can't lead the meeting with some kind of an agenda and somebody takes minutes.'

She also made the distinction between a Resident Council's complaint phrased as 'Mary Johns said that this person was mean to her' and 'The residents of the 200 Hallway complained in the evening shift that are not getting their call lights answered on time.' She said that the latter phrasing is preferable because it doesn't pinpoint a particular staff person and 'it isn't the paradigm that sets up for the retaliation.' The former phrasing could lead to a situation where the staff member will say, 'I know Mary Johns complained about me and so I am not going to help her anymore. I am going to ignore her requests' or 'She will be the last call light I answer today.' She added, 'I heard that before.'

Strategies to Address Staff Compromising Resident Councils

Representatives spoke about things they do to address situations where staff and managers compromise the intention of the Resident Council (additional statements related to this issue are described in the segment titled *Educating Residents and Staff About Resident Councils* in **Chapter 8** Ombudsman Representatives' Educational Efforts).

Examples of ways in which staff and managers may compromise Resident Councils:

Not respecting residents' choice to have a private meeting, interrupting, controlling, intimidating, influencing, taking minutes in a way that does not reflect residents' concerns, and not following through with concerns and suggestions raised during council meetings.

Before describing representatives' thoughts about these situations and how they handle them, it is important to note that not all representatives had that experience with Resident Councils. For example, when asked whether there are things staff do to compromise the intention of the Resident Council, one very experienced representative said, 'I haven't had that experience. I do think that some staff are more supportive of the Resident Council than others or maybe they minimize the role that the resident council plays but I haven't really found anyone that was trying to sort of manipulate things so that the resident council wouldn't have a voice…I haven't had that experience.' When asked about situations where in some care homes staff interrupt, control, and influence the Resident Council, she said, 'I haven't had that experience recently. I am aware that that happens.'

Most representatives who were asked about it were aware of at least some of the ways certain staff members in some care homes compromise the intention of these councils.

When asked about these scenarios, one of them said, 'That absolutely happens. And to be honest, sometimes staff they don't even know the difference…they don't even know any better. It's just the way it has always been.' She added, 'It's a problem, it's a problem. It's something we're trying to work with.'

Ombudsman Representatives' Presence in Resident Councils

Several representatives highlighted the importance of them [representatives] attending Resident Council meetings – whether to educate residents about their rights or to address staff and managers' actions or other factors that compromise the intention of the councils.

An experienced representative described her role in those situations, 'We get ourselves invited [said while laughing] as Ombudsmen. We want to try to attend the Resident Council meeting so we can see what happened and ask the council President if we can do a little presentation about the Ombudsman program, about their rights, about councils…and that it is *their* council, not mine, not the facility's, it's *theirs*, and what that looks like. Knowledge is power so they need to know that this is *their* meeting not anybody else's.'

Quote
"It is *their* council, not mine, not the facility's, it's *theirs*." – Ombudsman representative

When asked how she handles these situations, she said, ‘I definitely think our role is to get in there to teach people and to support them and get them set up and going.’ She then identified a challenge, ‘You know, it is sometimes manpower…we don’t always have the manpower to do it, you know, you’ve got to go with what’s important at the time…not that that’s not important but if you have an abuse case…so…you got it. But I definitely think that that’s part of our scope of work that we need to do. It’s important yeah.’

When asked how she handles situations where staff interrupt, control, or influence council meetings, one representative said, ‘I would want to ensure that the meeting is running the way the residents want it to run. Does that mean that I'm coming 20 minutes early to chat with the residents to ensure this is what they want to have happen?’

Another representative spoke about the value of her role modeling when she is attending these councils, educating, and demonstrating to residents how to protect their rights, and empowering them. She said, ‘By saying those things and to let the residents know, ‘Yeah, [de-identified name of representative] can do that. Well, we can too.’’

A very experienced representative said, ‘It is encompassed in attending those Resident Councils. We also make a point on our every routine visit which is quarterly that we meet with the Council President and talk to them about things that are going on and during that time we say, ‘How are things going with the meetings? Are you being allowed privacy? Is it going the way you want it to go? Are people coming back with answers to your issues?’ And from there, it is education to that President of the council.’

I then asked her, ‘What happens if the President says, ‘You know, we talk and talk. We write and write. We submit our concerns. Nothing happens.’ What do you do then?’

Her response was, ‘We say to that council President, ‘Could *we*, could *I* as an Ombudsman representative assist *you* with this matter on behalf of your council group?’’ I then said, ‘The President says, ‘Yes.’ What do you do next?’ To which she replied, ‘We go to the Administrator. Sometimes I start with the social worker or the activity director because I found that the role kind of starts there. I ask for a meeting. We go in and we discuss that, ‘Look, the purpose of the council is to empower your residents. It is to make you aware of problems in your building before we come and before the state comes with the regulatory book.’ It is beneficial. I think that one of the best tools you have is to make the nursing home feel like you’re helping them, ‘It is beneficial to you. It is going to keep you out of trouble if we can help this council really form and prove to them that you are here hearing and changing issues that need to be changed.’’

The following segment addresses different ways certain staff members compromise the intention of Resident Councils and how representatives work to handle these situations:

Interrupting / Not Respecting Residents' Right to Hold a Private Resident Council

Referring to staff interruptions of Resident Council meetings, one representative said, 'I've definitely sat at the back door sometimes to ensure that staff were not walking in because it's amazing how frequently that happens.'

Another said, 'Years ago, a nurse came in and actually gave an insulin to somebody in the meeting and didn't say a word…just came in and [said while making a head gesture indicating giving an injection]. Again, how do you educate your staff to not interrupt the resident council meeting? That that is their time.' Her colleague added, 'Giving an injection like that in a meeting would be a violation of rights…a demonstration of the problem.'

Quote
"*How do you educate your staff to not interrupt the resident council meeting? That that is their time*." – Ombudsman representative

When asked how she handles situations where staff members interrupt, control, and try to influence council meetings, one representative said, 'You hit it right on the nail…where they *don't* respect the Resident Council meetings. As Ombudsman, I often have to educate that, 'This is not your council. This is the residents' council. They should be able to hold their meeting in a private area or a place.' You've hit it right on the nail.'

When asked what she does when staff interrupts Resident Councils, a representative from another state said, 'We let the residents know if this is happening, that they need to contact us…to give us a call and we'll educate the staff. This is not allowed. And then what the repercussions are if they continue to do it…what's going to happen.'

When asked about her role when staff interrupt, control, and influence council meetings, one representative said, 'In Resident Councils, we're kind of sitting back and we're there to be there support system. We don't take over the meeting by any means. We're just there for them. But if I hear something, then of course I jump in and make my comment.'

Another representative said, 'I'll put the PRIVATE MEETING note on the door and then the first step staff will come through, I'll be like, 'You need to turn around' and then I will actually put that in the notes for the meeting and I'll even ask for the staff person's name as

they enter, ‘I need your name’ and then, ‘You need to turn around and leave.’ I capture all of that in the Resident Council’s minutes.’

When asked about representatives’ role in addressing situations where staff interrupt, control, and influence Resident Councils, a SLTCO said, ‘I throw anybody out that shouldn’t be there. I’ve caught them a lot of times in different homes. Having staff going in and taking blood pressure and giving them medication. I throw them right out. I tell them, ‘Get out.’ There should be only one person in there taking the notes and it is not the Administrator…it is usually the Activities person.’ When asked how she helps the council in these situations when she is not there, she said, ‘By calling the President of the Resident Council and asking them if it’s being run correctly.’ She added that she educates them on their rights and ‘ tell them to throw them out if they come in there.’

One representative said that she brings a copy of the federal law to the Resident Council meetings (‘We give it to them in writing’). She said that she educates the residents about what the federal law and regulations mean and how it is designed to protect them and the formation of the council. She said she educates residents about the Resident Council by giving them a Resident Council Toolkit. She added, ‘We try to provide residents with as much as we possibly can for the simple fact…education is key, knowledge is power. Staff have this obtuse attitude…it just irritates me…that they are entitled to be there in the meeting. If staff are sitting in a Resident Council meeting, we ask the Resident Council President, ‘Did you invite them?’ If the Resident Council President says, ‘No,’ here it’s in the regulation, remind them, ‘Upon invitation’ and you are in the catbird seat at this point. Residents didn’t feel that they had the right to do it because staff invited themselves. We educate them that their voice matters. This is a private meeting. Unless it affects that particular department, then you ask those folks to excuse themselves. And if you could see the attitudes on those staff when they have to leave because we have to explain to staff, ‘This is not your meeting.’’

When asked how she addressed staff practices that compromise the intention of the Resident Council, another representative said, ‘I try to attend all the Resident Councils every month and it’s our job to ensure that the Resident Council and the members who attend know all their rights and that it’s for them and we’re a tool and support for them. Staff shouldn’t be attending.’

Another said, ‘I have residents who call anonymously…they don’t want to give their name and they just want to ask a hypothetical question, ‘We were in a Resident Council meeting and someone has brought up an issue about food and the next thing you know the cook is in the Resident Council meeting and they’re questioning things, ‘Is that right? What can we do?’’ They’re calling to try to empower themselves, and speak up, and advocate for

themselves. We get those calls all day every day. We try to empower them the best that we can and let them know what can and can't happen and that should not be happening.'

A representative from another state said, 'I am actually working with a Council right now…who had decided that they do not want staff in there in the meetings because of staff retaliation…and it is their right to do that.' When asked about the nature of the retaliation, she said, 'A couple of residents had expressed that some of those subtle things were happening. They weren't invited to activities when they used to always be invited to activities. We weren't able to prove some of those things but they all felt collectively that this was an issue and also some of them [who] were more vocal during Resident Council meeting felt like the staff were not coming into their rooms because they didn't want to be complained about [said the two words complained about with a gesture indicating quotation marks]. They were not receiving the care that they needed. I've seen that…I've worked in a building and I've seen that with staff… They don't want to go into a room because they don't want someone to complain about them…so they just don't provide the care. So those were the things that the residents were voicing that were happening.' She confirmed that this led to the residents' decision to hold Resident Council as a private meeting, 'Yeah, the first one was yesterday…so we'll have to see as we move on if that changes what they've been seeing.'

She went on to say, 'The biggest thing is making sure that they have a pathway to take notes and to write down the grievances and they know who they can bring the grievances to for follow up…so that is what we've been working on…empowering that Resident Council to be more independent, which is what they want. They feel more protected because they can talk about the concern however they want to word it…they don't have to think about it if they're going to send a staff person. And then, just making sure whoever is responsible for communicating that concern, that there is a clear pathway for them to follow…they're using a form to kind of guide them so it makes it easier that they'll be able to give [it] and that there is going to be a response that the facility can give to the council. I think that clear pathways are important.'

When asked about his role when staff interrupt, influence, and control Resident Councils, one representative said, 'I wish we could solve all the world's problems. That's a great question. I'll start with…we don't deal with all of them. We deal with the ones that we can deal with as the time allows. What I would say is, typically, as things start to emerge within the iron fist culture, that power and control structure, it usually becomes pretty evident through the casework that we're doing or the outreach that we're doing. Each situation is a little bit different because I think sometimes professionals just kind of get caught up in the

hustle and bustle of what their job is and sometimes they may be just oblivious to the fact that this culture is kind of taking on its own course.'

He went on to say, 'In other places, sometimes it's very intentional and it's very control oriented and it's very rooted in the leadership style and the leadership strengths and or weaknesses of the person in that position.' He added, 'An aggravated level of a sense of retaliation, usually that is not in isolation….people don't move from one environment to the next to the next and just change their colors. If you have a leadership culture that's oppressive to one resident, let's find out who else is willing to talk within this group. All of a sudden, we start creating an emergence…a construct of a collective voice that includes…so that's probably been one of my most successful approaches.'

Controlling and Influencing

When asked about the impact of staff presence during Resident Council meetings, one representative spoke about ways in which staff try to control the issues discussed during the meeting, 'I feel that when building staff are involved, they try to manage the conversation. If there isn't any staff, people speak not just freely but also no one is trying to control the narrative. No one is trying to control the topic of the conversation.'

She added, 'I think that what the facilities do they control the narrative and they actually have this pre-printed…what *they* are going to address and then a lot of times they tell residents, 'No, we're not discussing that here.' Her colleague said, 'They'll say, 'Oh, we already discussed that in our last meeting. We already addressed it. We are not going to talk about it again.''

The first representative described how she handles these situations, 'I try to take staff out of it and just have a meeting with the residents so they can speak freely and then you'll see that they will *speak* freely when it's just us. Like when we go out to do Resident Council meetings sometimes, they will speak freely and tell us everything.'

When asked whether there are things staff do to compromise the intention of the Resident Council, another representative shared this **story**: 'One of the council meetings I went to…it was really *led* by the staff and there was a certain question asked…the question was, 'The food is getting better with our new cook. *Isn't it?*' None of the residents spoke up. That staff member was there taking minutes.' She explained, 'They are looking for one answer. They provided the answer in their question…they may not feel comfortable giving the correct answer…that's their answer…in front of the staff member who just asked it. They answered the question themselves when they asked it.'

She described how she handled it, ‘I kept my mouth shut until I was in private with the staff’ and then, ‘After the meeting, I spoke with the Resident Council President [and asked], ‘How do you feel about the staff member being there taking minutes? Is that something you guys prefer? Is that something that was agreed upon? Do you know how the other residents might feel about that?’ I talked with him about that, ‘You can change your mind anytime if you don’t want the staff there…if you guys prefer [not] to have a staff there.’ She added that after the meeting, ‘I went to the individual that was there…I believe it was a social worker and I said, ‘Look, just so you know, I wouldn’t have felt comfortable answering your question because you asked it.’ I said, ‘If I was eating the meal and you were asking me, ‘Isn’t it getting better? It’s getting better. Isn’t it?’ Well, you work here. I wouldn’t feel comfortable answering. I said, ‘Be sure that with each meeting you’re asking the residents, ‘Are you okay me being here for *this portion*? If you guys wanting to complain in private, I can leave.’ So that way it’s anonymous.’

When asked about the role of Ombudsman representatives when staff intentionally compromise the intention of the Resident Council such as by interrupting, influencing, and controlling the council meeting, one representative said, ‘We try to address it. We take direction from the Resident Council members and so if we see something like that, we address it in the way the Resident Council would like us to.’

She added, ‘Sometimes it means that we have to do it after the meeting because we might not want the residents to feel pressured and that's typically my style. I'll wait. If I'm going to a Resident Council meeting and I notice something like that where somebody's got their own agenda, they won't let the residents be independent, staff keep coming in and out, stuff like that, I probably go to the Resident Council President or maybe talk to few members or people and give them the Resident Council Handout from the National Ombudsman Resource Center…the consumer voice. I love that. And I’ll say, ‘This is what Resident Councils are’ and how can we help you with this? Can I address this?’’

When asked about the possibility that waiting until the end of the council meeting may mean that residents may have been afraid to speak up during the meeting and thus their concerns were left unaddressed, and they’ll now need to wait a month until the next council meeting to voice their concerns, she said, ‘It depends and again I've done it different ways but I think and so the staff and we have volunteers that do a lot of Resident Councils too and I think it depends sometimes. I think most of us would want to try to do something during the meeting but my example…the one I just mentioned was in situations where that wasn't going to…clearly not going to work.’ She explained, ‘We have some staff members that are just so aggressive that you need to. But you're absolutely right, the

consequence then is that a month passes and it's a big waste of time and also not good for the resident but yeah but if we can.'

A representative from another state described how in one of her buildings an Administrator tried to influence the Resident Council by working to remove a recently voted in Resident Council President, 'I have a very strong Resident Council in one of my buildings. So strong that they're actually…they were so scared of retaliation…and at some point in time last year they called me in for an emergency meeting. At this time, I had eleven people accuse all of the staff of abuse and it was real bad.' She shared that some of the issues had to do with a nebulizer thrown at a resident and a bariatric resident not allowed to get out of bed ('It's not your day to get up') and going 'months without getting a real shower. She was getting bed baths occasionally but no showers.'

She described her intervention, 'We worked it and we worked it hard. It took a whole long time to get it figured out but that is the strongest Resident Council I've ever had. They had new administration in that building. Well, during this process, those people had the [Resident Council] Toolkit, they run those meetings like they're supposed to, they're using the grievance forms like they're supposed to. When I say grievance form, that means they fill out a piece of paper with their grievances on them, they sign it, and they turn it in, they have to give it back to them. You know, really do it right and that's the only facility I have in nine counties that actually does it right. Well, when I was in there [de-identified time], the new Administrator doesn't like how the council being run and she has been encouraging the other staff members that they can vote the council President out, 'You can pick who you want' so I took her a copy of the Toolkit and basically said, 'You know, you really don't have a place in the Resident Council.''

The Administrator was trying to get the Resident Council President off her role. The representative said, 'They went around talking to the other residents and said, 'You know, if you don't like your President, you can change that out. You can have a meeting and you'll get to decide' and all those things.' The thing was, 'They've just done a revote. They do a revote every year and they've just voted the lady back in.'

The representative continued to describe her intervention, 'I gave the Administrator a Toolkit, I gave the President a new Toolkit and I told the Administrator, 'Look, it's best if you just stay out of that.' I told her, 'If you have a resident that has a problem with what's going on, you call me and I'll come down here and I'll talk to her and I'll maybe mediate some of the problems that are going on.' But she is not going to call because there's really no problem. It's her problem getting these grievance forms. She doesn't like that.'

When asked about the outcome of her intervention, she said that the residents are able to run the Resident Council in the way they wish to run it ('They still do what they do') and that the recently voted in President continues in her role.

Intimidating

Representatives said that staff and managers' presence during Resident Councils and things these employees say during councils could sometimes be intimidating for residents when it comes to speaking up about their care concerns.

When asked what happens to residents' comfort level when care staff members are present during Resident Councils, one of them said, 'Depending on the community. I've had both. It just depends on the community. I've had good and bad.'

Another representative shared her thoughts on staff actions that compromise the intention of councils, 'It's a case-by-case scenario. It's gonna depend on the facility, it's gonna depend on the administration that you're working with because for us it all starts at the top…the administration and how that administration's going to handle such concerns.'

Example of unwanted and intimidating presence of managers in Resident Councils:

One representative said, 'In my experience, Dietary and Nursing are the heavy complaint getters in Resident Councils so if the Director of Nursing is there and is upset that they're getting all of those complaints, you're not going to want to voice that concern.'

Another representative said, 'In one of my assisted livings the residents were pretty fearful of retaliation because it was like every head of like every department was in the Resident Council meeting and they're like [said with a fearful facial expression], 'Oh man, we just feel like there's a target on us in Resident Council.''

The representative explained to the residents that 'a true Resident Council does not have staff members in it.' He added, 'We actually started a Resident Council in that facility on the weekends when there's less staff and pretty much no management there. I came out to help facilitate a couple of them but then the residents did it themselves in the dining room in private with no staff and then just had a designated person or else I was there. I would write down all the issues and complaints they have and then I would be the one that would take it to the administration so the residents didn't have to fear that it was going to come back specifically on them.'

A representative from another state described what she saw as a missed opportunity when staff and managers attend Resident Councils, 'They are not able to be open and honest about the concerns that they have. If they have facility staff in there, how do you speak up about an aide that mistreated you the night before? I think that if it was *truly* a confidential,

safe space, that residents could mention those things, that they might find out that that aide is abusive to a couple of them. I think it shuts people down to be open and honest about staffing…specific staff persons and maybe the abuse and neglect they're feeling. My experience from Resident Councils is it's about activities, it's about dining, it's about the way the place looks. The room is not clean. I haven't gotten a shower. It is rarely ever have I seen or heard that they complain about an abusive situation that happened…that they want to be able to voice that to their fellow residents.'

When asked about her role in addressing these situations, she spoke about educating staff and managers ('We do our education to the facility') and added that her colleagues are able to do the 'follow up that's needed to see if those changes are sticking, you know, 'Are you now having the meetings without staff being present?' She went on to describe the education work her colleagues are doing with residents, 'You know you don't have to have that person in there?' And the resident will respond, 'Oh, we weren't aware of that.' That's correct. They have to be invited. 'You don't have to have the Administrator.' The educational piece of it is what's key…to have the knowledge and wherewithal [regarding] how it should be run. And then the follow through is also very important.'

One representative described how Administrators' presence in councils may affect the residents attending it, 'That feeling that they're not free to speak freely. The idea of the Resident Council is that it's anonymous. You're there and you're part of an organism and you can say, 'We're sick of chicken and we want stake' and 'We want our linen changed at this time,' 'the bathroom to be clean' or whatever but it comes from this larger organism and not this one individual. I think that's really the important part of the Resident Council. That it's a Resident Council voice…one voice and not individual voice…so it takes the burden of retaliation off of them. It takes the burden of the fear of retaliation off of them. And I do see people that were very reluctant to speak to us or to anybody…and we attend them very, very, very much of the time. We see more and more people…people we think, 'Oh, they're never going to say anything,' they'll start speaking up and realize it's safe for them to do so.' She added, 'We're seeing higher numbers. Prior to COVID, there would be 8 to 10 people in a 110-resident building. Now I am seeing groups of 30 coming in and I think that has to do…and I really mean that…us…we are really encouraging residents to get down to Resident Council.'

Another representative described how some Administrators intimidate residents during council meetings, 'We've had a few Administrators who have come into a Resident Council meeting *to address the minutes* from months before but has just basically come into a current Resident Council meeting and she was demanding who said what and wanted to know what was going on. And I don't have to tell you…it went south very quickly. Everybody

clammed up. Nobody had nothing to say quite a few meetings after that. Nobody would speak up because they were *fearful* somehow their name was going to come out. You've just intimidated a group of 50 to 75 residents…all in one swoop.'

Quote
"Everybody clammed up"
"*You've just intimidated a group of 50 to 75 residents…all in one swoop*." – Ombudsman representative referring to Administrator's presence during a Resident Council meeting

Another representative suggested, 'If the Director of Nursing is coming to the meeting, making sure the residents know that you have a voice. You can say, 'This is our meeting. You are not needed at the moment. If we need you, we'll get you but this is not for you.''

Challenges with Minutes

While minutes taking should result in an accurate record of concerns raised and suggestions made by residents during Resident Council meetings, sometimes taking minutes is done in a way that does not reflect residents' concerns or suggestions or it may be written in a way that could single out an individual resident and their concerns.

When asked about the role of the Resident Council in addressing residents' fear of retaliation, one representative said, 'Once those grievances are put down on paper, it's a footprint for change.' Another representative said that she educates Resident Council members, 'If it gets in the minutes, that it needs to be addressed.'

While many representatives recognized the importance of accurate minutes taking (i.e., ones that are complete and reliably reflecting residents' care concerns) during Resident Councils, they also identified concerning issues related to these minutes. Some of these representatives described how they address this challenge.

One of them said, 'It's a taggable event in the state of [de-identified state]. If you don't have your Resident Council notes up to par when the State Survey Agency comes in, you can be tagged for that. From an administrative standpoint, it is on the Activity Director to make *sure* that those Resident Council notes are *outstanding*. It doesn't matter if they are substantive. It doesn't matter if what's happening in those notes is real…just that when you hand them over to the survey agency during your annual survey, they read that and it's good enough for them. That's God's honest truth.'

Another representative shared how she educates residents about Resident Council notes, 'You don't even have to give them access to your minutes. You're able to keep your *minutes* to yourself. This is not part of the nursing home property. This is yours. It's considered *your* property. Not theirs.' Nursing homes try to get a handle on that information for themselves, but they do nothing with it when they get it, and they don't respond to those issued when they get it. They want it just so they'll know what's going on and what kinds of complaints are being voiced in Resident Council but the key to this is what are you going to do to address them? When they come back to the Resident Council meeting…any complaints that have been spoken about in Resident Council, they have to be responding back in writing from the staff. If they didn't respond back in writing, they did nothing. So we educate them to, 'Keep your minutes.' The staff…those are not their minutes…by law, this is your council. So we can empower them like that.'

Some representatives said that with permission from the residents, they (representatives) take minutes in a way that does not single out an individual resident, 'The way that I do it is I never quote one resident's name. It's *all* residents in the Resident Council. I make sure all of the notes say things like, 'Late for lunches' and 'It's been four weeks in this facility where residents have not even had one shower' and then I will put that in there.' She shared that she also inserts quotes from the federal regulations into the minutes such as those related to 'dignity and respect.'

Others said that they take minutes in a proactive effort to prevent a mismatch between staff minutes and actual residents' concerns. One of them said, 'I can keep my own notes so if last month there was a concern and this month it's just magically disappeared and we're not readdressing it, that can be something I can maybe assist with.'

Referring to Activity Directors taking minutes during Resident Councils, she said, '99% of mine are *fabulous*. They do really good but then I'll tell them [the residents] I can always take their minutes for them if they don't have anybody…if they're not comfortable with it because it's a big deal to get all that information and make sure that the correct departments are addressed, you know, dietary, nursing, whatever it is.'

When asked about characteristics of Activity Directors that take minutes in councils in ways that are helpful to residents, another representative spoke about the Activity Directors she has worked with, 'A lot of mine…the residents have seen the Activity Directors take complaints from the meeting and come back with results and check in with them at the next meeting and say, 'Was this resolved? Was this resolved? Was this resolved?' If their Activity Director no longer does that or they hire a new one that doesn't do that, I've had a facility kick them out and say, 'Nope, goodbye.' The representative said that this Activity Director 'has a terrible attitude in general. I don't think they liked her very much.' She

explained, ‘Because they have a bunch of complaints about activities so they don’t want to make complaints about activities in front of the director. It’s uncomfortable. I think that a lot of my Activity Directors that sit in the meetings they’re kind of advocates for them. To be honest, a couple of mine really are in my experience. They get results.’ She added that in staff meetings the Activity Directors tell other managers, ‘This is an issue. This is an issue. What’s your response?’’

With regards to minutes taking during Resident Council meetings, one representative said (referring to the care home), ‘What they usually do is they take the Activity Director and she or he becomes the minute taker. But as much as I am soured and skeptical about our system, I find the Activity Directors to be…in almost all cases except for one my whole career…the most trustworthy and the best person in the building.’

She added, ‘The State Department of Health has turned a blind eye to that practice that there can be somebody there from the staff and it’s almost always the Activity Director. They are the ones that get the residents down to the room, they are the ones who put it on the Activity [board], and they are the ones that all week long are saying, ‘This is your time.’ They are almost the most facility neutral people because they know each resident so well individually.’

When asked to elaborate about why she thinks minutes taking is a problem, she said, ‘The Activity Director does the minutes and the Administrator takes out things from her minutes.’ She explained, ‘Because the Activity Director takes accurate minutes but when it is given to the Administrator, the Administrator edits those minutes. He takes stuff that they don’t want to see addressed.’ When asked whether this practice has to do with the State Survey Agency’s practice of checking Resident Council meeting minutes, she said, ‘All Activity Director minutes are reviewed by the state during survey. So if there’s something that they either can’t resolve or don’t want to resolve or see a habitual presence of it, the Administrator will remove it from the minutes.’

She confirmed that these Administrators do it in order to portray the care home in a favorable light in the eyes of the state surveyors. She said, ‘Yeah, because what they are supposed to do after they get the minutes, they’re supposed to go point by point and give answers to the group that would be addressed at the next meeting. So I am complaining about ‘We don’t have any Pizza’ and the Administrator is going to respond with the solution. But if they don’t like any of the questions, then they just eliminate that.’

When asked how she knows it, she said, ‘We see it because we’re now to the point where we take separate minutes that we don’t share but we can see that it’s not lining up.’ She added, ‘We even got to the point…it was so bad in one of our facilities [that] we audiotaped

the meeting….we recorded it and then we gave the recording to the Department of Health. We said, 'This was the meeting. Compare the Administrator's minutes with what was actually said. Don't just take our word for it. Here is the recording of the meeting.''

She said that when state surveyors go into care homes 'and not all the time but I would say 25% of the time the surveyors are having Resident Council meetings. When they're there, they call one. They'll say to the Activity Director, 'Can you put together a Resident Council?' and the surveyors will attend.'

She explained why she thinks surveyors holding Resident Council meetings is important, 'To us, these Resident Councils are so important to the work that we do…not only to the work that we do but the possibility for change. It's really the only collective voice. Because…I assume the surveyors are federally mandated in how they operate. They are heavily interview-based these days. It changed about seven years ago. But a surveyor going to a resident's room to ask questions, if you have one of these very reluctant residents, they are not going to get much, you know, who is scared for retaliation…especially if it's a [State Survey Agency] person. So I think the Resident Council is a really important place to effect change or to effect at least knowledge or to get the knowledge. But if you got some stuff going on in the background, it's not helpful.'

Lack of Follow Through on Concerns Brought Up During Resident Councils

During a recent Moving Forward Coalition webinar reporting on updates from the Resident Councils Workgroup, concerns about follow-up from Resident Councils were discussed. Eliz Speidel, who works at the New Jersey LTCOP, said that this issue represents one of the biggest challenges and that it is why people stop coming to Resident Councils. She said that a lot of times, whether and how the concerns are addressed by the nursing home is not reported back to the council meeting. She added, 'That is a big issue.' Alice Bonner, Chair, the Moving Forward Nursing Home Quality Coalition, agreed, 'That is a huge issue.'

One representative said, 'I often just say, 'Hey, I am available. If you want me to attend a council meeting…I am happy to be invited and they do. Then when I am there at the meeting, sometimes they'll read through the minutes of last month and I'll say, 'Well, what did you do about it? How did you address it?' Well, you're talking about it but what was actually done?' We have a handbook that our program has…a Resident Council Handbook that we refer them to that and there's good information in there.'

A representative from another state also described how she checks minutes from previous Resident Council meetings to verify that prior concerns were addressed. She said, 'When I go in, I always ask to look at their notes from their monthly meeting if I didn't attend the meeting. She went on to share this **story**:

‘I’ve seen that they had two grievance forms out and one of them was…one of the residents didn’t get her money from the trust fund which she asked for it…and unless it’s on the weekend, they have to give them the money at that time they ask for it. They’re not supposed to make them wait and they were making them wait. I just took the regulation back up there and said, ‘Here’s your regulation for your trust fund. I’ve seen one of your grievance forms in the book and this is your answer to one of those.’ And she said, ‘Oh, yeah. We already looked that up and we have addressed that and I talked to the HR manager. We’re going to fix that.’ And I said, ‘Well, you didn’t have that in the book. I didn’t see the response from you…so I wanted to make sure you had that.’’

When asked about situations where Administrators don’t follow through on concerns from councils, one SLTCO said, ‘If it’s an observation that we see, we certainly address that with the Administrator and just give our observations of how we saw that occur within the Resident Council. We always talk about residents’ right to be able to meet alone and that it is their decision and that there needs to be *respect* for that and that you’re not there to drive Resident Council. Oftentimes what you’ll see is, ‘Hey, tell us what we’re doing great’ but then they don’t want to hear any concerns or complaints.’

Another SLTCO said, ‘A skilled Ombudsman is going to take into consideration what’s going on in that facility right now. If they’re in the thick of all of that and you can’t get anybody on your side within leadership to care about it or tend to it, that could be a dangerous situation for the residents to suffer more retaliation or abuse.’

Another representative shared that he encourages residents to use a form that can help residents avoid what he described as ‘an endless loop of B.S.’ that occurs when residents are ‘stuck in that cycle where the facility is like, ‘Yeah, yeah. We’re working on it’ (referring to care homes that make ongoing promises but do not follow through on minutes and concerns brought up by residents during previous council meetings). The representative said that the form is designed to close that loop, provide a paper trail of the minutes and concerns over time (across council meetings) and increase providers’ accountability. He explained, ‘Because it sets them up to respond to residents’ concerns and suggestions for improvement in a more structured way.’ He said, ‘I love that form for that reason.’’

Quote
‘*Yeah, yeah. We’re working on it*’ or what has been described by one Ombudsman representative as, ‘A*n endless loop of B.S.’*

When asked about what he sees as the value of using the form, he said, 'It's less about minute keeping or a paper trail…although it does create a paper trail. It's more about changing their approach from, 'This is a problem' and then you move on to the next topic, and then you run through repeat the next month…than moving it more to, 'Okay, we the Resident Council body identified this problem when we talked about it beforehand. Here is a creative solution that we want you to pursue. Since food is a common complaint, I'll use that as an example, 'We want to try a new vendor' or 'We want you to bring in your corporate chef to train folks down here who are doing it' and then it sets them up have to say back, 'No, we're not going to do that but this is what we're willing to do' or 'Yes, we're willing to do that' and so on and so forth.'

His colleague added that the importance of the form and the minute taking stems from the fact that the SSA looks at these forms. She said that surveyors may ask the Activity Director for Resident Council notes from the past six months and the Activity Director has to provide these. The surveyors can see, for example, with regards to ongoing issues with showers, 'the residents have brought it up the last three months and it doesn't look like you guys have done anything to resolve it because residents are still complaining about it.' That, to me, is the value of that.'

One SLTCO said, 'We heard Resident Council saying, 'Maybe we don't want that staff member in here…they don't take the notes right. They don't write things down the way it's happening.' She went on to say that during COVID-19, all Recreation Departments received an iPad from the state and so they [representatives] encouraged the residents to ask staff to leave the Resident Council meeting and use the iPad to record the meeting. She added, 'We have a Zoom license through the state…to use the Zoom…it'll be yours or just use the recording through notes, you know, maybe have a Resident Council notes section and hit record and let it record what's happening.' She added that with the recording, if staff interrupts the meeting, the recording will be the proof. She said, 'You can send that to the [State Survey Agency], you can send it to us. So really looking at how do we give them tools and strategies to empower them. And once you start to do that and they get a little confident around that, we've seen that gets the ball rolling.'

Negative Effects of Physical Environment on Resident Councils

When asked how often there's really a closed door in Resident Council meetings, one representative said, 'Rarely ever. It's rarely ever private private.' When asked, 'Even if residents want it to be private?' the representative said, 'Oh, if they say, 'I want no staff there,' I think they're more likely to have it be private but for a lot of facilities just finding the space to have an enclosed private room is not practical.'

A representative from another state said, ‘It has to be a private space and oftentimes it could be in the dining room or in a room where staff are walking back and forth, visitors could be walking by. It's not a safe place and it's not comfortable. For me, I try to at least once a year get to a Resident Council meeting. Usually the activities person asks residents [if it] is okay if I attend. I sit back and I see how they run it. I sometimes request a copy of the agenda if residents are okay with it…just to make sure they're actually doing it and doing it with a purpose…not just having a meeting just because. Some are definitely run better than others…yeah, it can be tough. Some don't even really have one. But I think, for me, if I can get to one to see a general idea of how it's run and get a copy of the agenda and the follow-up I try to as often as I can.’

She added, ‘I am not sure residents actually know their right to have a private space. I think if somebody just gets there and it's been in the dining room, well that's where it is. Some places don't have a private area designated. This is in one of my facilities and they don't have a space big enough, which is unfortunate. So I talked with the residents, ‘Okay, if you're uncomfortable bringing something up like staff walking by, have sort of a suggestion box where throughout the month you can put something in that box and then the staff will read it, which we've implemented which works somewhat. But if the building doesn't have a space, I can't create one. Some of this we've made referrals to licensing which doesn't get too far and then I'm stuck…my hands are tied.’

A representative from another state described how certain care homes make the residents hold their Resident Council in the cafeteria. She said, ‘The cafeteria is not closed in. I said, ‘No. We can’t have the Resident Council meeting out here. There is no privacy.’ So they had to find us a conference room big enough to accommodate.’

Her colleague said that some care homes make the residents use a small room for the Resident Council, ‘They go from the dining room to a small activity room or just to a really small room and that makes it that instead of having 30 residents in a Resident Council, it makes it down to maybe 5 or 7 residents. They do that purposely. I see that absolutely purposely done. It’s horrible.’ She explained, ‘They do that so residents don’t have a say in the Resident Council to bring up concerns.’

One representative said, ‘Sometimes they’ll have those meetings…say in the dining room and the kitchen staff are *real* good about interrupting. They will purposely leave the door open and [missed word] all the dishes so much that nobody can hear…much less when they’re hard of hearing.’ She added, ‘Sometimes they’ll call and say, ‘We can’t hardly even have a meeting.’ So I’ll go in a say, ‘You know, they’re supposed to have a private place and you’re supposed to have a sign saying that their meeting is still going on’ and all of those things. That is really a struggle sometimes because some of those buildings aren’t built

with a room that would hold a council. Now, some of them are and they have private rooms but if they have to have it in the dining room, that usually is going to create a problem or if they have to have it at the end of the hallways, those don't have doors on them. I'll see more staff on that hallway during a Resident Council meeting than 10 visits combined. I know that their purposely sending staff down there.'

Another representative said, 'If it's too loud. A lot of those places have the pop machines…so they have the refrigeration going and it's *really* loud…a lot of residents can't hear and I'll basically be like, 'That gets unplugged.''

Other Challenges with Resident Councils

Representatives identified several other challenges related to Resident Councils.

One of them said, 'It's important to inform residents of what Resident Councils are because a lot of times they don't know.'

Another representative described a challenge with Resident Councils when only a small number of residents participate in them (the challenge partially has to do with the risk of care homes singling residents out). The representative said, 'If I don't have a strong Resident Council, it's more difficult because that Administrator knows there are only four residents, maybe six residents in this Resident Council so that's a challenge.'

A representative from another state identified a challenge with Resident Councils with a high proportion of residents in advanced stages of dementia. She said, 'I've got two facilities that it's really hard to get people at the Resident Council because a high percentage of the population with moderate to severe dementia. There are very few alert and oriented residents in those buildings.'

She said, 'Here's how it will go, 'Okay, how is Nursing?' Nobody says anything. 'Okay, how is Housekeeping?' Somebody may say they lost a red shirt last week. 'Okay, we'll try to figure it out.' When I am there, they say, 'How's Nursing?' Nobody says anything and the staff person starts moving on to the next department and I'll say, 'Excuse me. Do you mind?' And of course, my residents know me quite well so they don't mind me speaking up and I'll ask, 'How are you getting your call lights answered?' *That* will start the conversation.' She added, 'Are you getting your medicines on time?' Things like that. But if I am not there, those things don't really happen. If I am not there, it is my understanding that those things don't really happen. They just breeze over everything.'

One SLTCO identified a challenge related to the way Resident Council Presidents lead the meeting, 'I have been in meetings…Resident Council Presidents sometimes have taken it off and going on their own agenda. I've even said, 'You know, keep in mind, this is for the

group.' These Presidents try to take the council meeting 'in their direction, which has nothing to do with what a Resident Council should be.'

She shared this **story**: 'We had several people that wanted it to be a religious experience. Nothing against religion. That's fine but it's a secular meeting. I've had some people…that's what they wanted Resident Council to be. And I've had others [where] it was all about them. They didn't include the group. They just said, 'Let me tell you my concerns' and they would list them and again, to explain to them, 'This is about the whole and about things in general and there's another time and place. Your concerns are important but there's another time and place for that.''

An experienced representative shared this **story**: 'I have two just this year. Two different Councils in two different facilities that I had to step in. The last one I just did this last [time de-identified] and this was a situation where the residents themselves were retaliating against each other. They had an election and one person they ignored others' votes and wanted to step in and they were issues with staff coming to the meeting.'

She added, 'So I attended their meeting and helped them run a Resident Council. I brought them bylaws, agenda on how to go through, shared that this was *their* meeting and their voice and that staff were invited guests, not assumed to be able to come in…that they were invited, and explain the different roles, how they elect officers. So next month we're going to have an election that gives everybody the opportunity to run for office and to be appointed, voted in. So I have worked with two groups that have been quite disruptive and worked through those things. It's just to kind of guide them in how to run a meeting where everyone's voice is heard and it's not one person dominating the meeting, a staff person not coming in dominating the Resident Council. That they fully understand what the purpose is and how to run a meeting.' She clarified that the vote was for who is going to be the President, Vice President, and Secretary of the Resident Council.

When asked to elaborate on the nature of retaliation, she said, 'One resident was the secretary and the Chairperson at the time wanted her friend to be the Secretary…so she fired her from the position and had someone else appointed. It was unfairly handled, there was a lot of grumbling, people felt that their voice was not heard…so that's kind of where that direction went. It's to make sure that all residents got the opportunity to be a part of the Resident Council.' When asked more specifically about the retaliation, she said, 'They did not get along so that's really why she got fired from her position and then went around to try to encourage others not to vote for her' (i.e. the President tried to get her off and replace her from the position of the Secretary of the Resident Council).

Another representative described a challenge with Resident Councils after COVID-19. She said, 'I think *many* Resident Councils particularly after COVID they ran roughshod…of course they didn't have any Resident Councils during COVID…and then when they came out of COVID, I think they…the impression…of course I am talking about staff and the administration, they could do whichever way they want…not really running Resident Councils correctly and some of them having the Administrator sitting there at the center of the room or not taking accurate minutes which the DOH [Department of Health] looks at when they come in and then the response…all that kind of thing. So we are here in Western [de-identified state] doing a lot of training and advocacy and making sure that the Resident Councils are being run correctly. Because it is so important to the residents. You can't say, 'Speak freely' and then having the Administrator sitting there for the entire meeting. It's fine if you invite him in and he addresses a problem but when he is there and that presence is there, it becomes a real problem.'

Several Representatives Thought that Resident Councils Are Ineffective

One representative said, 'A lot of those Resident Councils are not empowered the way that they need to be empowered…so that's work that we try…we need to do better…we need to get in there more.'

Another representative said, 'Most facilities do not do proper Resident Council meetings. I think part of it is they don't take the Resident Council President role seriously.' She added, 'It all comes down to the Resident Council President.'

A representative from another state, 'With the exception of one of my facilities, Resident Councils are completely ineffective…the way they currently exist.' She attributed it to the ways staff compromises councils and gave an example, 'It is pretty common for the Activities Department to lead the Resident Council so if I am not there, what they will do is they will go through and just read and I mean literally read off the activities calendar and then then will all go back to their rooms. They don't even go over complaints. They're telling them the activities for the next month and that's all they do in the meeting.'

She added, 'I've got one Resident Council that the facility actually does go down the form, 'How is Nursing doing? How is Housekeeping doing?' And they actually put an effort to address the issues that are brought up there. The others [said while shaking her head from side to side; she thought for a few seconds and then said], It varies widely.'

A very experienced representative said, 'I would have to say generally too that we are finding ourselves in a place where we have fewer and fewer resident councils that are even established so not every home here has an active resident council so that's probably part of me not necessarily experiencing someone negating their effectiveness [referring to an

earlier comment this representative made where she said that she doesn't have experience with staff compromising the intention of Resident Councils] because we probably don't have as strong of Resident Council presence in every particular home right now which is something that I think we've kind of thought a little bit more about. We have one particular staff person who's been working on that in her homes.'

When asked what underlies the trend where they have fewer Resident Councils, the representative said, 'I think for some homes it's been sort of a lack of active presence of residents that been willing or interested in participating either because they just weren't physically well enough to participate. I think the acuity of some resident populations has caused it to be more difficult to establish a resident council.'

Statewide Resident Council – A Vehicle for Legislative Changes

Several representatives from different states who were asked about it did not know about the existence of a Statewide Resident Council (such as those operated in Connecticut and Pennsylvania). When becoming informed about it, one representative said, 'That sounds kind of cool.' Her colleague added, 'That sounds interesting. I wish we did.'

This finding may suggest a need to encourage LTCOPs in states that do not operate a Statewide Resident Council to consider starting one.

Resource Box
A good example in general and when it comes to the role of the LTCOP on the 'systems advocacy' and legislative changes front is the Statewide Resident Council in Connecticut. Beyond other roles, this council was instrumental in the passage of bills aiming to enhance the rights and protections of LTC residents. For details, visit Connecticut LTCOP's Advocacy webpage. Another innovative initiative of the Connecticut LTCOP is the Statewide Family Council.

Examining 30-day Discharge Notices

Several representatives said that they examine 30-day discharge notices on a regular and time-sensitive basis to see whether the reasons stated by the nursing home warrant a discharge per the criteria set in the federal regulations or whether the reasons stated by the assisted living warrant a discharge per state regulations.

One of them said, ‘I'm kind of known as the King of Fair Hearings in the state so that's how I deal when it comes to discharges. When my facilities like to give residents discharges, I will meet with the residents and a lot of times they're just like, ‘Oh my gosh…there's nothing I can do about this…I got this notice and it's just going to get worse for me till they find me a different place. I've got to do it.’ And I'm like, ‘There's very few reasons why a 30-day notice can be issued’ and I go through it with them and if we really feel like they have a strong case or the facility didn't do stuff properly, I help initiate lots of fair hearings.’

The representative shared this **story**: ‘I've had one Administrator at an assisted living…he pulled me aside and he said, ‘You need to stop [de-identified name of representative].’ I said, ‘Stop what?’ and he said, ’Stop doing these fair hearings.’ He said I had cost him…he blamed me. He's like, ’You have cost me something to the tune of like $16,000 in legal fees because you keep taking us to fair hearings.’ My response to him was, ‘Follow the rules, follow the regulations, *you* know them. Don’t try to pull this stuff any longer.’’

Quote
“Follow the rules, follow the regulations, you know them. Don’t try to pull this stuff any longer.” – Ombudsman representative speaking with an Administrator about inappropriate discharge notices

The representative added that Administrators ‘will give a 30-day notice’ saying ‘residents are over a level of care. But really, are they? Who has diagnosed them as having over level of care? You know, just certain things like that or they're like, ‘Due to the “behaviors” [said with hands’ gesture indicating quotation marks] like, ‘Oh, they got caught smoking once in their room or right outside the facility so now behaviorally the facility can't meet their needs’ and it's like, *come on*.’

A representative from another state shared a **story** about a resident experiencing retaliatory wrongful involuntary discharge from a nursing home. The resident was ‘highly confident and to some staff very difficult to deal with.’ He had un unpaid bill of tens of thousands of dollars [figure de-identified] that he owed the nursing home. He didn’t have any family support.

The way he accrued this bill is that ‘he could no longer pay the liability amount of his Medicaid. It was just kind of piling up but then there was some irresponsibility of the resident as well. He knew very well the liability amount. There were times when he was just not cooperative of doing that but regardless, the regulations say no matter if the resident

has to pay or what not, the facility has to do their due diligence and allow the resident to return especially if they transfer from the hospital and they had that four free Medicaid stay and then also they did not issue him a 30-day discharge in accordance to the regulations. They did not allow him the right to be able to appeal. Because they did not follow these regulations, regardless of his high bill or his inability to pay, the facility was mandated to follow those regulations.'

The representative said that the resident 'knew his rights. He knew very well about the 30-day discharge and transfer regulations that CMS has and so he utilized his right…he wanted to do an appeal.' She added, 'Well, he got sick, and he had to be transferred to the hospital. The resident stayed one or two days…they were able to resolve his illness, and he was ready to return back to the nursing home where the Medicaid guidelines state that when a resident is transferred to a hospital, they do have that four-day coverage through Medicaid. Well, the facility of course told him that he could not return because he had this high bill. They were giving him a *really* difficult time. They also told him that because he disagreed to pay a bed hold, that they really did not have a bed for him and so he could not return.'

She went on to describe how she worked to resolve the situation, 'He reached out to me and I was able to intervene and talk with the administration. Of course, I could tell that they really didn't want this resident to return back but I of course educated them on the guidelines of the 30-day transfer and discharge policy. I also told the administration, 'He's only been in the hospital two days and that Medicaid would cover up to four days. He should return back to the nursing home. If this does not happen, then I will make a report.' And I know because I went to the facility and I know that his room has not been given to another resident. So I said, 'You really need to do your due diligence to abide by the regulations and allow the resident to come back…to return to the facility.' I did have some difficulty there but I did reach out to my State Ombudsman and the [de-identified state] Department of Public health so that sort of turned things around and encouraged them to, 'Well, we need to go ahead and do the right thing.' I was able to get the resident to return *back* to the facility and he was extremely grateful for my assistance.'

She said that the nursing home was in their right to mention his inability to pay his high bill. However, she added, 'The nursing home is mandated to ensure that the resident has a safe transfer, regardless. In most cases, the resident who is needing 24-hour care is not able to discharge or transfer out. The facility may be justified…give that 30-day or they may say, 'Hey, we'll find another…we'll look in other facilities that may be able to meet your needs' but until there is a safe discharge, and of course, as an Ombudsman, we really do make sure that it is a safe discharge, that they have the resources available, and that they have

one that is able to assure that their care needs are met, then they have to remain in the facility.'

Reflecting of this case, the representative said, 'I believe it was actual retaliation for the simple fact that the nursing home…the administration, they knew the regulations and guidelines…they *knew* that…so I didn't really have to of course say anything. I did reiterate the regulations that they have to follow but it was retaliation. They wanted to see what they could get away with. I wanted to make sure that I say that professionally. I do really believe that it was a form of retaliation and also making sure that they found every avenue for him not to return. I told them, 'Well, you didn't do a bed-hold policy, you didn't. No.' He felt that he was being retaliated against, 'They're trying to do everything in their power for me not to return back or be readmitted back in that facility' and I recognized that.'

Referring to wrongful involuntary discharges, another representative said, 'They are very time sensitive. We are very fortunate in our region. We have as part of our [de-identified information], we have a non-for-profit law firm that works with us…[de-identified name of organization]. We are extremely aggressive in filing legal action at the [State Survey Agency] level to stop that nonsense. If we identify that that person is getting close to getting a 30-day letter or got a 30-day letter, we are very aggressive at getting the discharge notice. And again, my greatest fear in this world is that I don't know what I don't know…I am always hoping that I am getting the majority of the discharge notices that are out there. But we go over the discharges notices every day as they come in…it's not like next week I am going to look at yesterday's. We act immediately if there's any suspicion that things are going south. Most of the time it is…we do see "behavior"…the nursing homes are getting smarter in terms of how they position it. Like, 'Not safe here' or things like that. They use to [write] 'behavior' or whatever but now they're becoming smart. We are very proactive in trying to stop the discharge. I've seen a lot of hotel discharges now, you know, attempts to do that. We even go to the point where we check the address that they give us on their notices.'

When asked to elaborate, she said, 'We find that they are intersections or vacant lots or all kinds of crazy stuff…because most groups don't have time to check but we check to make sure that or sometimes they just put anybody who is on the list of their immediate kin or somebody that has some kind of responsibility. And then we call them and say, 'Do you know that Joe Smith is destined to come to your house in 10 days?' And most of the times, 'No.' They'll throw anything in…because they used to put TBD and we call them on it because that automatically violates the discharge notice. We're a little detectives in that world.' She added that she and her colleagues also created an Excel Sheet that anyone can use to 'track discharge notices' (including, among others, how many residents went home

and how many were leaving AMA [Against Medical Advice]. She added, 'We're really into this. This is one of our passions because really crazy things happen.'

She shared a **story** about retaliatory wrongful involuntary discharge of a resident she described as 'a heavy-duty mental health situation.' She said, 'We actually had one guy going into a hospital dump that had a piece of paper and a safety pin on it that says, 'We're not taking him back.' I mean, it's pretty extreme here in the good old [de-identified name of city].' She said that the resident 'couldn't help himself' so the care home had asked the family to find a new place for him or to take control of his situation and 'they didn't want to do it…so that was their answer.' She added, 'But the irony is that in all the cases I've handled for the [de-identified name of organization] through all these years, they've all gone back to their original facility. No one was ever…I mean, that's the law and they have to…but it makes everything just slow down and very aggravating.'

One representative shared a proactive strategy he uses to prevent wrongful involuntary discharges. He said, 'I think anytime that we do casework that results in hopefully preventing the next situation to recreate itself.' He went on to give an example related to discharge and eviction, 'If provider is willing to work with me in collaboration through the process, I give them the checklist…the checklist that I give them is my actual defense that I would use if I appeal it. So let's just honor the rights on the front end, not having to worry about us working in contention on the rear end. We're being proactive. What ends up happening? Ninety-nine times out of a hundred, it never goes to the next step because once we're starting to check these things off, *something* substantiates resolution.'

Quote
"*Let's just honor the rights on the front end, not having to worry about us working in contention on the rear end*." – Ombudsman representative

Unwarranted Commitments to Psychiatric Hospital

One representative shared a **story** about retaliation against a resident in mid-stage dementia living in a nursing home. It consisted of multiple unwarranted commitments to a psychiatric hospital. She said, 'We have a resident who has been [de-identified name of state law]-acted numerous times.' The representative said, 'It's where they feel that they're mentally unstable and they're and they could potentially harm themselves and/or others.'

She added, ‘Once I picked up on this pattern that every 30, 45, sometimes 60 days, the resident was getting [de-identified state law]-acted. This is not going well for the resident. Because we are already in that dementia state…now we’re getting called out…having police come in…it has always been a turmoil. She was sent to a psychiatric unit at a local hospital to have her meds adjusted…to come back to only have it happen again.’

She added, ‘Somewhere in the mix of me going through discharge notices is when it became a pattern and I started keeping an eye on it. I went to the facility, made sure everybody's doing okay, and the resident was okay. She does have dementia. She can get very agitated, but I think the staff played off of that and tried to poke and knew what buttons to push to get the agitation going to that point.’

When asked about the nature of the resident’s ‘agitation,’ she said, ‘She just started throwing things, she’d take the pictures off the wall, she was throwing items at staff members. But conveniently, it was never all staff members, it was *certain* staff members. So that pinpointed to me who was actually trying to push the proverbial button because she had enough sense to know who was picking on her but didn't know how to deal with it. So when she got into these agitation states, it was always the same staff members that were having items thrown at them.’

She added, ‘But after she left, the facility decided they were no longer taking her back. That was a *whole big deal* because I notified our Regulatory agency that they're refusing to take her back into the facility and that promoted them opening up an investigation with imposing some fines as well as notifying CMS and they come back and are imposing fines as well. But the good side of it is because of the persistence, she is now in a memory care unit, she is thriving and had no outbursts whatsoever.’ The resident moved to a different care home where ‘there have been no issues whatsoever.’

When asked about the potential psychological impact on residents living with dementia when they are being taken to a psychiatric hospital, she said, ‘It’s harmful. When you think about it…they're already having issues depending on the level of dementia because they're realizing sometimes that they don't know what's going on and now you have law enforcement coming in and again we're dealing with older people who I think were raised to respect law enforcement and they knew that law enforcement don't just show up, they show up for a reason and now they are potentially taking this resident out either in handcuffs or without handcuffs depending on how combative the situation is. So it can be very traumatizing and it truly did affect this resident negatively…I truly believe.’

Resource Box
Media Coverage
Newspaper articles on arrests of people living with dementia: *The New York Times* article (2017) *CNN* article (2021) *The Marshall Project* article (2022)

Her colleague added, 'I think [de-identified name of her colleague who shared the story] brought up a very valid point with the [de-identified state law] Act. The facilities use that for retaliation, 'Oh, you're not gonna behave? Oh, we're gonna send you to the hospital to [de-identified name of state law] act you.'' She considered it a threat.

She added, 'They connive their way in getting them into the system. And sometimes they'll send a resident for a [de-identified name of state law] Act and as [de-identified name of her colleague] said, they'll leave them there. They won't accept them back…especially in our assisted living facilities…sometimes nursing homes but again, the residents in the nursing homes have a few more rights to protect them than the assisted living facilities.'

Referring to the threat of being [de-identified state law] acted, the first representative said, 'They do. And they will tell them, 'You are going to be put on a 72-hour mental health hold.'' She added, 'They called law enforcement because, again, she became so agitated that she was throwing stuff at staff. It was never at any other residents. Certain staff members could stand right next to this resident and not have anything thrown at them.' She said that the 'agitation' had to do with her needs not being met. She said, 'Very much so. I firmly believe that. I truly do. I think that they were…for a lack of a better term…they were picking on her, they were demeaning her because she had bad days, and her bad days were really bad. When she had those bad days, they would just…it was *ruthless*. And I told the Administrator, 'Do you not find it funny that every time she goes into an outburst, the same staff members are the ones who are being attacked if they're working? We need to look at the bigger picture. What are we doing here?''

Inappropriate Legal Holds

One representative shared a **story** about a resident who suffered primarily from 'anxiety.' She said, 'This one is actual retaliation. I was called into a case in a skilled nursing facility where a resident was sent into the hospital several times on a Legal Hold.'

Explanatory note: Legal Holds are used when a person appears to be in a mental health crisis. They meet the criteria for 'substantial likelihood of serious harm' to themselves or others due to mental illness. The person may be 'held involuntarily in a healthcare facility for evaluation, observation, and treatment for up to 72 hours.'

She explained that this measure is used by care homes 'when residents in skilled nursing or anywhere…I guess become to the point where they're a danger to themselves or someone else, then they call emergency services and they're taken to the psychiatric ward at a hospital.' She added, 'The resident was sent several times on Legal Holds but each time the hospital called to return the resident within an hour or even the next day.'

The representative said, 'The resident had a complaint multiple times about his care and treatment from a specific nurse and a CNA. The resident complained that they ignore his call light, giving his medications last ('He said that he was actually getting skipped'). The resident would wait until his frustration and everything would build up and then he would yell at the staff and that's when they would send him out. He wasn't yelling about anything that wasn't right or wasn't happening to him. I think they knew it. They knew what they were doing. After receiving consent, I investigated the call light and medication complaint by pressing the call light and documenting the time it took the staff to answer. That's something that we normally do. We come in and we try to make sure no one sees us when we come in and we press the call light to see how long it takes them to get there. Then I observed the medication passes…and this was over multiple visits…so I observed the medication passes and I observed the resident at his door waiting for his medication to be *very visibly* skipped until the end. I brought it to the attention of the Administrator and the Director of Nursing who were already aware and familiar with the resident's complaints. They said that they're sending him out for [Legal Hold] for the safety of the other residents. I told them what I've witnessed and described their violations of his rights and how they're using the hospital to retaliate. I requested the documents of each Legal Hold and brought it to the attention that the resident was readmitted to the community on the following *day* and that the resident never had any incidents of hitting another resident or a staff member or hurting himself. The resident received an apology and he hasn't been sent to the hospital on a Legal Hold since and that's all the resident wanted to do from it.'

When asked what made the care home send him out multiple times to a psychiatric hospital, she said, 'I think that's their way of…send him out because he was a resident that was labeled as "a complainer." But his complaints were valid even though he was still labeled as "a complainer." Sending him to the hospital…one day that he might just decide not to return to the facility and find somewhere else to go. They were trying to "patient dump" him.'

The representative said that he was labeled "a complainer" because he 'complained about the care.' He'd go to the nurses' station or even call the Administrator and complain. She added, 'He called the Ombudsman program a *lot* and made the complaints, but his complaints were always valid. They wouldn't come to him on time or they would skip over him for his medication. Whenever he did that…and he got upset enough, then they would call 911 and send him to the hospital saying that it's a Legal Hold.'

She added that the resident 'was afraid that they are going to take his capacity away so he wouldn't visit with a psychiatrist but he did have like a therapist come in. We worked that out too for him…to have a therapist come in and talk to him so he could have more people to talk to…the more eyes on him…the therapist would work with him too and help with complaints when he did have them. His complaints were valid.'

The representative shared her view that none of the send outs to the psychiatric hospital were valid. She explained, 'Because you get the progress notes from the doctor to see why, what was the reason, what did he actually do to be sent out? They're supposed to be licensed to be able to handle behavior issues if there's actually one. The resident isn't a danger. He shouldn't be sent out to the hospital multiple times.'

She reiterated that in her view those send outs were done in retaliation for the resident's complaints about his care. She said that the SSA became involved (one time when the resident called them himself and the second time when the representative did a referral for him). The representative said that no citation was issued 'because the resident is labeled as "a complainer" and they documented that he complains.'

When asked about the outcome for this resident, she said, 'I just know that everything settled down. After this big thing with me, with him, everything settled down and he didn't have any more complaints regarding the medication and the call light.' She confirmed that the situation was resolved to the resident's satisfaction.

Directly Confronting Administrators

While many representatives said that they generally prefer to use a collaborative approach with Administrators and work together with them to resolve residents' care concerns (see segment titled *Working Collaboratively with the Care Home* earlier in this chapter), some of them said that at times they need to assertively confront Administrators that are not responsive to residents' care concerns and/or that they cause residents to be fearful of retaliation, threaten to or actually retaliate against them.

One representative shared what she said to an Administrator, 'We know you're intimidating these residents. We know you're threatening to throw them out if they don't do exactly what

you want.' The representative added, 'So it stopped. It took about three or four visits and a couple of agencies before it really happened.'

A SLTCO said she sends out general Zoom calls to everybody in the care home, 'I want to remind everybody that if you are caught retaliating,…' and also individual Zoom calls 'if somebody is giving me hard time with that information' [referring to the initial general Zoom call] or 'If I get some bozo that turns around and says, 'Well, bla, bla, bla,' then I will do an individual Zoom meeting.'

Involving Corporate Office

Several representatives said that when their education and advocacy efforts do not bring about the change a resident wants to see happening, they may need to involve the corporate office (in care homes with corporate offices). Examples include situations where the Administrator is source of the problem (instilling a culture of fear of retaliation and/or actual retaliation) or when Administrators don't have the power to bring about the change.

One representative said that she sometimes offers residents to go together with the resident to speak with the Administrator or she'll say, 'Let me go get that person' or 'I can set up a meeting with that person when he or she is available.'' She said, 'Sometimes that's the solution' but then she added, 'But sometimes they are like, 'No. I don't want you to talk to the Administrator about this because he is the problem.''

Another representative said, 'Sometimes it's the Administrators…90% of the time it could be the Administrators [who are] retaliating against the residents based on what the staff is telling them as well.' She said that in these situations she considers 'taking it up to the corporate level because if we're saying to the Administrator, 'Hey, you're retaliating' or 'We think you're retaliating' and 'I think you are retaliating based on what we have found so far,' it doesn't get any further past that administration. I think we need to have the capabilities to take it up to the corporate levels in regard to those Administrators that are not willing to correct their actions.'

After identifying the challenge created by Administrators who are set in their ways and whose 'mindset' is dismissive of residents' care concerns, a representative from another state said that when her ongoing advocacy efforts in the care home are not effective, she contacts their regional corporate boss. She said, 'A little more pressure. I give him a couple of times. I'll go in there once, I'll go in there a second time…if they don't want to play nice, 'I'll get the regional boss' of the Administrator.'

When asked about situations where the problematic culture is coming from the corporate office, she said, 'We're getting our bosses…I am getting my State Ombudsman…we just take it to the next level. We try to handle it at the lowest level but if they don't want to play

nice and hear what the needs are for the residents and understand that they truly are fearful, then we take it to whatever level…professionally to handle it.'

One representative shared this **story**: A family frequently expressed care concerns for their loved one in a 'locked memory care unit in a nursing home,' which resulted in a retaliatory discharge notice. The representative considered it 'a clear retaliation.' The Administrator refused to remove the discharge after the representative explained that they can't do it, 'Listen, I understand you have these concerns with the family member but you can't take it out on the resident. You can't displace her from her home.' The representative said, 'He didn't care or he didn't get it.' That was when the representative reached out to corporate office who agreed that the discharge notice is inappropriate and got rid of it, educated the Administrator, and the resident is still there.'

Another representative shared this **story**: When a 'very power over oriented executive director of an assisted living made threats to discharge residents individually in their apartments, 'It was a really really concerning situation.' The representative said that he shared his concerns with the administrator of another building to whom this executive director reports to. That Administrator investigated it, provided re-education, and some corrective redirection. But 'it didn't solve it.' At that point, the representative went to this Administrator again and asked for the contact information of the chair of the board of directors of the organization 'and he took care of it.' The representative said, 'That was after multiple failed attempts to work with the executive director directly.' He added, 'All I had to do was ask for the name of the chair of the board and their contact information' and 'the Administrator 'terminated the executive director.'

When asked about the role of Ombudsman representatives when the source of the problem is the culture that is created by the Administrator, a SLTCO said, 'You start with the residents, you figure out what's happening, and you figure out the culture. And the thing is…sometimes you can't change it.' She added, 'Sometimes in Assisted Living the owner is the person that is the abuser. There is no corporate. So in the little Assisted Livings, you're kind of stuck. Other than making referrals to the world.'

She went on to say, 'If it's a corporate environment, if you have permission, you could go to the corporation and deal with that at that level but we have corporations in [de-identified state]…they are the problem. So then, they don't care. And then you have to bring in…we work real closely with the Attorney General's Office, we work with our licensing agency, we work with professional boards…so then we go outside.'

She added, 'These situations are hard because if [the residents] won't let us do anything, it's very hard for us to do any advocacy outside of the building and in that case we tell the

people like, ‘If this really gets to a point you’re not comfortable anymore, you can leave.’ She said, ‘So then we help them leave. We’re not a placement agency, we’re not discharge panners but we have expertise in those areas so we can help people figure out how to get out of the situation if that’s the *only* alternative…it’s to get the hell out of there. And that’s what we can try to help them [with].’

A representative from another state said, ‘Even the Administrator is not the decision-maker in many cases. It’s up at corporate. And I’ve been told that by the Administrators, you know, I complain about something and…for instance, here is one example…is food. There’s a food vendor in our part of the state that supplies all these facilities. And when the kitchen orders food, they send it up to corporate and corporate edits it so if there's something too expensive on the menu, they take it off or whatever. So I can complain to the Administrator 1,000 different ways that it would be nice not to have chicken one day a week…maybe something else…well, now chicken is expensive…but, you know, any variety of foods or fresh foods or fresh vegetables or fresh anything and they can send that order in but it's not going to be honored so a lot of the policies of our facilities are [de-identified part of the state] in our case way above the administrator.’

She added, ‘Then, if they are not listening to her, then we would go to the Cabinet Secretary for the [State Survey Agency; name of agency de-identified] and if they still won’t listen to her, then we [involve] the Governor. We’re kind of lucky here in the state of [de-identified state] the Governor used to be [de-identified role] and she has a passion for seniors. She will climb through a nursing home in a minute and contact all of her Cabinet and they’ll be on you before you even knew what the heck happened.’ The representative found this strategy effective. She added, ‘And it doesn’t have to be that serious for her to be in your building looking at you and having her Cabinet come down on you. She has a passion for our small agency. She’ll climb over anybody.’

One representative addressed a situation where the corporate office is the source of the problems and retaliation in the care home. She said, ‘Yes, and that is part of what the problem is at some of these buildings is this corporate level…not employed with that corporate company but a consulting group that uses a culture of anti-Ombudsman, anti-residents’ rights. It’s *wild*. Some of these buildings that use this consulting group have this negative view, this nasty view of us and thereby resident rights. It’s just a nuisance to them. So with that, I have conversations with him the best I can but I also have a pretty good corporate contact fortunately that he has been great when he steps in as interim at these different buildings and so even though he is part of this corporate company, he doesn’t have this nasty view point like some of his Administrators do.’

She explained why she tries to find a helpful person at the corporate office, 'Because some of them at corporate have been promoted from facilities so they know who we are. I've been around for [many years; number de-identified]. They know who we are. Sometimes they know who I am from working in my buildings and then going upward…I have a couple of buildings in larger chains so they know who I am, they know what we do. We frequently warn them that, 'If you guys don't work with us with what the problems are, then we have to go to the state' and nobody wants the state in there. We let them know and educate them, 'This is our process. Please don't make us go upwards. We just want to work with you guys and the resident to resolve this problem.''

Encouraging Residents to File a Complaint with the State Survey Agency

Representatives said that they educate residents about their right to file complaints with the SSA and under certain circumstances they empower and encourage them to do it.

One very experienced representative shared this **story** about how she encouraged a resident to file a complaint after she was abused by a nurse in response to questioning her about her medication. She said, 'We gave her the tools and encouragement to file her own complaint. She filed her own complaint online herself. It was investigated and they found her complaint to be valid. At first, she was afraid to file the complaint on her own and she thought maybe we needed to assist her to file it. My position was to educate her on how that complaint could be filed. She wrote her narrative, she explained everything herself, she filed it, she had a response back from the regulatory agency that the nursing home was in deficient practice in regard to her complaint, and she was *elated*.'

She added, 'She had been physically and emotionally abused and then she questioned the person about the medication that she was attempting to dispense and when they came in, she asked her to turn the light on because she couldn't see what she was taking in the cup…and she asked her to turn the light on and the nurse just jerked up the medication, wouldn't allow her to get it, they were having a tug of war with the medication cup. Hence, the nurse ended up injuring her arm. It was more of abuse than anything else. She filed her complaint and the nurse was found liable because it was physical abuse that caused this resident harm. Hers was very effective because of the encouragement and empowerment and she filed that complaint herself. We got the report back that the nurse was subsequently suspended from the facility. That was very effective on behalf of this resident to do it herself and not allow us to do it for her.'

A representative working in a very rural area ('rural…as rural as it gets') spoke about how she educates residents and families on how to file a complaint with the SSA. She shared this **story** about a troubling case she worked on in one nursing home:

‘The biggest case I ever worked.’ She said, ‘We have very high turnover in all our buildings when it comes to Administrators. We got a building with a new administrator and that administrator came in “hot” from the beginning.’ The Administrator ‘started moving people around…this was not a pleasant person…their general air was quite unpleasant almost scary to the residents…came in and started with a very strong hand from the beginning. We had multiple issues. The person came in *so strong* and so *harsh*. These residents not even knowing this person…they were automatically terrified. They didn’t know what was happening…people were moved around in rooms and all other things. These were people that I have been dealing with for years and know them and all of a sudden they didn't want me to work on *anything*. *Nothing*.’

She added, ‘They had no idea what was going on. It was a unique situation. And so I did a successful intervention but by the end of it, it wasn't me. So not only am I hearing it from residents, I started getting calls from families. So I decided that the only way…because I can't do anything…I can't advocate on behalf of…say on a certain day I'm in there and I hear from several people that there's an issue going on, I can try to advocate for the group…say, ‘Listen, here's what I'm hearing that's an issue today’ but a lot of issues were more specific. So I decided that the only way to make this work is to educate families [on] their ability to put forward complaints to the [State Survey Agency].’

She added, ‘Every family member that would call me saying, ‘My loved one is having this issue,’ I almost had a speech ready. I said, ‘Okay, I will go out and talk to your loved one, but I want you to understand that I can’t do anything without resident permission. We’re resident advocates. But I want you to know that you have the right to report these issues to the [State Survey Agency]. I said, ‘You have a right to report these on your own. You have a little more freedom in that than I do. It’s up to you. I am not telling you that you have to but you have the right to. If you’d like that contact information, I can provide that to you.’ Most of them did. The education part of that is what paid the dividends. It wasn’t me. It was these families calling the state and calling, and calling, and calling and so finally they entered.’

When asked how the SSA investigation went, she said, **‘**It did not go well. They got cited…I want to say for multiple instances of Immediate Jeopardy. Now they were able to…through the survey process to rectify those Immediate Jeopardies.’ She added, ‘They got tagged…and just a couple of days after the state exited, well the first time they actually did follow up, the Administrator was no longer there. But they did get a specific tag for Administration, you know, they can’t…they don’t tag specific people.’

When asked about the end outcome for the residents, she said, ‘The outcome for the residents was like a new day…it was like a new day for them. Like a burden was lifted. And what grew out of that was a Family Council.’ She said that there were no Family Councils in that area prior to this intervention and added, ‘It’s like pulling teeth to get a Family Council started. But those families that made all those calls…we’re going on [de-identified number] years…since the state entered that building for that survey and that Family Council still meets every month.’

When asked about the emotional state of the residents in that ‘new day,’ she said, ‘They were relieved, they were thankful…even to this day, I have a lot of them…the ones that are still there that remember it, they *still* remember it. It was very traumatic. Some of them still have some PTSD because of this time. I mean, I am not a mental health professional but that is what it appears to me.’

Later during the interview, when asked what advice she has for residents fearing retaliation she said [with tears in her eyes], ‘There’s really not a lot they can do. Nobody listens to them. It’s easy to say they can take their complaints to the administration or Resident Council but nothing happens. *Nothing* changes. *Nothing* changes.’

She added, ‘Even after that huge survey…after that horrible incident at that facility, those specific incidents with these forced room changes…that hasn’t repeated but they’re still dealing with other things. You know, they can’t get food that’s decent, there’s not enough staff, they [she became teary again]. I am sorry, they sit in their own waste for hours. And they can take those issues to anybody and nothing ever changes though, nothing happens, nothing fixes it.’

When asked what underlies the lack of response, she said, ‘They don’t have enough people and they are always worried about looking bad.’ She explained, ‘The facilities are afraid of looking bad…They’re afraid of getting cited for something. You don't have enough people to answer the call lights in a timely manner. They'll never admit that, ‘Oh, we have enough people.’ That's what they'll say…they have plenty of people, ‘We're fully staffed today’ and this resident is sitting in their own wet brief for an hour with their call light on. The facility has to put on a good face. They’re terrified of anybody calling them on anything.’

When asked why they are not changing it if they are so terrified and if they want to do the right thing, she said, ‘Doctor, if you can answer that, you can fix the whole system.’ She added, ‘It sucks. That’s what it does. It’s terrible.’

Involving the State Survey Agency

One representative said, ‘We do bring in the Department of Health when necessary.’

Referring to their involvement of the SSA, another representative explained, ‘I feel that getting together we can probably solve some of these problems.’

When asked about instances where she was successful in handling residents’ fear of retaliation and actual retaliation against them, another representative said, ‘Getting the Department of Health to go through and do their type of investigation to try to mitigate or show them where they’re wrong.’

One very experienced representative said, ‘We have the ability to bring general observations to the certification agency without kind of identifying individual people before survey so that might be one way that I'd strategize around this.’

When asked for her advice for residents fearing retaliation, another representative said, ‘We try to empower our residents and family members and ask them or educate them that sometimes what is helpful is to go to either the social worker or the Director of Nursing to say, ‘Listen, this is the problem we're having. Is there a way we can resolve it?’ This way the staff…they get defensive…but they tend to be more defensive when it's a state agency that gets involved so we try to have them resolve it with the facility staff first and then if they don't feel there's any resolution, then for us to come in and advocate a little bit further.’

A representative from another state (quoted earlier in the report) spoke about the staffing crisis as a major challenge and added that sometimes cultures of care in buildings with poor staffing levels are dismissive of residents’ care concerns. She said that the thinking in these care homes is, ‘We need staff and it doesn’t matter what goes on.’’

When asked how she handles these situations, she said [while sighing], ‘The way I would any of the other ones…just keep at it…and just be, ‘These are the regulations, these are the rights that they have…you have to…’ It might be a horrible place…building but ‘that’s what you’re here for’…so just remind them…so keep doing the way I would any other one.’

When asked how she handles situations where these efforts fail because the culture is dismissive, she said, ‘That does happen. If it is something that a resident wants to take to the next level to [State Survey Agency], we could do that…I mean if it is something that we as Ombudsman make a case out of, we can take it to the next level as well. Otherwise, just frustration.’ Her colleague added, ‘There are some facilities where you know you can sit down and have a good conversation with the staff and they would want to try to do the right thing and where that’s not the case. You get to know your facilities and know that. You approach the problem a little differently in those two different types of homes.’

A SLTCO shared a **story** about an assisted living residence where things 'spiraled out of control…actual retaliation, instilling fear of retaliation, and residents not wanting to talk to us. What we discovered was a pattern of financial abuse.' She added, 'The Administrator was literally taking residents to the bank and asking them to pull out money…saying that the rent went up so they need to pull out more money to pay for additional rent cost so then that person was pocketing the money.' The Administrator 'threatened residents not to say anything, trying to bribe them with gifts to stay quiet and not say anything…talk about the real fear of retaliation.' She said that several agencies were involved in this case including the SSA, Adult Protective Services, the Ombudsman program, the District Attorney, and local law enforcement. Eventually, the Administrator was fired, charged, and found guilty. As for the residents, 'The corporation was going to get the money back to them.'

Another representative spoke about the importance of 'bringing in outside agencies to back me up and educating the staff on not retaliating.' Examples of agencies (not already mentioned earlier in this segment) representatives said they'll consider involving depending on the circumstances included the Union, Disability Law Center, Mental Health Advocates, and the Attorney General Office / Medicaid Fraud Control Unit (MFCU).

One representative said, 'I can call the police advocate for that particular city…a policeman who has been assigned to go in and let them know that 'I need to meet with that particular person who is intimidating and the resident.''

Involving Medicaid Fraud Control Unit

When asked about the effectiveness of her SSA in investigating allegations and after I mentioned the report *Uninspected and Neglected: Nursing Home Inspection Agencies Are Severely Understaffed, Putting Residents at Risk* (U.S. Senate Special Committee on Aging, 2023), a very experienced SLTCO said, 'The next step for me is if they're on Medicaid, to turn it over to the person who does complaints of abuse in the Attorney General's Office. And if it is not…there's another division there if they're abusing a resident but usually the first division is regular nursing home patients and they mostly deal with financial exploitation but the Medicaid part of it…I think they're called Medicaid Fraud Control Unit. They'll go in and investigate if a resident is being intimidated.' For an example of MFCU's investigation of physical abuse of an 87-year-old resident with Alzheimer's disease by an employee in an assisted living in Florida, see this article.

Assisting the Resident to Move to a Different Care Home

One 'last resort' measure reported to be used by some representatives consists of education and advocacy related to moving the resident to a different care setting. One very experienced SLTCO said, 'If it continues to go on after taking all the measures…, then what I

do is I suggest the resident or the family member that we move the resident out of there because nothing is going to be solved, and they are afraid all the time.' She added, 'It may be traumatic but staying there is only going to make it worse for the resident.'

Another SLTCO shared this **story:** 'I had a resident who ambulated in a wheelchair, he was in a small assisted living home…it was like an [de-identified number of beds] facility and the resident would talk to me behind closed doors in their room and would really talk about all the problems in the facility as it related to their quality of care and life and *lots* of restrictions on resident rights…lots violations on various residents rights and the staff started to slowly but surely retaliate against the resident. For example, the resident's favorite thing to do is to cook and the resident love Thai food and the staff person would say, 'Oh, I saw you talking to the ombudsman. You can't cook this week.' Things like that and it kept going and going from there and I worked with this resident…I knew this resident already before the first complaint of retaliation and then the fear and so what they ended up doing was totally silencing the resident. The resident really wanted me to be careful when I visited because this was a small home it was [de-identified information] and then at one point didn't even want to see me in person and only wanted to talk to me on the phone it got so bad. What happened was the resident then started to try to voice their own concerns and complaints and the staff member started doing things like kicking their wheelchair, not allowing the resident to sit at the table with all the other residents, trying to confine them to their room, turned off their cable TV…I mean this person had almost no joy in their life.' She added, 'A year had gone by and I had just kept talking to this resident…I had visited when I was there because I wanted to meet with all the residents so I would go and just not visit with that particular resident because they asked me not to. It was kind of like weird domestic violence situation, you know, when you kind of think of the cycle of violence among survivors of domestic violence.'

She said, 'The breaking point was that the small assisted living home purchased a van and there was going to be an outing for all the residents. That particular resident started getting ready, wheeled himself out with his wheelchair to the van, and was told that they couldn't go. They were going to a *Thai* restaurant. So *that* was it. That was it. That was the breaking point. They ended up calling me. We worked behind the scenes to get that resident over to a new facility. To see it, to visit it first, and make a decision on moving. They did.'

She added, 'Then I got the [de-identified state] Disability Coalition, which advocates for disability rights to get their attorney to write a letter to that assisted living home that they can't deny access to the van and because someone lives with a disability. Then the owner tried to sue me. He retaliated against me as well. They just threatened. It never went

anywhere but they were threatening and then wanted me removed as the Ombudsman and all that stuff.'

The SLTCO added that interference in Ombudsman representatives' role is against the law. When asked about the outcome of her intervention and resident's move to the different care home, she said, 'A happy life and better quality of life and better treatment. I visited that resident often after the move and the person was so much happier with everything.'

Another representative shared this **story** about a for-profit care home: 'I had a resident who was bed bound and she had some developmental disabilities. She was at a very very bad facility. We gave her hope and we did get her out of that facility into another facility that was much better but she was still very frightened after her last experience in the really bad home. I talked the administrator [in the new care home]…this is how crazy I can be…into putting a phone line into her room…because she was bed bound… that only goes to the Administrator and she ended up being able to do it only once a day because, you know, she didn't get pickles with her sandwich she wanted to call…they created rules around that.' She said, 'I could never talk a for-profit into doing that…I don't think.' She added, 'One of the proudest things I've done because it calmed her down, it calmed the facility down because she was so vulnerable and so scared. We gave her a safe place to express herself.'

When asked about the care concerns, she said, 'In the first facility she was at it was one of our worst (e.g., 'Ulcers…that whole UTIs. All that bad stuff'). And in her condition, being bed bound and not getting changed enough or showered or anything. She was really in bad shape. She was one of those who is afraid that…believe it or not…that it could even get worst than that. So I talked to her sister who is her proxy into trying to find a better place for her and that worked but she took that fear with her from the first facility to the second facility. Even though I knew that she was in a whole new world but to her, you know.'

When asked about the nature of this resident's fear, she said, 'The nature of that fear is she perceived the non-care at the beginning, when she first arrived, she did complain. Like, you're not changing me enough and you're not answering my call bells. I don't think it was a case of retaliation. I think it was a case of non-staffing but she couldn't discern that difference. And maybe fear of retaliation but I really think it was that bad facility so.' She added, 'I also want to say she was younger [age range de-identified]. The nature of her fear was I think just a lack of control, I mean, because she couldn't get out of bed…because she was somewhat developmentally delayed and that is a problem with developmentally disabled population. She felt she was just not being heard. And that anything bad that happened to her, she perceived it as retaliation.'

She spoke about the outcome of the move to the new care home, ‘I don’t know if it would be to her satisfaction but a thousand times better. But I think she just shut down to such an extent in terms of emotionally shut down. I’ll give you one example. She was also a [name of medical condition de-identified] patient because it couldn’t get worse…right. Anyway, so they plunked her in a wheelchair…she was a bariatric patient that she got stuck in the first facility and she’d be dumped out onto the floor of the hospital to get her out of that chair. It was just extreme things that happened to her and she was so afraid that if she complained, even worse things would happen or they already did happen so she just kind of shut down.’

She added, ‘Moving her into a new facility, we had to figure out a way to learn to let her blossom and find a safe place for her. And those staff members were much more consistent. It was part of a hospital campus. I find that they tend to have a very disciplined staffing in terms of who is on, you know, they work more as a hospital type shifts. So she got to know her people but it took a long time to open up that fear.’

When asked about the outcome of her intervention, she said, ‘The end point outcome was that she certainly utilized that telephone. The irony is that once she did find her voice again, she expressed it a lot…so basically, she started to become a complainer, you know, like everything. She finally…it alleviated everybody having to hear her complain cause she knew she had the boss…that’s how she called him. She could talk to the boss. So it alleviated her anxiety and it took a lot of pressure off the staff to constantly try to water her and feed her and make her happy because they wanted to do that in that facility.’

When asked if the direct phone line to the Administrator gave her peace of mind, she said, ‘Yeah. Take that anxiety away. Like I said, she was very out of control in her feelings in the old facility. And she wasn’t about to trust anybody at that point. And once she realized that somebody is going to listen to her, he would come down if she needed him, you know, after that phone call. She actually saw some change in her surroundings. She needed yarn because she loved to crochet. He made sure that activities brought some yarn for her. She could see little increments of change. That’s all anybody really wants. We think when we go in there that they want us to pick them and take them home, which they would love that but sometimes it’s that incremental stuff that’s way so important. The hot coffee, whatever it is, favorite shoes that can be found, whatever it is.’ She shared a **story**, ‘I had a guy that lost the part of the glasses where you [illustrated the part that sits on the nose]. We got him a new nose piece and you would have thought I had solved the world. It’s not big stuff necessarily but if we can show them that hope, that there’s people listening to them, it makes a big impact.’

For Lessons Learned by Ombudsman representatives, see **Appendix 4**. For Advice for New Ombudsman Representatives, see **Appendix 5**.

Chapter 8

Ombudsman Representatives' Educational Efforts

Representatives described various ways in which they educate residents, families, staff, and Administrators in general and about residents' fear of retaliation and actual retaliation. Before describing these educational efforts, the following segment describes written materials developed and handed out by representatives to residents and families. In the words of one representative, 'We have a lot of written material that we pass out.'

Written Materials

In this context, it is important to recognize that some residents don't know that the Ombudsman program exists and how representatives may be able to assist them in realizing their right for dignified, professional, and safe care as well as their right to speak up about right violations, care concerns, and file mistreatment complaints without fear of retaliation and without retaliation against them.

Developing and handing out written material (whether the material is delivered to residents and families in a hard copy and/or electronic format or when the material is posted in a central location in the care home) is an important way to educate residents about the Ombudsman program, their rights, and the ways in which they can realize them.

Research Findings
A study by Wood and Stephens (2003) found that a significant portion of assisted living residents are not aware of the Ombudsman program.

Resource Box
What is an Ombudsman? How do they support resident's rights and why are they important? Video developed by Connecticut Long-Term Care Ombudsman Program

Representatives' descriptions of written materials they routinely provide to residents, families, and staff included (the list is not exhaustive):

Welcome Packets and Holiday Cards (to residents) and business cards (hard copies to residents, families, and staff). One representative said that she hands out large size business cards with her name, contact information, and photo (She said that residents are less likely to lose these compared to regular size business cards). Another representative said, 'I always give them my contact information so that they know and tell them, 'I am a call away.' Text, phone call, email away…however they want to contact me.'

Certain representatives said that they give out electronic business cards that residents with smart phones and other devices can more easily use to quickly contact the Ombudsman Program. They also said that they give it out to care staff members who can then more easily and privately share information with them.

A representative from another state said, 'I also find myself putting out my postcards all over assisted living and skilled nursing fairly regularly so that they're not just posting the contact [information] to the Ombudsman office underneath the license. You'll actually see a picture of me walking past that cork board.' He added, 'I think that photo…I think it's critical that people see our face on those postcards.'

One representative said that she offers residents brochures and business cards but 'if they are not interested, I always tell them, 'Here is where the poster in the building…a poster with our information.''

One SLTCO said, 'You make sure you give out material to the residents for them to read. We have something called 'What to do if you feel like you're being abused.'

Another SLTCO said, 'We're looking at our materials *constantly*. When I have new people that are coming into the Ombudsman program, it's an opportunity for fresh eyes. To look at our educational materials and to provide input. I want to hear from everybody. That is a precedent that I set as a leader here in [de-identified state] over the statewide program.'

Resident Education

One representative said, 'As far as educating residents, I think being present, being in the facilities more, getting more volunteers involved…just to see our presence there more.'

One SLTCO said, 'Information and education is what we do…all day long…primarily resident right, the right to speak up, the right to file a grievance, the right to be free from abuse…all those things.'

When asked about her role in educating residents on fear of retaliation, one representative said, 'Obviously, we advise on resident rights, let them know that you have the right to voice the concern, to make suggestions for improvement or voice a grievance, let them know that there are regulations in place that are supposed to protect them from retaliation and just kind of empower them to be their own advocate and let them know too about our role, how we can support them through working through some issues or concerns.'

One representative spoke about the importance of educating residents about their care concerns, 'I find a lot when a resident is educated about their specific concern…like their medicine…they know they have an hour before and an hour after. If they know that, they can use that when they are addressing their concern.'

She added, 'I feel like, in general, when we *sound* more well informed, people are going to hear us better and respond to us that way [versus] when they say, 'They are not giving me my medicine on time.' Well, what does that mean? And trying to work with the resident on how we are going to present it. I think that them getting that education so that they can present it in a manner that they at least *sound* more informed about the specific concern. You sound like you know what you're talking about so people are going to listen to you.' She added, 'I do find it more successful when it is not just me sounding informed but when the resident is also sounding informed, I do find it more successful.'

Quote
"*In general, when we sound more well informed, people are going to hear us better and respond to us that way*." – Ombudsman representative

When asked about effective strategies and practices in addressing residents' fear of retaliation, another representative said, 'Shining the light. Like increasing awareness among staff members and residents in what retaliation looks like, what the laws are, the regulations and the steps that residents can take if they experience it. Multiple visits and making the Ombudsman presence known. I think that is really important. I think the majority of staff are not okay with retaliation. I think that when most people know what's going on, they can help watch for it and stop it.'

Quote
"*I think the majority of staff are not okay with retaliation*." – Ombudsman representative

She added, 'I think staff need to know…there should be like a zero tolerance. They should know how to recognize it…retaliation in their staff members. To see what's going on and not be afraid to say something themselves.'

Retaliation against staff members for speaking up about care concerns and mistreatment has been reported in multiple media articles in recent years. For example, staff members alleged 'harassment and retaliation at a Veterans' nursing home in Minnesota (Magan, 2023). In Iowa, a dietary aide claimed she was fired in retaliation for reporting abuse and neglect of residents to the State Survey Agency who later verified her complaints (Kauffman, 2024). An LPN in Illinois claimed she was fired 'because she refused to follow orders from the Director of Nursing to 'double dose' agitated residents with anti-anxiety medications and refused to delete records of suspicious injuries' (Marselas, 2017).

Resource Box
Webinar
Webinar on staff fear of supervisors, managers, and co-workers' retaliation in nursing homes (Caspi, 2023; Hosted by Elder Voice Advocates).

When asked what she finds valuable in her efforts to address residents' fear of retaliation or actual retaliation, one representative said, 'I state what their right is…they have a right to be free from retaliation and that is federal [and] state law in their resident rights…that they are to be free of retaliation and I explain what that means whether it's simple, whether it's extreme and that if they receive that type of retaliation after voicing a complaint with me or with the regulatory agency, then that becomes even more serious and that can be punishable, it can be a misdemeanor for someone to retaliate against a resident by reporting to a state office on a complaint. You know, just explaining that I will continue to support them and follow up back *immediately* if there is any forms of retaliation.'

Another representative shared this **story**: 'A resident asked staff to wash her hands and put on gloves before she gave her eye drops and that upset the staff and she threw her gloves on the table in front of the resident and walked out. The resident didn't tell anybody for a couple of days. I happened to be visiting and she told me about it. After we talked, she decided to tell the Administrator what happened and she didn't want to because she thought things would get worse. It was a new staff. It was an agency staff so she didn't really know the person. But she was able to talk to the Administrator. She doesn't know what happened but she hasn't seen that staff since then. She didn't say anything for a couple of days and then I visited with her and reminded her that, 'You know, that's not okay, that's not right, she has no right to do that.' She was able to say something on her own.'

One representative spoke about educating residents about their confidentiality rights, 'One of the biggest things we talk about is that our conversations with them are confidential. We build trust and a rapport with them by letting them know if you don't want us to say anything to anyone, we can talk about this today and I can give you my card and when or if you're comfortable, you can come back or give me a call and we can address it then.'

A SLTCO spoke about the importance of educating residents during Resident Councils, 'I think one of the most important things with the Resident Councils is to have a meeting *with* the Resident Council…with their permission…to either ask them if we can present to them on the subject of retaliation or ask them to do it and give them the material that they need to be able to present it…but most of the time they let us come and do it.'

Educating Residents and Staff About Resident Councils

One representative spoke about the importance of educating residents about Resident Councils (what it is, their rights, how to run it well) and encouraging their participation.

Another said, 'if we're working with a specific resident and maybe they have feared retaliation on a call light or baths not being done or 'The food here is awful,' we encourage residents to go to Resident Council and be active in that because we feel like there's power in numbers…you may feel more comfortable speaking up or there's a trusted staff person there that residents have invited to be there and we offer to come and speak to Resident Councils or just be introduced so that we can be a support system for them as well.'

A representative from another state described her 'tandem' educational approach with the President of the Resident Council and Activities Directors who often facilitate these councils. She said, 'We would provide that person with the tools on how to be a President of the Resident Council, on how it runs and why it's good to have and then we would also provide those tools perhaps to the Activities Director so she would know how to run a Resident Council and what's expected of her whenever the State [Survey Agency] comes so

that she would have her stuff in order. So we educate both sides so they will know what to do and what to expect from each other and in the end, this empowers the residents because they see a change because people are working with them instead of them being angry at the resident. This has helped everybody. Because I think in the end, the facilities want to do a good job. I don't think they want to do bad. They want praise. They want [to hear], 'Hey, you guys did a good job today' or 'The facility is cleaned up.' They want to hear that. And so if we can help them through education whether it'd be on resident rights, on sexual intimacy in nursing homes, or how to run a Resident Council and what to expect…this is what they want, we can bring what the resident is saying to the facility and say, 'Hey, this is how they feel' so I think it helps both parties.'

One representative said that several years ago, 'One of our staff members took it upon herself to work with one of our nursing homes to develop a training for their staff on how to support a resident council and what their role is and how they can support it and what a good fully operating healthy resident-centered Resident Council looks like. We did a lot of research out there on what information is available and we condensed it and then provided an In-Service training to the facility and then we had that material shared with other Ombudsmen who can now take that into their facilities and share that information and now we have some general information that all staff and volunteers have to be able to go to either the residents or the facility to help them better understand how a Resident Council can work, should work in different ways for that to happen.'

A few excerpts from this training material are incorporated into the segment titled *Role of Resident Councils in Addressing Residents' Fear of Retaliation* in **Chapter 7** Strategies for Addressing Fear of Retaliation or Actual Retaliation.

Educating Residents About Their Right to Install a Camera in Their Bedrooms

Ombudsman representatives' education of residents and families about this issue is guided by state regulations governing specific types of care setting. These regulations determine the extent to which residents and families are permitted to install cameras in bedrooms and under what conditions and requirements they may be allowed to do it.

Representatives shared their views about this issue: One of them said, 'Those residents' families that have cameras installed, they provide better care services for those residents because of the cameras that they have in their rooms.' She said, however, that some residents are not receptive to a camera being placed in their bedroom and added that privacy issues and consent from all parties needs to be obtained but that once you pass all those hurdles, 'It would be very valuable because you will get your burden of proof when

residents agree and staff are not aware that there's a hidden camera in the room. It identifies and it protects that resident. That, to me, would be very positive.'

A representative from another state said, 'We have cameras now that are utilized in residents' rooms. You can see the retaliation.'

The issue of cameras in bedrooms is addressed in **Appendix 7** Assistive Technology.

Resource Box
Fact Sheet
Balancing Privacy & Protection: Surveillance Cameras in Nursing Home Residents' Rooms. Fact Sheet. Developed by the National Consumer Voice for Quality Long-Term Care for the National Center on Elder Abuse.

Educating Staff

Several representatives described the varied ways in which they provide education to direct care staff. One of them said, 'I try to train staff *whenever* they will let me in.' Another said, 'The more we can talk to staff, the more we can educate…I feel the better the outcome because then they buy in what we're pushing. So always educating everybody…families, residents, and staff. I am getting that buy in that care doesn't have to be mediocre.'

A very experienced representative said, 'We have this outreach campaign going where we're trying to get in there to present…not only for the residents but facility staff…not just administration of facilities but to direct care staff about the Ombudsman program and residents' rights. We think that's important…not just administration but all facility staff know who we are and what we do and that they can call us too…they can be a complainant and contact our program. It's again, having that presence in facilities and having relationships with facility staff too…so that they know who we are and what we do.' She confirmed that she also speaks with staff about residents' rights related to fear of retaliation, 'Yes and that residents have a right to complain and to have their voices heard…so we do talk about that in our training for staff.'

When asked about what staff can do to address residents' fear of retaliation and actual retaliation against them, a SLTCO said, 'Staff members need to remember what their role is…that they are there for residents and that they need to be that resident voice and be there to protect the residents. And they are mandated reporters.' She added, 'Other than

that, if they hear something, they need to intervene and if they notice one of their peers getting to a breaking point…we all have our breaking points…in a marriage partners do it…you step in when you see that someone is about to snap…you all get emotionally there, people get tired, staff are working longer hours, there are a lot of demands on them.'

She said, 'I think truly people have good intentions and there are bad outcomes sometimes. They need to partner, they need to be teaming, they need to be saying, 'It looks like you're getting to a place, some of the things I see you've done or some of the tone you're taking is not okay, I am going to step in at this point, I think you need to go take a minute.' And then you're showing the resident that you're identifying it's not okay, that you're making a safe space, you're letting that staff member peer know that you've seen it, it's not okay. You're not going to allow it, and you also letting them go cool down and come back in a head space that is better.'

A representative from another state spoke about the education she provides to staff, 'In some of the trainings that I do, reminding them…just because somebody has a concern about you, they shouldn't be punished just like if someone were to complain about me in my job. It really is a lot about education and I think with administration is to really make sure they're addressing it too and reminding them of resident rights. We think it's just a collaborative effort with everybody.'

Another representative shared that she and her colleagues delivered sensitivity staff training using a skit whereby during "admission" to the care home, staff are given and then stripped of all their possessions (e.g., keys, toy car, tennis shoes, their mail, and an American flag). She added, 'We go ahead and take that and basically say, 'You really don't have any rights at all because you're going to have to go by *our* rules.''

When asked whether she finds that this training raises staff awareness and sensitivity, she said, 'I think for a few days maybe or *maybe* a week but I'm always not shocked because they are going to be like, 'Oh well, we don't do that' and then I'll give them an example, 'So when did you get to breath fresh air on all of your windows?' Then they're like, 'Yeah, I guess…yeah…they don't get to go outside when they want to just have air.' So I think that's with them for a very short time and then everything goes back to normal.'

When asked about effective practices and strategies for alleviating and resolving residents' fear of staff retaliation, one representative said, 'Education, In-Services. I always ask to do In-Service. And I get pretty dramatic when I am doing In-Service.' She explained, 'I basically say, 'I am hearing this. Residents are fearful of retaliation.' And then we go through what retaliation is. I might stomp my foot a little bit to get the staff attention.'

She added, ‘I focus on those staff being special. I try to give them good feelings and that they are the only ones, that residents want to protect them, and they won’t complain. I try to make them feel good and make them want to help the residents as well. I also let the staff know I realize their hands are *tied* sometimes because they might be told by administration, ‘Oh, you can’t do this because we don’t have enough staff or we don’t have money.’ Your staff wants to do a good *job* but they may not have enough staff to do what they really want to do.’

When speaking about the educational efforts she and her colleagues deliver to care staff, one representative highlighted the challenge of staff turnover, ‘We don’t do a lot of in-services in the facilities because the turnover is just so great.’ She added, ‘We used to be invited to every graduating class of CNA group. That has gone down the wayside. You know, they don’t even list in [de-identified state] the list of Administrators on the State Licensing page anymore…because the turnover is so great. And many of the Administrators…we’re really in a bad shape here in [de-identified state]. A lot of our Administrators do not have licensure. They are working off of somebody else’s license. Even our social workers…some don’t have degrees or licensures. We catch them and we try to address them but it’s just *really, really* hard. It’s a big chess board with people moving around so much.’

She added that things may be different in some rural areas in her state, ‘I think that my rural friends…I have two rural groups…specific Ombudsmen that are dedicated into those two…would have a much better time…their staffing tend to be much more stable…because they are so out in the sticks sort of kind of concept that the staffing are their neighbors and it’s sort of like the old days. In the cities, staff get a $500 bonus if they move to another facility, and they’re gone and it’s hard to beat.’

One representative spoke about the importance of staff education in her efforts to reduce residents’ fear of retaliation, ‘I think it’s not about changing the resident to make them less fearful. I think it’s more about training the staff like, ‘Why did you take his food? He is not done’ gives that resident a little more oomph, you know, ‘I can have a say.’’ Details about this incident and the resident’s fear of retaliation are described *in a segment titled Detection – Potential Signs of Fear of Retaliation* in **Chapter 7** Strategies for Addressing Fear of Retaliation and Actual Retaliation.

One SLTCO said that with new legislation in her state, all staff in assisted living and nursing homes are now required to receive training on dementia care. She added, ‘I think just secondarily, it could help with training people to care and have concern and maybe not take retaliatory acts or instill fear in people.’

Interestingly, one representative said that he educates staff about residents' right to attend *staff* education sessions, 'If there's a resident that wants to be there, the staff would be like, 'No, you gotta go, you gotta go. This is just staff training.' And I am always like, 'The resident has a right to be here. It's their place.''

A Subgroup of Staff Members Unaware Things They Do or Say Are Perceived as Retaliation

Representatives interviewed for this project said that some care staff members say or do things to residents when they are unaware that residents perceive these acts as retaliation. These findings reinforce the need for extensive and ongoing staff education on retaliation.

This issue is longstanding. For example, the late Brian Capshaw who served on the Executive Board of Connecticut Presidents of Resident Councils stated in 2012, 'Nursing home staff may feel they are acting in a proper manner, but to a resident it may be just the opposite.' Referring to Robison et al. (2007; 2011) study, Nancy Shaffer, former Connecticut SLTCO stated, 'We have learned that in fact, sometimes staff do not recognize that their actions and behavior are perceived as retaliation by the resident.'

When asked about common ways in which staff retaliate against residents, one representative interviewed for the current project said, 'I think it's subconscious and it's conscious…I think you're certainly hoping it's not more conscious, but I think it's both.'

When asked whether, and if so, to what extent staff say or do things to residents when they are unaware that the residents perceive these words and actions as retaliation, one representative replied, 'All the time.' Her colleague said, 'Quite frequently.' Their colleague confirmed, 'Yeah. We do see that kind of thing.'

When asked the same question, another representative said, 'In my experience, I think it happens often.' Her colleague considered it as a barrier, 'The staff lack of compassion or education on what retaliation looks like or truly understanding that their action is retaliatory in nature. It's the same principle when resident rights are violated. If they don't understand everything that is encompassed with that…I think that's a big piece of it.'

A representative from another state said, 'I would say probably 50% of the staff that I've interacted with over the years are so dismissive in the form of not having the acuity or not having the thought that they are doing that. It's not a conscious effort in about 50% of the staff. They really don't know that they are doing it or they don't see it as a negative.' She added that this is the kind of education she provides to care staff members.

When asked about effective practices and strategies in addressing residents' fear of retaliation, one representative said, 'I will hold trainings for staff on resident rights and mandatory reporting. And honestly, when going through those a lot of staff don't think

about, you know, you're stepping into this person's home…so remind them of their tone, the language, their facial expressions, body language and how some of these things that they do can look like retaliation. If a resident happens to make a complaint or a concern to a staff and their language is a little bit different or they may not be polite or they may not knock on somebody's door…just to make them aware because I think education and reminders are important especially with new staff that, you know, the trainings are pretty quick so they might not even be aware.'

In a follow up question, I asked whether there are situations where staff are not aware that things they do or say might be considered or perceived as retaliatory in the eyes of the residents, she said, 'Yeah definitely. When I've done those training, staff come up and say, 'I have other questions can I ask you?' or they just weren't aware of some of the things that they should be doing or even if someone has a concern about them, they're nervous about working with that resident in the future. But again, it's just about education. So I think those trainings are really helpful and building a relationship with those staff and knowing that if they have questions or they're not sure what to do, they can come to me.'

One very experienced representative said, 'I think there are some people that aren't aware that that's how they're reacting to what is being said and done and then I think there are people that probably to *some* degree kind of *use* those subtle indicators to express, you know, they do have an awareness like they know that they can't shout at a person and they know that they can't maybe say what they really want to say but they feel free to do these types of things because there's a variable in how that might be interpreted. I think there's a mix. I think there are people that are unaware of themselves and they're expressions and I think there are people that maybe use it with some type of manipulative intent.'

When asked whether sometimes staff will do or say something to residents when they are unaware that it is being perceived by residents as retaliation, a very experienced representative said, 'I think so but I can't think of anything right on top of my head to give you an example but I truly do believe that it happens.'

One representative spoke about elements of paranoia as a factor in residents' experience of fear or retaliation. He said that as 'an element to the fear of retaliation or *real* retaliation, there's also an element of potential paranoia that comes into play. To use an analogy, if I complain about the food in front of me at a restaurant and I send it back, in the back of my mind I'm concerned that someone might spit in it and the kitchen and does that actually happen or not. I would guess, normally it doesn't happen, but we still have that psychological construct that is a byproduct of the mere fact that we complained about something so that plays a part too.'

When this representative was asked whether some staff may say or do things to residents when they are unaware that these things are perceived by residents as retaliation, he said, 'Absolutely and that's what I was talking about that sense of paranoia. You know, when you're talking about soft skills…coming in saying, 'Hello.' I maybe walk in that particular morning and it was just really poor timing because this concern was brought up yesterday, I came in the next day as a staff member and I was preoccupied in my own mind and just simply overlook that. It wasn't intentional, I did do it, I can concede to it, but that resident is now taking it personally and they're internalizing it.'

Another representative described situations where under certain circumstances, staff prioritization of care tasks could be perceived by residents as retaliatory. He spoke about a care environment consisting of competition for staff resources, 'We see these people on the floor every day and we see how hard these direct care staff are most oftentimes working and so they do end up having to prioritize things and as unfortunate as it is and as much as it's not supposed to be, that's the way it unfolds…that's the way we see it every day when we go into these places. What ends up happening is that the next level of this retaliatory action would be just picking other residents even amid a hierarchy when call lights come in for example or putting them on ice a little bit longer than they might otherwise have been or just simply delaying for the simple fact of delay.'

Educating Administrators

As part of their efforts to educate managers and Administrators, representatives reported that they attend management meetings with all departments' heads, deliver 'mini' educational moments, hold Zoom educational calls, and send Zoom mails.

Representatives also said that at times they need to confront Administrators about ongoing but unaddressed care concerns (see the segment titled *Directly Confronting Administrators* in **Chapter 7** Strategies for Addressing Fear of Retaliation and Actual Retaliation).

One representative spoke about the importance of reminding Administrators, 'These are the regulations and the rights that they have and they need to be upheld.'

An experienced representative from another state said, 'One of the things I would do when I was [de-identified leadership position at the LTCOP] was regularly give a presentation to groups of individuals that were becoming Administrators and Operators in our state [Operators in this state run fairly small assisted living residences; number of beds de-identified]. I would challenge those staff…I had heard a statistic that one of four residents would be afraid of retaliation if they report abuse, neglect or exploitation…and I encourage them to spend their day, you know, on a regular basis just like every fourth person that they saw that day that they would statistically be afraid to report abuse for fear of

retaliation…and to have that mindset. It may not be in your facility but generally this is the statistic and help them to think about what that might mean in their building and how they might work to make that not true in their building.'

Another representative described how she educates Administrators about the impact retaliation can have on residents, 'I try to always bring it back to where they can understand or relate. Like with retaliation against a resident in the facility, I will ask the Administrator, 'If that was your family member in that bed and the *same* situation happened, how would you feel?' And they'll say, 'Well, of course we would be upset.' So you can't expect the family not to be upset with you right now. Now *that's* why they're upset. It's just kind of brings it home and hopefully opens their eyes a little bit.'

Quote
"*If that was your family member in that bed and the same situation happened, how would you feel?*" – Ombudsman representative telling an Administrator

The same representative described the impact retaliatory threats of discharge could exert on residents and how she educated Administrators about it, 'It's a major impact because you're affecting their home. That's where they live. This is something that I have a discussion with my Administrators about…whether it is an assisted living or a nursing home. I tell them, 'How would you like me to come into *your* home and basically tell you, it's time for you to leave? You can't gather anything. It's *time* for you to go.' And they will say, 'Well, we never really thought about it that way.' Well, maybe we need to start thinking about it that way.'

A representative from another state shared a **story** illustrating how she works to instill sensitivity and empathy among Administrators. She said, 'One case that I had was the facility kept using plastic utensils. They weren't using sliver utensils. This was even after COVID. They're using plastic utensils and I am like, 'Seriously, what is going on here?' So I visited them several times about using plastic utensils. It's a dignity thing. Nobody wants to use that all the time. I went to the Administrator and I said, 'Where did you have for lunch today?' you know, just as a conversation. 'Oh, I went to [de-identified name of restaurant]. 'What kind of silverware did you use?' 'Well, I used what they had.' 'Really? Well, your residents use plastic silverware. They couldn't cut their meat and whenever they tried to with their plastic fork, then the little tongs broke inside their meat and then they chewed on

it and it was sharp. And then they couldn't cut things with that knife because it was flimsy. What knife did you use?' If you pull these things together so that they can actually *feel* what's going on and we can take the institutionalization out of these facilities and bring it back to a home environment, and dignity and respect because I think they lose that. It's all about education.'

When asked what works in addressing residents' fear of retaliation and actual retaliation, a very experienced representative said, 'I think education is the largest piece of it. Reminding people that warm bodies don't equate good care. I am talking about management. We may go and attend management meetings. Most nursing facilities have a…they call it 'stand up' some of them but they have a morning meeting where all the departments' heads meet together. We target those and do little mini in-services, 'Hi, just want to remind you of things we're seeing around and here are some things we can share with you.' We offer handout material.'

A representative from another state said, 'I have certain buildings that are…repeat offenders I guess you would say. They will ask to see my documentation during a visit or they want to know who did I speak with…and I am like, 'No, that's not what we do. We're a confidential program' and reminding them about that and really just training all of the staff…I think some of the staff are familiar with the program and some staff are not. So just letting them know 'I will or not be sharing that with you' and particularly to new Administrators and we all know that there's an abundance of turnover or depending upon what state they came from or what area of the state they came from in a previous role, some are used to having frequent Ombudsman visits and some are not. So just providing that educational piece to them about what you can expect from me and what I expect from you.' She gave an example of an issue she provides education to Administrators on: 'I have had one home in particular that had repeated calls that after my visits the staff were in their rooms and I do believe there are cameras in that facility.'

During an online forum dedicated to the issue of residents' fear of retaliation (the forum was not part of this project), one SLTCO said that she'd be curious to know what the Nursing Home Association and the Nursing Home Administrators Association think about this issue and whether they have specific training programs for direct care staff members and nurses. She added, 'They are at the forefront of it.'

Educational Efforts and Programs Delivered by Ombudsman Representatives

Many representatives recognized the need for increased education – to all parties – on the issues of residents' fear of retaliation, threats of retaliation, and actual retaliation.

For example, during a forum dedicated to residents' fear of retaliation, one of them said, 'There has to be so much more education. So many residents in long-term care facilities…whether it's assisted living or otherwise, they don't know that they have the same rights they had when they resided in their home. They think that they've lost some things when they walked through the threshold of a long-term care facility.'

Educational efforts identified included delivering In-Services to care staff members and educational programs to residents. One representative said, 'You need to continuously in-service employees,' including delivering mini education sessions on topics such as Resident Rights Training, Right for Dignity and Respect, and right to file grievances without fear of retaliation and without retaliation. She added, 'I just try to educate them about the right to be free from retaliation and I do always say, 'It is not legal for them to retaliate against you. That doesn't mean it's not going to happen. I can't make any guarantees. But I will do everything in my power to help you here.''

Another representative said, 'We all do Resident Rights Training and mainly that is done with the staff to go through resident rights. I always start my training off that resident rights aren't something that people just got together out of the blue, 'We're going to come up with resident rights or federal regulations.' When I start those off, I kind of let it be known in my opening statement that resident rights are serious. They really do have these rights. This isn't just something somebody made up somewhere. This is legit.'

Representatives shared that they deliver Abuse and Neglect Training. One of them said, 'We do provide in-services and we try to do it on abuse and neglect because they correlate with retaliation as well.' As reported in detail earlier in this report, representatives also provide education to residents and staff on Resident Councils.

Many representatives said that they typically educate residents about fear of retaliation and actual retaliation as part of broader educational sessions – not so much as a standalone educational program. This finding doesn't necessarily mean that education about the issues of fear of retaliation and actual retaliation always needs to be delivered as a standalone (separate from Resident Rights or another broader topic). This is a finding that LTCOPs across the country and national Ombudsman organizations may want to take into consideration as they develop educational programs on this topic and as they guide Ombudsman representatives in ways to educate the different parties on it.

The following segment contains representatives' statements suggesting that in most cases, education about fear of retaliation and actual retaliation is delivered by representatives as part of broader educational programs.

One representative said, 'Not specifically. We do speak at Resident Councils…we do speak at Family Councils but that's not necessarily a topic of itself.'

When asked if she provides education exclusively on fear of retaliation, another representative said, 'No. I would say not exclusively about that but Resident Rights and/or Abuse, Neglect, Exploitation…like what to look for, how to prevent, things like that."

When asked the same question, one representative said, 'Under Resident Rights yes but do we have the time to do the education piece that our job was supposed to do? No.' Her colleague added, 'I feel like with the buildings specifically…no.'

When asked basically the same question, another representative said, 'It's been more of a Resident Rights. It's something I would love to do. The pandemic kind of ruined a lot of…I know it did for other states too…the training that we do to facilities. We're trying to, you know, as we identify a need that's what we try to do…is we try to offer training. And if we're not qualified to do it…let's just say that in that county the Ombudsman…it's not really something that she has done before, then we can try to find somebody else that could do it. Statewide, I arrange trainings for the staff and I try to bring trainers about areas that they need and so for instance, if we saw that this is a systemic…it is a big problem but if it were a problem that is bigger than others, then we probably try to bring in a speaker sooner than later. But you know how it is…there is a long list of things we need to do training and re-training. We would prioritize training like that for our staff so they can gain the skills.' She added, 'I always tell my staff, 'If you don't know what you need to know, then let me know and I can help you get what you need.''

When asked if she'd like to see a course on fear of retaliation and actual retaliation that she and her Ombudsman representatives could use to educate residents, families, staff, and Administrators, she said, 'Yes. Bring it to me. Right now. [laughs] Yes actually, with all seriousness, that would be fantastic.'

When interviewing an experienced representative, I asked: Have you worked to reduce residents' fear of retaliation by providing training to residents, families, staff, and Administrators? Her response was, 'Absolutely. I've spoken with facility staff…I do Resident Rights training, and we specifically focus on retaliation, what that looks like so they fully understand…when you do your resident rights…what the subtle retaliation looks like as well as the blatant retaliation looks like. I've spoken with Family Councils so they understand…if they voice their concern or their resident voices a concern, that any backfire that they get

from that is considered retaliation and to definitely report. As well as residents…when I present to the Resident Councils, them understanding what retaliation is and that it is their right to be free from retaliation.'

I followed up with this question: Do you have any written material? Do you have any In-Services? Any videos? Any resources to educate any of these entities in your state?

Her response was, 'I go through the Resident Rights and give examples of what retaliation looks like. I gave the example of 'I used to talk to this resident every day and now that you ignored him or you're ignoring cries for help.' Those are examples and I give kind of real-life examples of what the retaliation looks like.'

I then asked: Are you aware of an educational video about this phenomenon of fear of retaliation in long-term care homes? Her response was, 'No. But I would be interested.'

I told her that there is a good though old video developed in Connecticut called Voices Speak Out Against Retaliation. I then asked: Would you like to see an updated video education that you can take into Resident Councils, Family Councils, maybe sit with staff…In-Service or Administrators to educate them? She said, 'Absolutely.' She added, 'Yes. Any materials, any new information would be wonderful. Very useful.'

One very experienced representative described how she weaves the issue of residents' fear of retaliation into staff educational programs she delivers on Resident Rights / Dignity and Respect. She said, 'The educational component has been around resident rights and the way I have tried to address fear of retaliation has been to turn it into how staff treat residents with dignity and respect.' She added that she uses examples of residents' fear of retaliation and 'I present those as opportunities for staff to show respect and dignity towards residents. We talk about tone of voice or I'll ask the group, 'What things do you do for individual residents that show them that they're treated with dignity and respect?' And they may give me some answers, 'Oh, I know what particular clothes that an individual wants to wear' and then we roll that into some of those same indicators that the residents tell me they're fearful of tone of voice, eye contact, how they're touched when they're turned in bed or assisted to a chair, the way someone puts a water glass down in front of them at the dining table. I try to use those same examples that residents tell me they're fearful of as a way to tell staff that's how they can show dignity and respect for individuals…to try to be thoughtful about every subtle interaction they have because residents it's on their radar screen…they see it, they feel it, they sense it, and that they're key to that experience.'

In a follow-up question, I asked about the extent to which she finds that dignity is related to the phenomenon at the center of this project, she said, 'I really think it comes down to how we as humans interact with each other. Dignity is treating someone as we would want to be treated, as we would want our mother, father, sister, brother to be treated by another individual. I think it's really at its core. If people feel that they are treated with dignity and respect, they will be less fearful of retaliation because they know they can count on that from that individual staff person or a culture within a home. If a home has a culture that *supports* and *encourages* staff to treat residents with dignity and respect, I think we'll have a culture that will be less fear of retaliation.'

Quote
"*If people feel that they are treated with dignity and respect, they will be less fearful of retaliation*." – Ombudsman representative

One representative said that she and her colleagues offer In-Service to care staff members, 'We start off with their basic rights under the constitution. They're American, they have these rights.' She said, 'We all have these rights no matter what environment we live in, no matter what location we live in. Those don't change just because you cross the threshold of a facility.' She spoke about the freedom of speech, the freedom of choice, and the freedom of association, 'Who do you want to be with? Who do you want to be around?' Those are the fundamental freedoms that forefathers fought for and put in writing in the Constitution.'

She said that she then talks with staff about, 'As you age, how those rights that you had sometimes go away.' She gave an example, 'Maybe you can't drive anymore because your eyesight has diminished or your health has diminished so now you can't drive so now you're not able to go out and maybe meet friends or be with the people you choose to be with because you can't get there. Maybe you need the care of someone else so now you're moving to a facility and you lived in a 1,500 square foot house before and now and now you're going to live in a room that's maybe 20 by 20 and you get half of it because you have to share it with a roommate. So we talk about that loss and things that you're losing as you age. Maybe your spouse passes away and how does that impact you and so when you start taking all these things away like their car keys, their home, their health…when you get to the end, what do you still have? They still have the fundamental rights that they were born with as an American…the right to choose, the right to religion, the right to live their life they way

they want. You started at birth with those and you still end your life with those. Those are not ones that get taken away because of unfortunately a disease process or a circumstance. Those are still fundamental and when we explain that to staff, 'Nobody tells you that you can't go to McDonald's at midnight and get a bite to eat so the resident still has the same right to ask you for something to eat at midnight because they still have the same fundamental right even though they're in this living environment.''

Quote
"*Those don't change just because you cross the threshold of a facility*." – Ombudsman representative referring to people's rights under the Constitution

She explained, 'When we do that with staff, you do see a lot of light bulbs go on above their heads where they think, 'Oh yeah, nobody stops me from going and getting McDonald's in the middle of the night, nobody stops me from choosing the doctor I want to be with. When you relate it to them maybe in a way that they think about themselves or they think about their life and what they have or don't have and how you relate it back to those fundamental principles of our Constitution, it really does drive home to them that, 'Yeah, this person has the right to choose and we shouldn't be enforcing our preferences, our choices, our will upon them. They still have the same rights that I do. I just don't live here. I work here.' I say that to staff all the time, 'You work where they live.''

She gave an example, 'If you have a home or wherever you live and let's say you bought an appliance and that person showed up at your house a day late, and tracked mud through your house, and hooked up the wrong appliance, and was *rude* to you, you would not allow that to happen now would you? No. So why is it acceptable for a resident to accept the fact that you showed up late for work, you came in not prepared for work…not in your uniform or whatever…and then you came into their space and turned on the TV so you could watch the show you wanted maybe not what they wanted and you were grumpy…you were unpleasant to them. Why do you get to do that when you would not let a delivery person do that to you? And would you not complain? Sure you would. You're gonna call that company that you bought that appliance from and say, 'Your delivery guy is blank, blank, blank.' Residents have that same right. They can call the facility or fill out the form or verbalize it, 'I don't like this. I don't like how I was treated.' That is the same right *we* have for those of us that live outside the facility for goods and services that we purchase. It's not different.'

She added, ‘When you break it down like that for staff and really get them to understand that residents are paying…someone's paying for the goods and services that these staff are to deliver and you compare it to the delivery of an appliance or something to their home, it really strikes a cord with them going, ‘Oh, whoa, wait a minute, yeah, I don't have the right to just be dismissive or ignore behavior or be unkind in their space or unkind to them in their space.’ It *really* just drives that home for them. I've had many staff come up after that presentation and go, ‘Wow, that was really powerful because I never thought about it that way.’ That, for me, is where you truly see change happen. Even if you can get five employees to see that, and accept that, and really own that, then you're going to see them treat residents better.’

A couple of representatives said that they deliver In-Services specifically on the topic of Residents’ Fear of Retaliation**.** One of them who is a very experienced representative recommended using the booklet titled Facilitator’s Guide on Fear of Retaliation (developed by University of Wisconsin, Oshkosh, 2016). She said that she finds it ‘very useful’ in providing In-Service to staff, ‘I use it quite a lot.’ She added, ‘This guide is very good’ and ‘It is very very powerful.’

Another representative said, ‘We do in-services just on retaliation sometimes.’ She added, ‘If we find that it is an issue in a building, we will create one and we have one that we use for retaliation.’ When asked if they have a manual, she said, ‘No, it’s just one of my staff…she has [de-identified number of] nursing homes. She was finding it a lot in her in her buildings so she just created some…we did it as a group…some bullets…some ways she had seen staff retaliating…they know because they are the ones doing it but just to let them know that we know that it’s happening.’

When asked about her thoughts related to ‘Reflexive” retaliation (an issue addressed in **Chapter 6** Challenges and Barriers in Addressing Residents’ Fear of Retaliation), one representative shared a **story** about how representatives sometimes educate care staff members and managers – in real time – how to approach residents in advanced stages of dementia who reject care. She said that one of her colleagues walked into a public space of a care home where they saw an employee trying to force a resident with dementia out of a broken wheelchair by pulling the resident out (the wheelchair was sliding). The resident was screaming, ‘No, no, stop, stop, stop’ while the employee ‘continued to do what they were doing.’ The representative said, ‘I think she was scared. It was my understanding she was scared the way she was lifting her.’ She added, ‘She had bruises all over because according to her, they do it all the time to her.’ The colleague who witnessed it intervened and stopped it, ‘You don’t understand, if somebody says, ‘No,’ it’s *no*.’ She said, ‘You do realize that that is abuse. If somebody tells you, ‘No, stop,’ then you stop.’

The representative went on to say, 'The Ombudsman, which really, we're not supposed to help, she was able to demonstrate…she got down to her eye level…so she felt safe…and she was able to effectively and safely move the resident to another chair. The Ombudsman did. They just [weren't] taking time.' She added that it turned out that the employee doing it to the resident was the Director of Nurses. The representative 'didn't know it because she didn't wear her name tag on. That's a whole other problem…but yeah, she figured that out.'

She added, 'People I think become desensitized. That's the only thing I can…I can't imagine that all these people started out this way…I don't know…do they just become desensitized? They're short staffed so they're kind of like robots so they're just going through the motions, and they forget that they're dealing with human beings.'

The representative added, 'I feel like training probably…so if you're showering somebody…they don't take enough time to figure out where is this behavior coming from. Why is the person lashing out? Why is the person saying 'No'? Why are they combative? That's their way of communicating so what does that mean? And that's just doesn't happen. Maybe it's a little old lady dementia resident and you have two males giving her a shower and that's *really uncomfortable* for her. I see that all the time and it angers me. There's just not enough time. I think that happens and it's so sad…it makes me really sad when those types of things happen. So training is a part of it…education is a part of that but also just taking the time. They talk [about] "person-centered care" [said it with hands gesture indicating quotation marks] is supposed to be a thing [shakes her head from side to side]. I have yet to see where that's happening.'

Need for Structured Stand-Alone Educational Programs on Fear of Retaliation

As noted earlier, a preliminary trend was identified whereby most educational efforts delivered to care staff members by Ombudsman representatives typically addressed the issue of residents' fear or retaliation *as part of broader* educational programs such as on Resident Rights, Dignity and Respect, or Abuse and Neglect. In other words, structured stand-alone staff educational programs solely dedicated to this issue were rarely reported by the Ombudsman representatives interviewed for this project.

One representative said, 'I've done Resident Rights, I've done costumer service to staff members in skilled nursing, but it just touches on retaliation. It doesn't go in depth.'

In the words of one SLTCO, 'Just the standard In-Service programs. When we teach abuse, it's combined into that but certainly, you can't spend enough time on that because you have to spend more time just on what abuse is, neglect, and mistreatment.'

Another representative said, 'When we go out and do training on residents' rights, retaliation is a topic that we cover and what does that look like.'

One representative (#1) said, 'We've also done trainings on retaliation but that doesn't work too well.' When asked to elaborate, she said, 'I just said that because retaliation is something that is prevalent in the nursing homes.'

Her colleague (#2) added, 'They're in denial about it' to which representative #1 added, 'Yeah. They are in denial about it, and it continues.' They quoted staff saying, 'That doesn't happen. We don't do that. You know we wouldn't do that' and 'I trust my staff.' Representative #3 chimed in, 'And then they actually do that to gaslight the residents. I mean, they gaslight the residents every single day.'

Resource Box
Industry Representative Quote
"The premise of this bill is that, somehow, those of us who have dedicated our lives to caring for the frail elderly will now "retaliate" against them. It is an outrageous premise, frankly." – Martin Sbriglio, President, CEO, Ryder's Health Management, March 8, 2012, five weeks prior to the bill's passage in Connecticut. Source: An Act Concerning Fear of Retaliation in Nursing Homes.

Referring to residents who are scared to express their care concerns, a representative from another state said that managers 'don't know what they don't know.'

When asked whether her Ombudsman Office has any material about fear of retaliation that she uses to educate residents, families or staff members, another representative said, 'I don't have specific topic under the fear of retaliation. Just basically, we do educate in Resident Rights in specific areas such as right to express a grievance, right to be able to participate in your plan of care, right to know their medications. I choose specific rights that I know…that I feel sometimes the facility doesn't honor. When the residents do, they are educated and they know, 'Hey, I have a right to get a list of my medications. I have a right to ask questions if I don't understand and staff may get very upset and agitated. So I find that those specific areas of the Resident Rights I have to focus on.'

When asked if she would like to see material or a video on fear of retaliation that she can use during Resident Council meetings, Family Council meetings, and with CNAs and managers, she said, 'I would. I would like to see a resource where I am able to do that.'

Need for Educational Material on Fear of Retaliation / Retaliation

Several representatives shared that their LTCOPs do not have educational material specifically on residents' fear of retaliation or actual retaliation. One of them said, 'Just what we do. That's all. There is nothing specific. To my knowledge, there is nobody you can call and say, 'Would you go into this home and do an in-service on staff retaliation?''

Resource Box
Fact Sheet on Retaliation
During this quality improvement project, a Fact Sheet titled Addressing Concerns About Retaliation was published by The National Consumer Voice for Quality Long-Term Care (June 2024).

Several representatives stated that they would like to see educational resources and videos and films on fear of retaliation (so they can use these to educate residents, families, staff, managers, and Administrators). One very experienced SLTCO said, 'If we had a film, we could show it to the Resident Council.'

Resource Box
Educational Film
Educational film titled Voices Speak Out Against Retaliation in Connecticut. The film is from 2010 and needs to be updated.

Representatives from certain LTCOPs use the educational film as part of their training program. For example, one representative said that the video is used during their training**,** 'Once it's viewed, there's so much conversation that follows that.' Her colleague added, 'A lot of our videos are out of date too but they are still meaty.'

Referring to the aforementioned educational film, a representative from another state said, 'Resident Council with the fear…they watch the retaliation video at every Resident Council…most of them and the residents, they just need more education around it because I don't think they…even around Resident Council…what it stand for because a lot of times the facilitators are the staff. We just have to do a lot more education around, 'It's your meeting' and what retaliation is so residents know what it is when they see it and how to address it. But I think we need to do a lot more work around it. Because, again, that video

is probably 20 years old and a lot of them leave when you pop it in. I just think we need to do more work around retaliation.' This representative confirmed that she'd like to see a new educational video for residents, families, and staff members.

Quote
"*I just think we need to do more work around retaliation*." – Ombudsman representative

Another representative recommended developing a webinar on retaliation that could be shown to residents and families (such as during Resident Councils and Family Councils). She shared her idea in response to my question on the role of assistive technology in addressing the issue of fear of retaliation. She said, 'I think assistive technology could be a very great thing because the more resources that the residents and the family hear about this, the better because now you have of course the Ombudsman, you might have staff talking about retaliation. I think it would be *wonderful* if residents and staff and family members could actually view a webinar on actual retaliation, that this is something that happens, how it can be addressed, etcetera. Here are some things that you can do to address it etcetera. I think the more resources the better.'

Resource Box
Webinar: How Fear of Retaliation Scares Residents into Silence (Hosted by Long Term Care Community Coalition). Podcast: Nursing Home Residents Fear of Retaliation (Hosted by Rhode Island Elder Info).

Relating to her recommendation to develop a webinar on retaliation, she added, 'I would say it would have to be much shorter, more direct, and more to the reading level of…because we know our residents generally have 8th grade education. Shorter words, that sort of thing. I think it would be very helpful to residents. They need to know that they are not the only ones this is happening to. I think it needs to get out.'

Examples of topics that could be addressed in the webinar may include, among others, residents' relevant rights, definitions, detection (including the distinction between subtle and blatant retaliation), what can residents and families do about fear of retaliation, threats of retaliation, and actual retaliation, reporting procedures, and provider's responsibilities.

One representative said she'd like to see care homes required to offer classes to residents on retaliation (see details on an innovative law in Connecticut in **Chapter 9** Areas in Need of Legislative Changes).

Several representatives said that they are not aware of any educational resources in their state on the issue of fear of retaliation or actual retaliation. One SLTCO said, 'I am looking to have a dedicated trainer. I want continuity in training. I want somebody that can capture all of this stuff that is *really* important for our knowledge and expertise but also our training purposes so that we can provide the *best* Ombudsmen services to residents, the best advocacy that we possibly can.'

Need for Increased Collaboration and Education Across States

One representative saw a need to increase shared learning among Ombudsman representatives across states, 'I do think it would be great if states had more collaboration with other states. I just think it's really important because it's something that residents and families mostly all fear. It is in the back of their minds. I think it's the one least talked about to be honest. I feel like it's just an issue that is *not* really talked about. It happens all the time. Families and residents tell me this all the time but there is really no direction and there's no guarantees. Again, I don't know if it's training, education or just even talked about more. I think it's really important.'

Quote
"*I think it's the one least talked about to be honest*." – Ombudsman representative referring to the issue of residents and families' fear of retaliation

Areas for Improvement in Training Provided to Ombudsman Representatives

Several representatives praised the new 10-module training program titled *Trainee Manual: Initial Certification Training Curriculum for Long-Term Care Ombudsman Programs* (January 2022) developed by The National Long-Term Care Ombudsman Resource Center (NORC).

One of them said, 'NORC completely re-did the training last year. They did a great job. Of course, those modules are very general.'

Several representatives thought that the current training representatives receive is adequate in addressing residents' fear of retaliation and actual retaliation. For example, one of them said, 'I don't know of any gaps necessarily.' Another representative said, 'I'm always open to more training but I do think that we are trained to look for retaliation and how to investigate it with consent. We do have our supervisors and the State Ombudsman we can call anytime with questions. I do feel like fear of retaliation we are…because we look for the marks, we look for the bruising, we look at the resident when a staff walks into the room…we see if there's a change in how the resident is…so we've been trained in that.'

When asked if the education she receives is adequate when it comes to addressing residents' fear of retaliation and actual retaliation, one representative praised her SLTCO and described her as a 'Star person of education' (i.e., doing a fabulous job in educating all representatives on 'plethora of topics'). She said, 'Most definitely. My [missing word] and executive director, they encourage us to be able to take advantage of any education training or opportunity that is presented so we have free rein of those…so I feel confident in being able to do my job adequately because we're getting that training that we need.'

Others saw a need to strengthen the initial certification training provided to representatives on residents' fear of retaliation and actual retaliation against them.

When asked whether she sees a need for improvement in the training representatives receive on residents' fear of retaliation and actual retaliation, a very experienced representative said, 'There's always, always room for improvement. We can always learn more because we're talking about people and people change, techniques change. We can always use more information. I am a firm believer in educate, educate, educate. That means us. So yes, and I think what you're doing in terms of best practices…[the] feeling that I get with this study, I think would be *tremendous*. Yes, Ombudsman do need more education.' When asked whether there are specific things she'd like to see improved, she said, 'I really can't right now other than just give us more…that's all I can say.'

Another representative said, 'Retaliation is the number one fear of residents. I know that I have to find the resources because it is an interest of mine. I think that it should be one of

the four most things that we should be taught as Ombudsmen.' She added, 'I think it should be more prominent in our training because we hear that *all* the time.'

Another very experienced representative said, 'Preparing for the interview made me think that we should probably be discussing this at our staff meetings from time to time. We should probably be collecting stories around it just so that we can learn from each other around it and maybe to look at our initial certification training to see…I think we *touch* upon it but maybe to question, Do we really say enough? or Could there be more that we could do to support the staff when they are confronted with this particular issue?' She added that she'd like to see case studies, discussion, and strategies related to this issue.

Resource Box
For a compilation of excerpts on fear of retaliation and retaliation from the Trainee Manual: Initial Certification Training Curriculum for Long-Term Care Ombudsman Programs, see **Appendix 3.** *Other parts of the Trainee Manual may also address these issues.

When asked what is of value in her efforts to address fear of retaliation and actual retaliation, a new representative said, 'Number one, I *really* think we need more training on this. I want to help my residents better. I feel really ill-equipped to handle retaliation issues. Yes, I try my best even in bringing up tools even in [de-identified state] on how we can help.'

Quote
"I *really* think we need more training on this. I want to help my residents better. I feel really ill-equipped to handle retaliation issues." – New Ombudsman representative

Later during the interview, when asked about how she educates residents, families, and staff about retaliation, she said, 'I need more. I'll be honest. I need more.' At a later point in the interview, she returned to this issue when she said that she'd like to see more education on this topic 'for all of us,' referring to care staff and representatives. She asked, 'What tools in a toolbox can we bring to staff, to residents?'

As other representatives stated earlier in this repot, she said that she'd like to see an educational video that she could use to educate residents during Resident Councils (she knew about the educational video titled *Voices Speak Up Against Retaliation* in Connecticut (published in 2010) but added that she'd like to see it updated).

She said that she'd like to have an education program on retaliation that she could deliver to residents, 'There are some resident rights listed on the wall but maybe they can't see them. Of course, I am present but I can't talk to everybody. They need to be aware of all the rights and what retaliation is.' She added, 'I don't think residents know their rights as well even though they might be listed.' She added that mandatory care staff training on retaliation such as required in nursing homes in Connecticut 'would be wonderful.'

When asked about the extent to which her current training adequately addresses how to respond to residents' fear of retaliation, she said, 'No.' She added that she'd like to see improvement related to 'the four components' (i.e. fear of retaliation, alleged threats of retaliation, perceived retaliation, and actual retaliation) adding, 'It's all important to break that down.' These four components were examined in my recent study (Caspi, 2024).

That said, she did go on to describe how she tells residents that 'retaliation is against the law,' that she 'can't promise it won't happen,' how going with an anonymous complaint might be helpful, and how she tries to empower them with their voice. She said, 'I always try to empower them first with their own voice because they've lost so much control in their life but if they need me, I am here.' She added, 'I don't want any harm coming to them, but I do want them to know that their voice really does matter.'

Quote
"More knowledge for us is needed in this effort." – A very experienced Ombudsman representative

One very experienced representative said, 'I think we get plenty of education on abuse and neglect and financial exploitation. But do we get enough training on how to identify possible retaliation?' She added that she believes the Ombudsman program could have more training on retaliation, fear of retaliation, and threats of retaliation.

Another representative said, 'I think there's a huge area for improvement in our trainings….in how to handle that…those types of situations. I think that that's one of the trainings that we are lacking in as a state…unfortunately.'

Her colleague said, ‘I agree. Especially with the new people coming in.’ She said that the majority of Ombudsman representatives in her state have less than 5 years of experience in the role. She said that as an experienced representative, she and her colleagues ‘have kind of adapted and done our own research and bounced off of each other and attended webinars and things like that’ and ‘I think there needs to be a very direct approach on education on how to deal with retaliation because of the new staff.’

She added, ‘We just normally will have state conferences that all staff will go to and it will be specific training on specific areas. This is something I really think that needs to be addressed. I think that statewide…and it’s nothing against our State Ombudsman…our current State Ombudsman is awesome and offers as much training as possible, but I just think this is something that needs to be moved up a little bit higher on the priority list.’ It needs to be recognized, however, that at the time of the interview, this representative did not yet had a chance to review the new 10-module Trainee Manual.

After speaking about the importance of continuing education to representatives, I asked an experienced representative this question: Do you feel that what you receive now or what your Ombudsman colleagues receive is adequate in addressing this phenomenon?

Her response was, ‘I would love more information.’ I asked, ‘Like what?’ She said, ‘I think the education that we receive is good, but I think *more* is needed in terms of retaliation…on how to deal with that and how to appropriately address that.’ She confirmed that she’d like to see more information on residents’ fear of retaliation.

When I asked her later whether she can think of things that do not currently exist that if existed would have helped her better address residents’ fear of retaliation and actual retaliation, she returned to the same issue, ‘Additional resources like the training videos, materials that we can share with residents, steps for a resident to take if they have experienced any type of retaliation. Empowering tools for residents.’

Additional Ombudsman representatives’ statements about the need for improvement:

When asked whether she sees areas for improvement in the education representatives receive on residents’ fear of retaliation and actual retaliation, one representative said, ‘I don't think retaliation is recognized as much as it should.’ When asked to elaborate, she said, ‘There's a lot of when we go over resident rights, there's a lot of big ones. I don't think retaliation is one that's really focused on a whole lot, and I think it's one that probably everybody feels to some extent…family members, probably most residents. They're nervous that if they express concerns or complaints, that they will be targeted and sometimes they've been right. I just feel like it's something that most people would feel naturally, and it's really not focused on a whole lot…so I do you see a need.’

She said she ‘definitely’ sees a need for increased education on fear of retaliation and actual retaliation. She provided detail: ‘I think different trainings or collaborations…what we see in [de-identified state] and how we handle it could be very different from New Hampshire, Massachusetts, California. I think coming together in different ways that they've seen it…big cities may function very differently in a nursing home than somebody in [de-identified rural town in her state]. I do think there's a missing piece of trainings on it because there's really not a lot. We all recognize it to be a fear. What do you do about it? I feel like we're kind of left to our own.’

When asked if her comments are also applicable to the new 10-module Ombudsman Trainee Manual, she confirmed and said, ‘When you're dealing with real people and a lot of love and emotion, different personalities, different nursing home personalities, it's really difficult. It's really that people want 100% assurance, and we can never give that to them. So what can we do instead?’

A representative from another state said that she’d like to see a curriculum on fear of retaliation and actual retaliation that she could use to educate residents and families. She said, ‘If I had a curriculum, I’d be happy.’ She added, ‘I am happy to share a curriculum like that at a Resident Councils for instance and the Family Councils would be thrilled to have something like that because the Family Councils seem to be the most enthusiastic group out there…in our world. They are constantly looking for solutions. Residents are trying to survive. Families are trying to find solutions. If I can say, ‘These are some things you can talk to your loved ones about to overcome their fear or this is how we can change policy’ you know, anything that gives them a solution.’

She then shared her views about the curriculum currently used to educate Ombudsman representatives, ‘Now, in our certification training we have curriculum on retaliation but all it shows is yes, there are some residents that are scared, a couple of pointers, and about how maybe to overcome it but a great stress is made in our training that we are not to break confidentiality and we are not mandated reporters. It errs on the point that yes, you’re going to get pushback from encouraging people to complain but it's something you’re going to have to live with because we don’t want to break confidentiality even if we see some egregious things happening.’ She added, ‘But I definitely would love to have a curriculum for speakers of 45 minutes or so I could call on to come to our…we have an In-Service every month for all our staff and all our volunteers via Zoom. If I could just call on somebody to come and speak on it, I would be thrilled.’

When asked about areas for improvement in Ombudsman’s training on the issue of fear of retaliation, another representative said that the training she took about seven years ago didn’t adequately address it [i.e., before the new 10-module Trainee Manual was released],

‘I really honestly didn’t receive a lot of training on retaliation when I went through the training program.’ She added that it is addressed in the new 10-module Trainee Manual (the extent to which she thought it was addressed in it was unclear because she hasn’t finished it). She did say that she’d like to see more scenarios in the training and what to do in different circumstances (‘I think that would be great.’). She added, ‘I don’t know what the answers are. How do you prove it? How do you get people to not dismiss it? I don’t know if there’s an answer to that but if there is, I’d love to know it.’

As noted earlier, a few representatives expressed a need to strengthen efforts to learn from practices used in other states to address this issue. One of them said that there’s a lot of shared learning across different LTCOPs and that it takes place through the Office of the State Long-Term Care Ombudsman. At the same time, she recognized a need to learn from other states’ experiences and practices pertaining to fear of retaliation. She said, ‘Maybe we all as a whole are able to learn from each other because everybody’s style and technique is different and our understanding of it is different.’ She added, ‘If we were in unison, I think we would be better positioned to figure out what it is we need to do to combat what’s going on.’

One good example of learning from other states is the LA PEER – Louisiana’s Program for Empowering Every Resident, which was originally developed in Pennsylvania. The LA PEER is ‘a ‘train-the residents-to-self advocate’ program. The program consists of a series of interactive training sessions for LTC residents. The program trains residents ‘to advocate for themselves through a six-part empowerment program and teaches them to help their fellow residents to improve day-to-day life in their home facility. The residents are trained to think in terms of advocacy and act as problem solvers through critical thinking.’ Graduates of the program – called LA PEERS – ‘continue to meet monthly with the Ombudsman to further hone their advocacy skills.’

During a forum dedicated to discussing residents’ fear of retaliation, one representative said, ‘What has happened and this is also part of the LA PEER program, it has given them purpose, it has given them confidence and we now have these LA PEERs who are at the forefront of the training are now communicating with other LA PEERs at other nursing homes and we have one coming up where our Louisiana LA PEERs are communicating with the Pennsylvania PEERs. Residents are communicating with each other, ‘How are you self-advocating? How are you helping your peers? What have you done that have been successful programs?’ [addressing] issues of smoking, issues of abuse, issues of late breakfast. The LA PEER program has given them the skill set how to complain, not just yelling and shouting, jumping and putting their feast on the table but finding out who to contact, what’s the solutions, what’s the law, and how to approach it.’

One very experienced representative expressed a need to strengthen the confidentiality section of the Trainee Manual. She said, 'We use the new training that rolled out. We use the 10 modules. I've used them. Our State Ombudsman now does the whole training. She has a staff person at the state level that does the whole training for everyone here, which is *really* helpful. I think that training is pretty good but there could be more…just in the confidentiality section…because it covers that in multiple different ways but there can always be more…it can always be better.'

When asked whether she meant that the Confidentiality section needs to be improved in general or in the context of fear of retaliation, she said, 'I think there could probably be more in the confidentiality section about fear of retaliation…what that looks like…but the training is good about ways you can combat that…like visiting multiple residents…Resident Councils.' She added, 'The problem is…when you go through that training and you actually go out and do the work, it needs to be revisited over and over because it's a lot, it's a lot.'

One representative said, 'I would love to see more specific training.' When asked for examples, she said, 'Such as Naomi Feil's Validation Method. Make Validation a thing nationwide.' She added, 'I think understanding dementia is important to this whole thing too. But just training, training, training.'

When asked about the extent to which the new 10-module Trainee Manual adequately address how to respond to fear of retaliation, she said, 'Adequate? No. They are probably too general. Are they a good start? Yes. But I don't think they spend enough time specifically on retaliation or fear of retaliation, no, no. There is not enough focus on that, no.' She went on to say that she'd like to see 'a specific training in a specific protocol. Maybe some case studies. Case studies speak to me. I don't know if anybody else. I learn a lot from them. Here's a situation. Now, what would you do Ombudsman? Training Ombudsman…what would you do? You've got a 20-year Ombudsman vet saying, 'That's a good idea. Your response what good. Here's how I would tweak that…''

Two representatives from another state said that their main source of education on retaliation is during routine work meetings with their colleagues. One of them said, 'Our training is basically in our meetings when we talk about these things. It's really hard to train on retaliation. We do touch on it in our learning [missed word] but I think the experiences and listening to [de-identified name of her very experienced colleague] talk about some of the retaliation issues he's had, I really feel that's where we learn the most.'

Her colleague agreed and added, 'Yeah, I think a lot of it is definitely on the job. You can only take so much from the books and trainings and put it to use. It's on the job training. It's amongst ourselves. We learn from each other. We're on the phone constantly with each

other going through scenarios and situations. Is that technically considered training? Not necessarily but it's how we reach out to each other.'

In accordance, a representative from another state said, 'Every situation is so different. It's almost like you have to figure it out as you go when you're in a situation.'

One representative who said that she is not aware of any gaps in the current Ombudsman training went on to describe a challenge related to the training program. She said, 'The other challenge is that it is a *lot* to absorb when you first become an Ombudsman. It is a *lot*. You have to review things over and over because you can't absorb it all fast enough…I don't think…at the beginning.'

Need to Strengthen Resident and Family Education in Assisted Living Residences

In response to a question about the role of Family Councils in addressing the issue of fear of retaliation, a SLTCO said, 'Right now we are working with the assisted living families because we try to beef them up like we do with the nursing homes…and teach them that just because you're paying money doesn't mean you don't have rights to speak up and there's a way to report all of it. The assisted living people were very mad when we started that and I said, 'Well, the hell with them.' Just because you're paying money doesn't mean you haven't got a voice.' She added, 'Our goal is to let the families and the residents know in the assisted living that there's a way to handle problems.' She said that they encourage families to put together a Family Council (She added that in assisted living residences in her state these councils have a different name).

When asked if there is something uniquely different in assisted living from nursing homes in the context of residents' fear of retaliation, she said, 'The people in assisted living don't think they have any rights because they haven't been educated. Yes, there is a Bill of Rights but nobody really explains it to them. You know what happens? Somebody is admitted and it's thrown into the pile of the admission papers. Who knows if the resident ever gets to see it. It is important to educate them about what their rights are.'

Chapter 9

Areas in Need of Legislative Changes

Representatives were asked whether they see a need for legislative changes pertaining to the issue of residents' fear of retaliation or actual retaliation against them.

Some representatives didn't see a need for it. For example, when asked whether there is any law or policy that limits representatives in their ability to address residents' fear of retaliation and actual retaliation, a very experienced SLTCO said, 'There is no policy that limits us. We have pretty free rein as far as addressing issues and we do bring in the Department of Health when necessary. We could use more volunteers…of course…and we can use more staff…that's what we're trying to do right now.'

A representative from another state said, 'CMS has several guidelines, protocols and procedures and also state regulations have been put in place and they address everything from culture change to Resident Rights whether it has to do with LGBTQ and Aging and what to do when residents report abuse. There's a whole plethora of things. I think we have what we need to have in place. It is just a matter of knowing those policies and regulations and being able to do [she didn't complete the sentence]. We understand and look at those and also making sure that with those regulations, that they don't violate the rights of the residents but in all, I think we do have regulations in place…enough regulations in place from CMS for facilities to abide by.'

That said, when asked for her thoughts about the enforcement of existing regulations, she said, 'The enforcement is a different story. I am going to give you one example. You have regulations stating that the facility must or where they have to make sure that there's adequate staffing to provide the care. That has been a problem…is making sure that there's adequate staffing…the ratio, the staff to particular residents. I am seeing that to be a problem. To me, personally, one CNA to every 10 residents…it's overwhelming. I think that CMS really needs and nursing home associations…they really need to take a look at that. We are not doing an adequate job with making sure that we have adequate staffing in the nursing homes to be able to effectively care for the residents. I really do feel that that is an issue that I'm seeing.'

She added her concern for staff, 'Not only for the resident but for the staff as well. They are overworked so it causes a danger for them as well so I would like to see the enforcement of that. You have that regulation facilities must ensure that you have adequate staffing, but do you have the means to be able to do that so that the residents could receive the care and also to protect the staff?'

When asked about the extent to which State Survey Agencies cite nursing homes for "sufficient staffing" of competent staff to meet residents' needs, she said, 'It's not enough. It's not enough and this is the complaint that we get. One of the biggest complaints is not enough staff. I don't think the state really takes a look at it but it's probably above them as well so enforcement I think is very important…' When asked if she sees a relationship between poor staffing levels and the phenomenon at the center of this project, she said, 'Do I see a relationship? Yes, I do.'

Other representatives identified areas in need for legislative changes. Some of them saw a need for more specific language on fear of retaliation and actual retaliation in the laws and regulations. For example, one very experienced SLTCO said, 'Everything is very general in the laws and in the Bill of Rights. Nobody gets into the specifics. You actually have to explain to people what mistreatment, neglect, and abuse is and if you don't, they don't understand it.' She went on to refer to CMS State Operations Manual Guidance to Surveyors, 'It's not strong enough, it's not explicit enough. They'll give you four examples of what it means to neglect somebody, but you won't get four examples of what it means to retaliate against somebody.'

A representative from another state said, 'I do know that I always hear like the staff member say, 'I haven't received any complaints.' It's like they don't understand what fear of retaliation is and I have to explain it to them. I would like to see a regulation where everyone understood what fear of retaliation was, what it really means…for the staff members to easily recognize it. It's always the Activity Director, 'Oh, no one complained to me' and I am like, 'It's not the ones that are complaining to you, it's the ones that are *afraid* to complain to you. Talk to *them*, the ones that you don't know, go talk to *them*.'

When asked if she'd like to see a state law or Federal law requiring staff to receive an annual In-Service training on fear of retaliation, threats of retaliation, and actual retaliation, she said, 'Yes. Absolutely.' She added, 'I feel like there should be reporting laws. You see your staff member retaliating. If you see something, there should be…even if it's just verbal or even if you feel it, there should be something like that…they have to be required to…I know there's mandatory reporters but still.' When I said that CMS considers retaliation as abuse and that staff are supposed to know that, she said, 'They're supposed to know that…but I don't feel like they do or that they see it that way.'

A representative from another state identified a gap in the guidance for mandated reporting for allegations of abuse and neglect in her state, 'Nothing in here says anything about reprisal or retaliation. The language needs to be re-written to include that. It lists it, 'without fear of reprisal' but it doesn't identify what it entails *specifically*. Without fear of reprisal. In what way? If you have an outline of what way, it may be effective that way but the way it's

written, it doesn't capture it enough for me.' She added that she'd also like to see more explicit language on fear of retaliation in the Federal Nursing Home Regulations, CMS State Operations Manual Guidance to Surveyors, and Interpretive Guidelines.

Several representatives recognized the need for other states to replicate Connecticut's laws such as the 2012 law titled *An Act Concerning Fear of Retaliation Training in Nursing Home Facilities* requiring annual in-service training to all staff in nursing homes or a rest home with nursing supervision (the law needs to be expanded to assisted living residences) and a 2021 law allowing residents to use 'any technology of their choosing' in their bedrooms (the law titled Public Act 21-55 "allows nursing home residents to use technology of their choosing that facilitates virtual monitoring or virtual visitation and it establishes related notification, use, and consent requirements").

A SLTCO shared that her colleague searched but couldn't find a state legislation requiring staff training on fear of retaliation and actual retaliation in LTC homes. She also said that she sees a need for similar legislation in her state. She was also unaware of similar legislation in other states beyond the one in Connecticut (her colleague also couldn't find state legislation requiring Abuse Prevention Training). She added, 'We're going to look a little further just to make sure we're not missing it but, to me, that's basic. Anybody that is working with other human beings should be taking that abuse prevention training who can then also highlight the fear and retaliation.'

When asked if she is aware of any law or regulation in her state that requires either nursing homes and/or assisted living residences to provide staff education on residents' fear of retaliation or actual retaliation, a very experienced SLTCO from another state said, 'No.' She added, 'Just the standard In-Service programs.' When asked if she is aware of retaliation-related training requirements in other states, she said, 'No.' Referring to the law in Connecticut, she said, 'I think it is a good law. I didn't realize she had it. Then, when I read it, I thought, well, let's see what I can get from this interview and now that you say there's a report going out, I can include that with the law and go to one of the legislators.'

Another representative recommended, 'I think that the facility should be required to offer classes available if residents want to join about the same issues…retaliation…just to offer the class. They can have a video they can show where the Administrators are there talking with residents. I think that it should be offered for residents so they can have that class available to them right there in the facility.'

Need for Stronger CMS / SSA Oversight and Enforcement

Several representatives saw a need for stronger CMS / SSA enforcement of existing regulations pertaining to residents' fear of retaliation and actual retaliation. When asked if she can think of an existing law or regulation that prevents or limits her from fulfilling her role in addressing these issues, one representative said, 'Just some zero tolerance. Something with zero tolerance for retaliation and fear of retaliation.'

A representative from another state said, 'I don't understand for the life of me how that all works but…because if facilities were held accountable, if they were *fined*…if they hit them in the pocket, which is what they seem to care about the most, then maybe some of all these issues that we have would start to get resolved…but they don't.' She gave an example of a very low substantiation rate of the complaints her Ombudsman program submits to the SSA. She estimated it at approximately 4% substantiation rate.

Another representative said, 'I think the fines must be much higher. Instead of a facility being able to say, 'We'll just take the hit' because that happens quite a bit. When they're trying to discharge a resident. They'll send them out to the hospital and not let them come back. And they will tell us right on the phone, 'We're not letting him come back. We're just gonna take the hit' because the aggravation in the work that they're going to have to do to place that resident because of so much documentation is something they don't want to deal with.' She added, 'They'd rather take the hit and pay the fine.'

A representative from another state said, 'I think some buildings are aware of it. Some buildings *absolutely* know what they're doing and they don't want to hear it even though they know they are violating residents' rights. I've even heard buildings say they'd rather get tagged for residents' rights than for something else.' Her colleague gave these examples, 'Like a wound or neglect because they can get charged for abuse whereas resident rights doesn't weigh much at all.'

One representative spoke about lack of perpetrator accountability, 'I know that there have been staff in some places that it's been documented they've pushed a resident or twisted their arm…various things and they've just gotten sort of a write up from the facility and they still work there where they've actually physically *abused* someone and they just basically get a warning and it feels like there should be more done as if somebody abused a *child* that was defenseless. There has to be something better than just giving a written warning.'

Quote
"*It feels like there should be more done as if somebody abused a child that was defenseless. There has to be something better than just giving a written warning*." – Ombudsman representative

When asked whether state survey deficiency citations or the Abuse icon on CMS Care Compare website or the Nurse Aide Registry or the Nurse Registry has oversight value, she said, 'Yeah, if it gets that high. I don't feel like it does unless it's really really extreme. I think there's lesser cases, but I'll see people that have marks on them or there's just a lot of where a person's frustrations have come out on residents and there's a gap and I don't know what the answer would be.' She added, 'If they get caught, then they could just go to another nursing home who's desperate for staffing. You can get a write-up. You may not work your next shift. But there are not enough people to care for these other human beings appropriately. It's *not* good quality of care…at all, at all. Very scary.'

Another representative saw a need to improve the transparency of care homes' appeals process, 'On a systems level is that transparency that with the [State Survey Agency] and the way that…even when they tag these buildings, so much of it is done in the dark because of the appeals…the right of the nursing home to appeal…they don't have enough people…voices from the families and the residents to speak to the abuse or retaliatory practices. That's what I would like to add…that we need to have more transparency.'

Resource Box
Article: How nursing homes' worst offenses are hidden from the public. *The New York Times*.

One representative suggested passing legislation to ensure that X% of profits will go back into direct care for the residents. Specifically, when asked about what she sees as characteristics of care homes with less or no fear of retaliation, she said, 'I think they are investing back into the facility, they are investing back into the residents, they're *providing* what residents need on a daily basis.'

Resource Box
Article: Court affirms ruling that New York nursing homes must spend 70% of revenue on direct resident care and limit profits to 5%. Source: Edelman (July 3, 2024). Center for Medicare Advocacy.

She went on to contrast it with, 'Right now they are not giving back. It is very clear that they are putting their money in their pockets or going on trips or doing whatever and not actually investing back into these residents that are paying a lot of *money* to be cared for and where families trusting facilities to be doing their best for their loved ones. It's not happening. There's no law, there's no regulation. When you look at our rules, it's very broad, very board and it goes back to holding them accountable. I know I am held accountable so if I am held accountable at this level, why are we not holding these companies taking care of 100 residents accountable?'

She added, 'As far as politically, I don't get into whose fault or where…I just know that something needs to change in these nursing homes. Something needs to change for these assisted livings because our dads, our moms, our grandparents…they worked very hard, *very* hard to get Social Security, to be in those places that nobody ever plans to be in, nobody. But because they're there, they depend on somebody to feed them, to bathe them, to clothe them. It has to change. If it's forced through you…nationwide… you're interviewing different states…just to get it out there and to say, 'It's time for change.' We *really* have to hold these nursing companies accountable.'

Quote
"It's time for change. We really have to hold these nursing companies accountable." – Ombudsman representative

A representative from another state spoke about the inadequacy of Federal regulations pertaining to staffing ratios in nursing homes. She said, 'Let's talk about staffing because we get many complaints about that. The Federal regulations do not provide a numerical equation for staffing, you know, 10 residents for every one nurse or something like that.'

She said that the "sufficient staffing" requirement 'is subjective. When you explain that to residents or family…because they'll say [in a worried tone of voice], 'They don't have enough staff. How can they do this?' When you explain to them, 'There is no numerical equation that is used.' It is all on the subjective term that they have to have "sufficient staffing" to meet the physical, medical, psychosocial, spiritual, and emotional needs of all residents. Well, that is a *completely* subjective opinion. That is a barrier that many people are just *stunned* that there isn't some numerical equation. But also that their perception of what is needed and the facility perception of what is needed is so *vastly* apart. It's a huge canyon there.'

When asked how it plays into interactions with residents, she said, 'I think it works two ways. You have staff who tries really hard to meet everyone's needs, who are constantly apologetic to residents and families for not getting there in time or 'Look, I had to take of these three other people first.' So you have that dynamic.'

She went on to say, 'Then you have the other, which I see more in the management side than in the direct care staff. The management side are saying, 'We have plenty of staff. We have it staffed well enough to be able to care for the needs of these residents.' And that is probably based on a business plan. They believe, very confidently sometimes, that they are staffed appropriately because they are meeting the business plan that the corporation has laid out to them. However, there is evidence that that does not meet the needs of the residents…that they are not getting all their needs met in a timely fashion. I think it is interesting that you have these two dynamics there. You have management who'd say, 'Oh yeah, it's fine' but you have direct care workers who are often apologetic for not meeting enough of the needs or as much as they would like to.'

She added, 'Then just getting residents or their family members to understand that as "consumers." [said the word consumers with a hand gesture indicating quotation marks] You know, where is the consumer protection here? I've often said that, 'I don't understand why there are no consumer protections for residents, family members who are entrusting their loved ones to the care of the company.' You know, any other avenue…you buy a car, a house, goods and services you buy, there are consumer protections, you get a disclosure, you sign off on the disclosure, you get this, you sign off on that. That doesn't happen in long-term care. I have my theory of why that happens but again, what dynamic do we live in where we buy goods and services and not disclose to us in some kind of contract or some kind of written document my responsibility, your responsibility in exchange for…usually it's money…let's be real, it costs money to get goods and services…but where else that dynamic not present, that full disclosure doesn't happen? Because if I had that call once, I

probably have it twice a week where family members…when I educate them…[say], 'I can't believe that there is not a numerical staffing ratio.' They are just *stunned* by that.'

Tying it to residents' fear of retaliation, she said, 'It's the fact that if I complain too much about not having enough staff to meet my needs, then they'll probably kick me out or they'll make me the last person served… I always say to residents, 'The squeaky wheel does get oil' right? That's the theory in life if you complain enough. But in long-term care, that's not what happens. If you're the squeaky wheel, you'll get your needs attended to last. If you want to complain a lot…let's say you put on your call light very frequently. One day you fall and you put on your call light, they're going to think, 'Oh well, she is on the call light again.' They are passively dismissing that person when really, they should be going and seeing what that person needs whether it be, 'I need a cup of ice' or 'I've fallen on the floor.''

Quote
"*I always say to residents, 'The squeaky wheel does get oil' right? That's the theory in life if you complain enough. But in long-term care, that's not what happens. If you're the squeaky wheel, you'll get your needs attended to last*." – Ombudsman representative

When asked whether there are things that do not currently exist that if existed, would have helped her in better addressing the issue of residents' fear of retaliation, she said, 'I think the mandatory numerical equation for staffing would be *huge*. To say, for every four residents you have to have one CNA. From my perspective, that type of numerical equation would be really beneficial to minimizing retaliation to residents by staff. Because, again, I think 50% of the retaliation is passive, it's not a conscious effort by the staff. It is ignoring the behavior because it happens all the time, it's disregarding somebody's call lights because, 'Well, they just want a cup of ice.' Kind of minimizing it. If there was a better ratio, I believe it wouldn't be as difficult for staff to disregard that because they would have the ability to see those people on a more routine basis. If they only see the resident on the morning shift, say from 7 to 3, they see them in the morning at breakfast and let's say the lay them down for a nap after lunch, and they're gone for the day, they may have only an hour or two to interact with them in an 8-hour shift and maybe not even that many minutes. If you had higher staffing ratio, you'd have that CNA probably doing more tasks with that resident throughout their given shift and that's going to help with the lack of care or the retaliation. 'I am not going to go in there again because I know she just wants a cup of ice.'

To me, those are the simple things that a CNA can do. Those simple requests I hear are so annoying to staff. They are I guess "disruptive" maybe the word I want to use. I want to be like, 'Well, you're in the business of caring for people.' That means a cup of ice to a fall on the floor, it's a spectrum. You have to be able to attend to everything on the spectrum.'

A representative from another state said that there is a need for legislation that will require care homes that are required to submit incident reports to the SSA to also submit them to the LTCOP. She said, 'I wish that we as Ombudsman were told more about these incident reports that are filed for abuse allegations and other significant incidents because if we were given the reports just like the [State Survey Agency] is given. The [State Survey Agency] will come out only if they flag it for some reason, then they'll come out…they don't always come out…most of the times they don't. But *we* could get one and go talk to the resident because the vast majority of them are "unsubstantiated." Because if a facility substantiates an abuse allegation, they automatically receive a citation and it's categorized as an abuse citation, which then it's the red flag on Medicare.gov [i.e., Abuse Icon on CMS *Care* Compare website] so they will do *everything* to either not report it as abuse, not substantiate it…even though, in our opinion, talking to the resident, talking to the staff…*clearly* substantiated. They won't substantiate it unless it is *very* egregious. So if we got those incident reports, we could go and talk to the residents, reassert their rights, do that process, and make sure that they feel that though they didn't substantiate it…the staff was maybe still fired…but it wasn't substantiated…that they still feel that everything was followed on and kind of making sure they're kind of feeling okay after a retaliation situation.'

She clarified, 'If a facility is told of retaliation, it should spawn an abuse investigation. When those abuse investigations happen, the facility generates an incident report so those are not documents the Ombudsman has access to under our authority right now. [De-identified state] is working on us being able to be given authority to at least demand the facility give us a copy of the incident report…their investigation report.'

She said that at the time of this interview, these incident reports are not automatically being sent to the LTCOP 'but us going to the facility and asking for a copy of it.' She added that there is an effort to pass this legislation in her state 'that will allow us to ask for it under our current authority to access records because right now facilities can give them to us if they want to but they don't have to…so most of them don't.' She said that as a result of this legislation, 'We would have more information about what happened, about what the outcome is…truthfully what the outcome was, it would give more transparency to us and thereby the resident as to what happened because otherwise we're at the mercy of what the facility is telling us happened.'

A representative from another state said that his state is one of only five states requiring mandated reporters to submit a form consisting of allegations of abuse to the LTCOP (among other state agencies such as the SSA and local police). When asked about the value he sees in this requirement, he said, 'We all have different roles there…so licensing is going to be looking at regs and compliance and all that but Ombudsman, we're there to really help being a resident advocate and everything that we've been talking about here and just get to them as soon as we can and offer whatever we can to help figure out what's going on and then help them resolve the problem in the future usually with us in house.'

He added, 'I see that [de-identified name of form used in his state] as no different than a phone call or something we will meet a resident while we're there. It allows us an opportunity to connect with someone and to see if we can be of assistance. It also allows us an opportunity to provide an in-service training to the facility if we do have consent to reveal someone's identity or maybe it's a general thing that we can do over time, it will allow us then to address some issues with the facility that we see.'

When asked whether it would be beneficial for other states to pass similar laws, he said, 'Yeah, I think so because I am not sure why an outside agency…I mean, we are the ones with knowledge of this environment, we are 'boots on the ground,' we are in it, we know the licensing, we know the regs, we know a lot of things. I think it would be hard for an outside agency to come in and do an effective job of investigating an allegation of abuse when you have so many things at play. I think the Ombudsman program seems like an appropriate agency to receive those.' He added, 'But the problem is that that level of response really requires more of a staff type of response in most cases.' He then talked about challenges in training volunteer Ombudsmen when they volunteer 10 hours a month.

Another issue identified relates to state laws on camera installation in bedrooms. One representative said, 'By state law, there has to be a sign out in the hallway…on the door whatever…that says, 'Camera in Use.' I think that limits a lot of stuff because if someone knows they're going to be on camera, more than likely they are gonna change their ways at least for a little bit of time that they're in there. We'd like it where you didn't have to announce it to the world that there's a camera in use in the room.'

Need to Address Gaps in Laws and Regulations in the Assisted Living Sector

Ombudsman representatives identified a series of gaps in state regulations in assisted living residences (beyond their observations which were described in this report under the segment titled *Weak State Regulations in Assisted Living Residences* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation).

One representative said, 'And we haven't even gotten to the horrible world of adult care facilities because I am not a fan. [in this state, this type of care setting also consists of assisted living]. Assisted living. Just the idea that it lacks at so many regulations and any kind of external knowledge on the quality of an assisted living is not known to people.'

Another representative identified lack of consumer protection and lack of full and honest disclosure of services as a major gap in the assisted living sector. She said, 'Consumer protection…meaning, having true disclosure of what you're getting versus what you perceive you're getting. Assisted living is just a title. The regulations refer to assisted living as Residential Care Facilities. Assisted Living is something somebody in marketing brought up…kind of makes you feel warm and fuzzy…right. Assisted living…you're going to assist me with my living, you're going to assist me with my care. Well, that's true but there are limits on what they'll do…and they are *expenses* for that. You can live here and it's four grand a month but we don't provide any care. You need help with a bath and you need help with medication, that's another $1,200 a month. I feel like that consumer protection is not there where people agree or move in and then maybe got a little bit of a "bait and switch." You know, 'Oh, they got the first month for free' but now they can't afford to live there because now all these fees are getting…I would say nickeled and dimed…kind of depending on the pay structure of the facility…but they are getting nicked an dimed to death and now they can't afford to live there or they can't afford to pay for the care so they try to do it themselves and then they decline.' Tying it to residents' fear of retaliation, she said, 'If you complain about the lack of care or whatever, they are going to say, 'Well, we're just going to raise your rent then' or 'We're going to charge you more because you want this.' If you are on a fixed income and resources are limited, you're afraid to speak up and ask for help, request help because you can't afford it.'

She spoke about lack of recourse for assisted living residents, 'When they do assess the charges…and it depends, some people do a la carte pricing, it's so much for this, it's so much for this versus leveled pricing. If you have two needs, you're in this first bracket so it kind of depends but the assessment is done by the facility staff and the resident doesn't really have any recourse. If that facility says, 'You need help with a bath and you need help with medication,' and the resident is saying, 'I did for a week post-surgery but not *permanently*,' the facility says, 'Well, you needed it so we have to bill you for it.' Again, there

is no recourse for that resident to change or limit the fees that are charged to them. As a consumer, you should have the right to pick the goods and services…and not be forced to…when I say forced…again, you chose to live there…but forced to always have to be compliant with what they say you need.' She said that this issue of lack of consumer protection could be alleviated somewhat if there were full and enforceable disclosure requirements (for services and fees) in assisted living residences.

Resource Box
Article: Extra fees drive assisted living profits. *The New York Times* (November 19, 2023).

When asked what challenges and barriers stand in her way of addressing the issue of residents' fear of fear of retaliation, one representative said, 'The one that I find rather frustrating is assisted living. There is no real teeth in regulations…I mean, there's not a lot of regulation. And 'Basic Care' that is under [de-identified name of State Survey Agency] but they're surveyed every four or five years or if there are complaints, they are not a high priority. There's no teeth. What can you do?'

Quote
"The one that I find rather frustrating is assisted living. There is no real teeth in regulations…I mean, there's not a lot of regulation." – Ombudsman representative

She added, 'In my perspective, with retaliation, there's no oversight is what I am getting at. There is no oversight. So residents…other than complaining to the Board of Nursing, say it is a CNA or a nurse…that's your recourse but there isn't anything to alleviate that fear still for a resident because the Ombudsman alone cannot do it alone.'

She went on to say, 'I think that there needs to be something that we can fall back on. For example, I can fall back on residents having more *choices* in skilled nursing facilities. They have the [State Survey Agency] behind them. The teeth is maybe if nurses knew about retaliation and didn't do anything about it and that becomes a neglect of a resident. But in Basic Care or assisted living, where are the regulations that support the resident? We can't say *anything* will happen as far as retaliation. There is nothing in there to protect the

resident. What are the protections? There isn't any. Yeah, there isn't anything. I can try to do what I can. But [shrugged her shoulders].'

One representative thought that retaliatory discharges are more common in assisted living than in nursing homes. When asked what underlies the difference, she said, 'Because their statutes and their rules and regulations at least in [de-identified state] are very vague. It is so vague it's not even funny. They can give you a 45-day notice because they don't like the color of your clothes or because you disagree with them. It doesn't make a difference…they can give you a 45-day notice whereas the nursing homes are regulated so they need to fill out the regulatory forms and it has to be submitted so it's a little bit…although they try…I will say that they try…there are times where they put out those forms. On the paperwork, some of the things that they write, it's clearly blatant and we call them out on it. They still try with the nursing homes, but they are less [missed word] to do it at the nursing homes. The assisted living facilities are notorious for…whatever the reason may be. Residents go to the hospital and they dump them in the hospital and they don't take them back.'

In accordance, a very experienced representative who spoke about unsafe discharges said, 'Here in [de-identified state] what we deal with that contributes to this whole problem is…our regulations for assisted living say they can give a discharge notice for 'any other reason.'' When asked, 'Other than what?' she said, 'Other than no payment or we can't meet your needs…'any other reason'…so talk about fear.' She added, 'I am referring to assisted living regulations that don't look out for residents' best interests.' She added, 'It is a big fear and that's probably [vary] from state to state where the regulations for assisted living are so different and don't always protect residents like the federal nursing home regs.'

When asked about things that do not currently exist that if existed, would have enabled her to better address residents' fear of retaliation, she returned to this issue, 'The one I was just telling you about 30-day discharge for any other reason from assisted living here in [de-identified state]. That needs to change because that just contributes to that fear where residents don't want to complain because, 'They can just discharge me.''

When asked what she would like to see with regards to this issue, she said, 'I would like to see that just completely removed from the regulations. It can't be just for any other reason. It needs to be *real specific* like the federal nursing home regulations. Not just, 'We're just going to give you a 30-day notice.'' She considered this issue 'a big problem.'

When asked about the threat of wrongful involuntary discharges, a very experienced representative from another state shared this **story**: 'Just [de-identified time] there were two reports of that from one homeowner. One resident was sent out to the hospital for "behaviors" [said the word with hands' gesture indicating quotes] and another one was

discharged with no notice from one personal care home to another. The second personal care home felt they were not told about the "behaviors." After two days, brought the person back to the first home and I get a call, 'This individual is sitting on the porch with nowhere to go.'' She said that they wouldn't let the person in and added, 'And you may already have someone who has some mental health issues…think about that kind of bouncing around. It happens all the time and it is common in personal care homes because federal law does not regulate them. Federal law regulates nursing homes. It still happens there. But it is a little more [missing word].'

When asked whether there's a law or regulation that prevents or limits them from fulfilling their role in addressing the issues of fear of retaliation, a representative from another state spoke about an additional gap she sees in the context of involuntary discharges, 'Assisted living facilities do not have the appeals rights. Definitely a big one for me.' She added, 'Because assisted living do not have any federal regulation. They're all state. And in the state regs there is nothing in there that you can appeal a discharge.'

When asked about things that do not currently exist that if existed, would have helped her better address the issue of residents' fear of retaliation, she said, 'I guess the fear of being involuntarily discharged is very real. And we here in [de-identified state] been trying to get the right to appeal involuntary discharge for those assisted living facilities in our state. It hasn't been successful with the [de-identified] bill…I don't think… It is not getting any traction again this year.'

Another representative spoke about the lack of consumer protections pertaining to involuntary wrongful discharges in assisted living residences in her state. She quoted staff telling a resident, 'You don't fit in here. You don't like it here. You complain too much. You would probably be happier somewhere else. Don't you *think*? Let us help you find some place where you're going to be happy at.' That's the kind of statements that residents hear.'

One SLTCO described a legislation passed in her state related to protections from involuntary discharges in assisted living residences. She said, '[De-identified time], we were able to pass a regulation for appeals rights to apply for residents in assisted living homes and mirror that of the nursing home appeal rights for involuntary discharge. Involuntary discharge we found could be a retaliatory act from the facility because maybe they don't want to deal with a "difficult" family member or what have you and so they take it out on the resident in the form of involuntary discharge. We were able to put that law in.'

The description of this legislation was included here so that other states that don't have similar legislation in assisted living residences may consider passing it.

Chapter 10

Other Recommendations

Need for Adequate Ombudsman-to-LTC beds Ratio

Having an adequate Ombudsman-to-LTC beds ratio was described by several representatives as critical for their ability to have direct access to as many residents as possible, provide them with education and advocacy services, and to be effective in resolving their care concerns, fear of retaliation, and actual retaliation against them. It could also enable them to increase their systems' advocacy (e.g., legislative changes).

When asked whether there are things that do not currently exist that if existed, would have helped her better address residents' fear of retaliation, one representative said, 'More funding for us for our program to be able to meet the needs of the residents in a better way and to be more accessible to them…to have more staff.'

One SLTCO said, 'I would say first and foremost, we need more Ombudsmen. That's my plug for…always increase funding…we're under-resourced. Our rural areas need more support. My office needs more staff.' Referring their services and advocacy for residents, she added, 'If we have more bandwidth to do that…more people to do that with quality, I think that we'll remove some of the challenges and barriers that we have right now.'

In accordance, a representative from another state spoke about the problem of 'not enough Ombudsmen.' She explained, 'That is a huge barrier because I can't be in five counties probably even once a week. I can probably be in a couple of them once a week. We need more Ombudsmen because I can't be everywhere.' Another representative said, 'It is something we struggle with here in [de-identified state] and we are in the process of advocating for more funding to increase our staffing to deal with this.'

A representative from another state said, 'Even just our manpower in the facilities to help the residents but manpower on the streets of ombudsmen. Again, I'm sure [de-identified name of SLTCO] would tell you, for eight years we…the entire state of [de-identified state] was relying on less than [$ amount de-identified] of funding for our program and that includes [de-identified city] so we're now up to little I think [$ amount de-identified]. It's still a drop in the bucket compared to what we need because we wanna do those specialty things. We wanna do the discharge transfer stuff, we want to do hospital dumps, we wanna do systems advocacy, and we wanna get out there and speak to as many consumers as I can. I wanna get involved in responding to new legislation and all that kind of stuff but just doesn't have the manpower. I really think we're the only other group other than the [State Survey Agency] that's in these facilities as an overseer and I really think we've proven

ourselves over the last two years just with the little extra money that we have and we're getting more calls than ever.'

When asked what are things that currently do not exist that if existed would have allowed them to better address residents' fear of retaliation, a representative from another state said, 'If we had more staff.' She explained, 'We can be in buildings more regularly. If we had more staff, we could almost have a catchment area where…let's say, on my team, I have one staff person that has 15 buildings…he has 15 buildings that he goes to and he goes to them on a schedule. If we had scheduled…not announced but if we had a schedule where we were in on a regular basis we would have a better opportunity to make greater connections with residents and also when we go in, we're going in as the Ombudsman's office and we're there and we do our job and then we leave. My team goes in more regularly but not as regularly as I would like to and you don't get the sense of comfort and feel with a regular presence that you do if I was going in once a week.'

Another representative spoke about the importance of having enough Ombudsman representatives to be able to do outreach and be accessible to residents, 'I don't know that it will ever be perfect unless we had an increase level of Ombudsmen that could actually be on-site. *Accessibility* is always gonna prove to be a challenge.'

GAO Study
A study by the U.S. Government Accountability Office (2024) found that certain Long-Term Care Ombudsman Programs experience challenges that 'make it difficult for them to provide all the services they are responsible for providing' (e.g., 'handling increasingly complex cases, increasing number of facilities, as well as limitations in resources such as staffing and funding').

Need to Re-evaluate Institute of Medicine's 1:2,000 Ratio Recommendation (One Paid FTE Ombudsman Staff Person Per Licensed LTC Beds) with Adjustment to Rural Areas

One representative said, 'The only one I think needs to be addressed federally…I know it's only a recommendation but the 1,2,000-bed recommendation. For rural people, that can be a big thing. We don't have buildings with 500 people. When we say we cover 2,000 beds, that might be within 3,000 miles…so 3,000 miles every month to see our people, that's really hard when you think about somebody in New York that maybe has just like a corner of town. They only have to go to one area. So sometimes, when they say that 1:2,000 bed recommendation, a lot of our buildings are only 40 people.'

This representative said that sometimes it takes 4 hours to drive one way to get to a building. She added, 'We want to be more of a presence' and 'when we talk about having more of a presence and being in the buildings and being able to respond to complaints in a timely manner and stuff like that…when we try to meet those recommendations along with the bed recommendation, sometimes that just doesn't mesh. I just wish that they would lower that recommendation and maybe the states would start hiring more. I know a lot of states rely on almost all volunteers and are AOAs or AAAs or other agencies but I just think if the recommendation was maybe a little bit more giving, those states would follow.'

She added, 'Pretty much every year they request an FTE and it gets shut down at legislation. If that ratio were to change, they might have to look at that a little bit differently.' This representative made this recommendation in light of the vast geographic distances (very long windshield time) she needs to drive to get to a building and visit with residents. She said that she'd like to see a more rural-sensitive allocation of resources and funding to Ombudsman programs working in rural parts of her state.

An experienced SLTCO from another state agreed that the recommended 1:2,000 ratio isn't fair to Ombudsmen in rural regions. She said, 'That's something to look into for sure.' She added, 'I have some Ombudsmen in rural areas that have to drive 4 hours one way to get to a facility. That's a lot of windshield time. I am starting to think about how to make a case for having more paid Ombudsmen in those regions as well.'

A SLTCO of a LTCOP with an Ombudsmen-to-LTC bed ratio of X (over 1:1,000; number de-identified) stated (August 1, 2024), 'While I'm sure this is significantly lower than a lot of states, I would like to point out that we are a very rural state. So each ombudsman has to cover a lot more mileage to visit those X beds than they would in a city. Some ombudsmen travel for three hours (six hours round trip) to reach the ends of their service area.' She added that her representatives also cover people who receive care in their homes (under the state LTC Medicaid waiver program) and that these people are not included in the ratio.

An example of an internal adjustment of the ratio was described by a representative serving a predominantly rural region in another state. She said that her state-wide LTCOP has a 1:1,800 Ombudsman-to-LTC bed ratio but that an Ombudsman representative in a more densely populated region in her state might have a 1:2,000 ratio 'but since I travel so much…I travel the most distance, I will have less residents.' She said, 'I have 1:1,400.'

When asked if she thinks that the 1:2,000 recommended ratio needs to be adjusted to rural areas, a representative working in a region consisting of a 'combination' of urban and rural (she later added that it takes her 3.5 hours to get to one remote care home), said, 'I don't know because I know we open up every case. So we're still out there once a month at least in the community. We are in every community once a month for our routine visit. And then whenever there's a case, we're out there and we open it up there for that case. So they are getting visited the same amount of time as everybody else.' She added that they just hired many [number de-identified] Ombudsmen. She added, 'For a long time, we were short-staffed, and the legislator recently gave us more new positions.' When asked whether she feels that with their current ratio she is able to get into care homes in a frequency she considers adequate, she said, 'Yes. If fully staffed, yes.'

The limited information gathered in this project on this issue suggests that an expert panel should conduct a review of this issue and a research study should be conducted to examine whether and if so, in what ways the nearly 30 years old Institute of Medicine (IoM) recommendation of a ratio of 1:2,000 needs to be adjusted in general and in rural regions in particular (the Institute of Medicine is now part of the National Academies of Sciences, Engineering, and Medicine [NASEM]; the recommendation was made by the IoM in 1995).

Coincidently, on July 23, 2024: Senator Tim Kaine (D-VA) and Bob Casey (D-PA) members of the Senate Health, Education, Labor, and Pensions (HELP) Committee, introduced the *Strengthening Advocacy for Long-Term Carte Residents Act* to improve the LTCOP. If passed, this Act would strengthen the program by, among others:

'Requiring the NASEM to study and issue a report with a recommendation for the number of ombudsmen per LTC facility bed. This would give states and the Administration for Community Living better insight into the current needs of the program. In 1995, the Institute of Medicine (now part of NASEM) released a report recommending a staffing ratio of one ombudsman per 2,000 beds for the Ombudsman program. This staffing ratio has not been updated in nearly 30 years.'

Expand Ombudsman Complaint Code D06: Retaliation to Include the Fear of Retaliation

One SLTCO said, 'I think that if there was something different that we could do with our data points and capturing the fear of retaliation versus the actual intent and actual retaliation, it would probably be one of the number one data points that we capture.'

She explained, 'The way that our data points are stated is that there has to be intent and actual retaliation…the act of retaliating for that to be marked as opening up a case and attaching that to the complaint so one thing that would be good to look at is the *fear* of retaliation. If a resident is able to say to you, 'No, I am too fearful. I don't want to speak up. I am concerned about this,' then I would like a way to have a data point in there that matches the federal reporting structure.'

After the SLTCO brought up the need to expand the definition of Complaint Code D06 on Retaliation, I asked how she thinks it would be helpful? She said, 'I think that it would be helpful because number one, we're highlighting the issue. I think it's a form of abuse and power and control when we have a strong differential of power and control inside the homes. We know who holds the power…number one. Number two, I would say for systemic advocacy and to really hold the feet to the fire of CMS of the intention of the regulation. And all of the good things and all the *good* work that could come from shining a light on the fear of retaliation in the homes.'

When asked if it goes along the lines of, 'If you don't capture it, in effect it doesn't exist?' she replied, 'Yeah. And we say that all the time about our documentation, 'If you didn't document it, it didn't happen.' Later on in the interview, she returned to this issue and said that she wants to 'collect some data points on it even if we just have to do tick marks…we did education and information on this, we received a complaint on this…because my database won't collect that information but we're going to find a way to do it.' Later during the interview, she said, 'We need to put more attention to this. There needs to be more systemic advocacy. We need to be able to collect the data to change the culture of this *horrible* phenomenon.'

When I asked about things that do not exist that if existed would have enabled her to better address residents' fear of retaliation, she returned to speak about the 'data points' and that if they would be allowed to capture fear of retaliation, it 'would help contribute to the systemic policy making and potentially look at the regulation changing.'

Chapter 11

Characteristics of Care Homes with Less or No Fear of Retaliation

Ombudsman representatives were asked about the characteristics of care homes with less or no residents' fear of retaliation when voicing care concerns. Their responses included:

One representative said, 'If you want to solve problems, it's always easier to solve them at the lowest level. If you can solve problems between me and you, it's easier than me having to go to Resident Council. It's easier than me having to go to leadership. It's easier than having me having to escalate things. Cultures that understand the *value* of the *voice* of the most powerless within long-term care are the ones that have the lowest likelihood of fear of retaliation…because everyone is valued.'

Quote
"*Cultures that understand the value of the voice of the most powerless within long-term care are the ones that have the lowest likelihood of fear of retaliation…because everyone is valued*." – Ombudsman representative

When asked the same question, another representative said, 'Person-centered care. Everybody believes in it. Their whole outlook is based on it. The residents are valued and staff members are supported. They have higher pay…compensation, flexibility. I think the most important thing is if staff members are held to higher expectations, they're already up here [said with a hand gesture above her head], so they'll treat the residents better.'

Another representative said, 'Person-centered. They look at the resident as an individual. We're trying to get away from the word resident, but we look at them as individuals and their individual care needs. They choose staff that are passionate about this industry…who came to healthcare to love and serve people. When you have that in a building where you have good staff, good morale, and the staffing ratios are 1 to 8 instead of 1 to 15, you have better outcomes. If you're not working staff members to *death* and you have great *morale*, it trickles down to the residents. The residents get to feel that because they don't have overworked staff, the recreation is great, people are able to leave and come as they want, they don't feel like their rights are being trampled on. That's what they're doing good. It has to do with staffing.'

A very experienced representative said, 'It would be a very home-like environment. They would have *long-term trained* staff. Not agency staff, not new staff every week but staff that knows their people. I think that they would have constant education. I think there would be more of a supervisory piece where management staff is held accountable for being sure that residents are being treated with dignity and respect at all times. I think residents need to have privacy always available…not ward beds where we have four beds in a room. Privacy is an important piece. They need to have a phone to be able to reach out and stay connected with the world as well…that empowers people. I think that we need more family involvement, we need more community involvement inside facilities…that has really lessened since COVID. Inside a long-term care facility, we need *everything* that we have in our home…in our comfortable safe homes…that we do.'

In response to the same question, many representatives highlighted the critical role of the Administrator in instilling a culture of care where residents do not fear staff retaliation when voicing care concerns. This issue will be addressed in more detail in **Chapter 12**.

One representative said, 'The administration…how they run the building. I personally feel like that's the biggest thing. If they care, if they are on top of things.' Another representative said, 'It goes back to strong leadership, from the top down'.

A representative from another state said, 'It starts at the top. The culture is from the top down. I don't know anything about their corporation. I am talking about their administration and the Director of Nursing in the building. They set the tone for the whole building.' She added, 'If you can get the Administrator and the Director of Nursing on board to *really* try to support the residents, it sets the tone for the whole building.'

Quote
"*It starts at the top. The culture is from the top down*." – Ombudsman representative

A very experienced representative said, 'It starts at the top with the administration. Everything runs downhill. If you have an Administrator who is very resident-centered, resident focused, listens to residents, addresses these issues but the administration also treats all staff with respect and dignity, it keeps going. That is what I see as *different* in some of those buildings…is staff are treated well, they stay in the position a long time, they have long-term staff and then residents are treated with respect too because the direct care staff are. It's a cycle. That is what I see as what really helps.'

She said that it is a culture 'where the staff are respected and they respect the residents too.' She added, 'You're always going to get those outliers that don't go well but then administration addresses it.'

One SLTCO said, 'They *care*. That sounds so cheesy but it's the culture. It starts from the top and it filters down and it's *all* about the resident, that's what it is and then everything follows…person-centered care, good staff training, a lot of making sure the resident is okay, lots of conversations with the administration and the staff, and making sure the residents are good, having an Ambassador program or something like that, doing lots of positive things for the residents…and following up on things so that way when the resident has an issue they know that they can trust you and they're going to come talk to you and that's it but it really has to do with this. There's lots of things. We could talk all day just about that but I think it's the culture that comes from the top and you *feel* it when you walk in. It's warm and welcoming and you know it in your gut as opposed to the place you walk in and it feels like you've been hit with an iceberg…you're like, 'What is wrong in this place?''

Resource Box
The Warmth Survey
"You *feel* it when you walk in." – Ombudsman representative The Warmth Survey (three versions: employees, families, and staff) was developed based on the principles of The Eden Alternative (Yeung et al. 2016). The resident version includes satisfaction survey and overall satisfaction with care.

She added, 'My favorite place [described as having 'warm fuzzy greatness') unfortunately was taken over by one of these corporations that were nameless and gradually all the staff are leaving and the food is changing and the culture of complaints is changing but [prior to it], the staff were always *giddy* to see the ombudsman. They were like, 'We're so glad you're here today.' If they welcome us, they welcome the resident…whereas the other places are like running from me. They're like hiding from me.'

When asked to clarify who runs away from her, she said, 'Residents and staff…if it's a horrible place.' When asked if residents are hiding from her because they are fearful of retaliation, she said, 'Yeah. They don't want to be seen talking to the Ombudsman because they've been told not to talk to us. That's the worst-case scenario.'

Another representative spoke about the atmosphere in the care home as an indicator, ‘When I walk into a home, the atmosphere is different. You can also kind of tell that the staff and administration that they care…that they’re listening to what the residents say.’

She added, ‘If the residents are saying…and this is just a silly ridiculous example that’s probably not even real but if they’re saying that they want an upside-down Christmas tree this year, then they’re not only hearing that but they act on it and they act on it in a timely manner. That makes residents feel *heard*, it makes them feel valued and it makes them feel comfortable and safe. Obviously, the Christmas tree example is ridiculous but it is a decent example of no request is too small, no request is too silly if it’s important to the residents and the facilities that put value in that and put value n the residents, those are the facilities that even if they’re short staff, residents feel comfortable and safe and they feel heard.’

A representative from another state said, ‘Communities that have an *engaged,* caring Administrator or director…somebody that takes the *time* to be *out* of their office to engage with these residents would go a *long* way.’ She added, ‘They’ll get a new Administrator and they’re really engaging or a new dietary director…somebody in there spends a *lot* of time with these residents and then they fold back in their offices and it’s like they don’t matter anymore. I just think if people would take the time, like these Administrators and just come out of their offices and engage with these residents, that would be huge.’ Her colleague said, ‘The Administrators’ attitude *absolutely*… Have you heard the term ‘Your cup runneth over’? If your cup is full of negativity, that’s the Kool-Aid everybody is going to be drinking. It *truly is* effective in those facilities with those Administrators. If those Administrators are positive and they *care*, their ‘cup runneth over’ and their staff is going to care *way* more.’

An experienced representative said, ‘When you have *strong* management in the facility, it makes or breaks the facility. When residents feel supported, when they feel encouraged, when their needs are being met, and their voices are being *heard* by a management that focuses on providing *quality* care for their residents, you have less complaints, less fear of retaliation versus you have a facility where there’s a turnover in management or management that spends most of their time in their office with a closed door versus management that’s on the floor walking, knowing their residents, supervising their staff…I think that makes the biggest difference. The biggest difference is management in the building. Because when the management is also providing for their staff and taking care of their staff, recognizing the job of the staff, it reflects in their care of the residents.’

One representative said, ‘I think those that have lower amount of incidents of retaliation have staff members who are mature, they have the compassion and the care for the residents, and they're patient and so they're able to understand the *needs* of the residents

and how they're able to care for the residents. It takes the leadership. If you have the *right* leadership in that nursing facility, it goes a *long* way.'

A representative from another state said, 'Consistent staffing, strong leadership, employees who are valued, investment in training and in their wages and their benefits, staff that are confident and competent in their role. When you have the staff all right where they need to be…feeling good and trained well, then your residents are going to have a much better outcome.' Her colleague said, 'That sounds like a dream. It's great. No, I think it is about attitude…it is about the culture that the management has in the facility and that they support and encourage to grow in the facility…that's important. A place where the staff recognize that they work in these people's home…they [the residents] are not living in their workplace. It is their home first, not a workplace first.'

When asked whether in a paradoxical way, a resident expressing fear of retaliation could be an asset for the care home because they are communicating something important, the colleague said, 'I think in the facility that [de-identified name of her colleague] described, if a resident is fearful of retaliation, they are going to respond in a way that benefits the resident. It all depends on what is the culture in the facility is where that is occurring at…because it is not like in that magical facility that she described that bad things aren't going to happen…stuff is going to go wrong…it is people caring for people. It is all about how you respond to that.'

Another representative described what these care homes do when problems come up, 'Generally, if they run a good home, they'll turn around and they'll take care of it with you.'

Another representative said, 'It goes back to a leadership structure that has a sense of understanding the value of the feedback loop on their performance standards.'

Another representative said that care homes with low rates of fear of retaliation see residents' voice and concerns as an opportunity for learning and improvement, 'They ask the residents' input, they visit with them, they talk to them, they ask what they want instead of, 'Well, you're diabetic. You need your shot.' It's, 'What can we do to make you feel better?' It's working *with* them instead of *to* them.'

One representative identified Administrators' helpful practice consisting of 'Open door policy,' explaining, 'They're more willing to listen and you can tell they care.'

Another highlighted the value of 'strong communication so then you can avoid some of those gaps in the first place.'

One SLTCO spoke about the importance of 'creating that safe space and exercising that right for complaints. The Ombudsman program will talk to Administrators about that. The more you do that, the more you can resolve the concerns for the residents, and it wouldn't have to involve anybody else.' She also spoke about the need to create 'a *strong* grievance process and then sticking to it and continuing to talk about how important that is to you as a provider, to your [residents], to your customers, to the family members.'

A representative from another state spoke about care homes that see the grievance process as an opportunity for improvement. She said, 'It is the overall culture of the home and it starts at the very top. When the administration is very open to concerns and having positive relationship with the grievance process, then staff follow suit. It is not seen as a negative thing…it is seen as, 'Oh, how can I make things better?''

She added, 'I have a home that encouragers the residents to use that grievance process at any time…like everything is written on a grievance even if it might seem small to somebody. If it was a missing piece of clothes to a care concern, they would encourage them to write it down because there was a written response [from] the facility so the resident would have something tangible. I don't really have complaints in that home at the Ombudsman level because the facility typically handles those concerns pretty well and they are very positive about it. They're like, 'Oh, we're human. People make mistakes. What can we do to make it better?' So just having this more positive viewpoint that it is not a *complaint*, it's a concern, 'Something didn't go right, how can we fix it?''

Quote
"*Oh, we're human. People make mistakes. What can we do to make it better?*" – Ombudsman representative quoting staff in a care home that encourages residents to use the grievance process

When asked what separates these care homes and what do they understand that the low performing nursing homes don't, she said, 'It's hard to say. I think they understand that happier residents ultimately, selfishly for the facility, is going to make their job a lot easier and I try to tell facilities that, 'You know, if your residents are happy, your end game is things go smoother…your job is probably going to be a little easier.''

She went on to speak about the difference between corporations that empower their Administrators versus those that don't, 'There is corporate…and it probably depends on the

facility…we have some facilities where corporate is not as involved and it does stop at the Administrator. This particular facility that I was talking about, their corporate is less involved. They empower their Administrator to actually be an Administrator but there are facilities where the Administrator really does not have power. Who calls the shots? How many resources [are being] put into staffing and training…for RNs, etcetera. All that.'

Her colleague added, 'Because we are so rural in our region, you have a lot what I am going to call 'absentee owners,' owners from other states or the corporate office is 300 miles away or whatever that is. The more local the supervision and the oversight, the better care outcomes we see. In addition to that, I think that staffing plays a *huge* piece…obviously, you have bad staff and good staff but education and then overall staffing because in thinking about retaliation, if you do the same thing every day, you're going to have the same outcome. You're able to put this resident with another staff member…maybe that previously had a poor experience…change things up a little bit etcetera, you have better outcomes.'

One representative said, 'Good leadership. I would say administration makes all the difference. I've seen the worst care home in my area turn into the best care home in my area just by a different Administrator. Residents who weren't feeling comfortable talking, did feel comfortable talking directly to the Administrator. I think the communication between administration and residents needs to be a lot better than it is. When that happens, I see less retaliation. I see less complaints when the Administrators are more involved with the residents. I've had to ask Administrators, 'When's the last time you talked with this resident?' [and the Administrator would reply], 'Oh, I've never spoken with the resident.' [and the Ombudsman representative would say], 'Well, don't you think you should go around and at least introduce yourself?''

Quote
"*Administration makes all the difference. I've seen the worst care home in my area turn into the best care home in my area just by a different Administrator.*" – Ombudsman representative

Her colleague shared this **story**: 'Several years ago, there were two Administrators…they were sharing their role. There was one Administrator being there on Tuesdays and Wednesdays and the other the rest of the week. When I walked into that facility, I could tell which Administrator was on duty. I could tell by the way the residents communicated with me. I could tell because I could ask which is the Administrator today? If the residents were

happy and sharing information, I knew which one it was. If they were just backed off and not interacting with me, I knew who was on duty that day.'

One of them shared that when new Administrators ask them, 'What advice do you have for us?' our advice would be, 'Be on the floor and know your residents.''

Her colleague said, 'Know the residents. That good communication…it builds trust. They can see because they watch obviously…it's their home…they can see what happens. The residents know that that Administrator *has* their back if something happens, they know if their Administrator will stand by their word, if they are going to be supported, if they are going to be protected. So yeah, I think that makes all the difference.'

Her colleague added, 'That's not just the Administrator. That goes for the Directors of Nurses as well. For them being out on the floor and getting to know the residents and residents know that if they have a problem or an issue, it's going to be taken care of.'

When asked about the main challenges and barriers in addressing residents' fear of retaliation, one very experienced representative said, 'It can be the leadership within the home. I think the culture of the home starts from the top down.' She went on to describe a type of leadership that does it right, 'I think that if the leadership first respects their staff, then their staff respects their residents. I think it just trickles down without even consciousness about it. If the leadership in a home and to some degree the ownership of a home creates a culture of dignity and respect at all levels, I think you have a better experience with this situation. If a home genuinely wants to be the best they can be, they wanna know what's wrong and they wanna fix it and that's been my experience. If a home really wants quality of care, they're going to embrace this and they're going to make a change and they're gonna make it so that residents are not fearful.'

Quote
"*If the leadership first respects their staff, then their staff respects their residents*." – Ombudsman representative

One representative spoke about the importance of staff relationships and engagement with residents, 'When you have staff that are not there just to have a job…that they are fully engaged. You can tell a big difference when I am walking down the hallway with staff and residents and the staff are saying, 'Julie, your family came last week from Tennessee. How was that visit? Tell me about it.' That staff engagement. And then also with the residents,

whether there's that back and forth…banter back and forth or whatever versus where I've seen in another nursing home, the staff hardly say anything…it could be brushing a resident's hair and not saying a word. But those that have staff fully engaged, they're laughing, they're talking, they're with residents just talking with them and visiting with them and there's that respect going on. That makes a *huge* difference on who residents can trust and they're being cared for. These residents are not fearful of retaliation. They're just not.' She added, 'I think those relationships very much help and that is when residents feel like they are listened to, that they are part of the whole community of the facility, that they have say in how things are. Huge difference. Rather than going in there and, 'Here are the rules.' The residents have to be engaged as well. You have to include them. And bringing the community outside the facility into the community of the nursing home is another great…and you see that lots of times in those facilities that are just so good for residents.'

A very experienced representative said, 'Families in these areas, they frequently visit the nursing home. It is a love of church, community, and family. Everyone knows each other…everyone in that town…in that city, they all know each other. It is like a family reunion of sorts. Families frequently visit the facility, they possess a *great* relationship with the nursing home staff and that community, we notice, rallies around their love and participating and supporting the nursing facility as a whole.'

She added, 'We have found that there is no fear of retaliation in those homes because the community treats it as *family*…even the staff, they're family, they're taking care of their family. The community wants the facility to know that we support you in any way we can. There are several facilities that are like that and we wish that more facilities had that mindset. It is because of their *love*, and their *religion* of *faith* that they have in the community with each other. That's what we have found. We talked about it…the other Ombudsman and myself….about what sets this one apart from the other ones and that's what we've discovered. She found another facility that had the same similarities. These [folks] are in these facilities and they are volunteering so they see what's going on in their community because they are there all the time. So we don't see any fear and they never talk to us about it. They are happy.'

When asked to clarify who the volunteers are, she said, 'The community, the family members. They volunteer. Plus the Church. They volunteer in the facility as well. They are there all the time. They are always bringing things to the facility to assist them. They do ruffles and all kinds of stuff because they want to help. They are always there. There has not been a time that I've been in that facility that if it's the Minister, the Deacons…there is someone from the Church or the community in that facility. And the Administrator *loves* it

because the Administrator is local from that area as well. We find there is no fear in facilities like that. They go above and beyond for their residents there.'

Ombudsman representatives identified other characteristics of care homes with less or no fear of retaliation identified, including:

One of them spoke about the importance of small-scale care homes and the need to 'reduce the number of residents in a single facility overall. We do think that sometimes the smaller facilities…there's an opportunity there for staff to build good relationships with those people. In some instances, people that are residents in these smaller communities helped build that community, they helped build the city where they live and there are long standing relationships there because maybe they were the judge, the Sunday school teacher, you know…whatever.' She added, 'Smaller facilities don't have like hundreds of people that they are trying to care for…150 apartments of whatever. I think that sometimes…and it's not always true…but sometimes the most success in quality of care and quality of life with a vibrant community where residents are having all their care needs off of what *they* want for themselves…living the best life that *they* want…can occur in a smaller home.'

In accordance, another representative shared her view about care homes that have a low rate of residents' fear of retaliation, 'I think that smaller homes, independently owned homes, it's the home where you don't have a high turnover of your staff, where the staff know the residents, know the families…all the basics…all the good stuff.'

Representatives spoke about a home-like setting versus one that looks and feels more like an institution and/or hospital. When asked about characteristics of care homes that have less or no fear of retaliation, one representative spoke about the business model and asked, 'Are they using a hospital model of care?' She gave the examples of long hallways and a nurse's station 'or are they doing what I call pod or greenhouse living where you have smaller homes with multiple rooms and a common area for dining and lounging' and 'maybe you have three or four staff in that pod. That's usually the biggest differences I see. The greenhouse or the pod living seems to have a higher staffing ratio, it seems to have less complaints about care from our perspective and again, that's my opinion…I don't know that I have quantitative data to prove that but that's my experience.'

One representative spoke about the importance of 'a positive peer culture. Instead of this worker being a worker, it's, 'We're all in it together' and 'We're all equal.''

Another representative spoke about the importance of hiring people with 'built-in' compassion and supporting them to be successful in their hard jobs.

In this context, it Is worth mentioning the term 'supportive guidance' provided daily by experienced and professional managers to direct care staff members (a term coined by Registered Nurse Nancy Haugen, President, Elder Voice Advocates, Minnesota).

Representatives spoke about the importance of high-quality staff education. The best educational programs typically consist of three interrelated components: Orientation education, monthly In-Services, and 'experiential learning' on the floor.

When asked about characteristics of care homes with very low levels of residents' fear of retaliation, a very experienced SLTCO said, 'You've got a seasoned Administrator, you've got an in-service director or a Director of Nursing that continuously educates, you make it part of the Orientation for the brand new aides that are coming in…not just send them something and say, 'Here, sit down and watch this' but you actually orient them which is one of the things I did when I was a [de-identified profession]. Orientation, infection control, things like that.' She added, 'I think it all revolves around the Administrator and them *stressing* the importance of not abusing residents and not retaliating. It's education, education…but it has to be brought in from the top.'

Representatives highlighted the critical importance of staffing levels that enable care staff to 'meet residents' highest practicable function and well-being at all times and for staff to do their job well.' This central issue is addressed in detail under the segment titled *Poor Staffing Levels and Inadequate Training* in **Chapter 4** Contributing Factors to Fear of Retaliation and Actual Retaliation. It is also addressed in the segment titled *Staffing Crisis* in **Chapter 6** Challenges and Barriers in Addressing Residents' Fear of Retaliation.

After speaking about the need for strong leadership, one SLTCO, said, 'That culture has to be established, it has to be engrained and a high standard of expectation for professionalism, pride being established for staff, good staffing standards…having the appropriate amount…adequate staffing is key because inadequate staffing leads to more inadequate staffing because people leave…it becomes a revolving door because they get loaded up with all these job duties that they can't perform. It sets them up for failure.'

One representative spoke about the importance of consistent staffing (also described by Dr. Allen Power as 'Dedicated Staffing') and described it briefly in the following way, 'If the resident knows who the staff are, I think is a big one.'

Another said, 'If there's a facility that has consistent staffing, they really get to know the residents, people that know what their schedule is, 'Oh, it's 2 o'clock. Mary likes her chocolate ice cream at this time of the day' and they show up and they are proactive other than reactive. When you have a lot of agency staff in the building who don't know the residents, they don't know those kinds of things. They don't know that Mary likes a bath in

the evening and prefers to have a whirlpool instead of a shower. Consistency with staff I think really helps support the residents and make them feel that security and comfort knowing that the people that are caring for them that really know them and care about them and know their routine, I think that provides a lot of comfort for residents.'

Another representative spoke about consistent staffing and what can happen when a care home operates with inconsistent staffing. She said, 'Another avenue for me is consistent staffing. For us, it's always been a struggle for staffing in a facility. That's not a new concept but there's a lot of data out there about consistent staffing. If you have in theory about 7 to 8 caregivers in a week…the same ones that work the day shift, the same ones that work the night shift, the overnight and maybe a few variety on the weekends, they know those residents day in day out, they know their patterns, they sometimes know their symptoms. When you don't have consistent staffing and you have 21 different caregivers in a week, 3 shifts a day, seven days a week…21 different people, then they don't know those residents. You have 21 different CNAs, they are not in tune with that resident's patterns, behaviors, likes, dislikes, preferences….so you have this issue where then residents are like, 'Oh well, we've got somebody new again. She is not going to help me because the last four different people couldn't help me so therefore, I am not going to ask for help because I am going to get the same treatment that I got from the previous four people.''

Another said, 'I think a large part of this is the…and it happens in the good facilities and the bad facilities…the high volume of people that service them. If you think about it, they have 3 shifts a day and this is just for CNAs…3 shifts a day, seven days a week, 21 shifts and they see so many people because the schedule is not standardized. I mean, they want it to be standardized but they agency nurses and the call outs and all that kind of thing so in the course of a week in 21 shifts they may have been seen by let's say 12 different people. They can't even form a relationship with the people that service them every day.'

She added, 'When you're in a hospital, you think I hate the second shift nurse but the third shift nurse is wonderful and the first shift nurse…they pretty much are stabilized for days until the weekend comes and it gets a little dicey because of the weekend…but it's pretty solid and you may not like one nurse but you probably like the other two or you may like all three. In a nursing home, you don't have that privilege. In a nursing home, we don't have the privilege of consistency of your aides. In that kind of environment, every day they're learning how to manage and work with a new person. I am not saying all, every day, but many of our facilities have temporary agency nurses or aides…a good 40% of them are. They come, they go…so it's hard for them to connect with people in the facility.'

She added, 'What I try to do is look back at their schedule of service by their aides in their building. Are they seeing *so* many people that their fear of retaliation is because they're so

disoriented? And of course, with different conditions, you're more disoriented…so if you have either mental health issues or dementia issues, that's a disorienting…let alone seeing different people in there all the time.'

When asked about characteristics of care homes with less or no fear of retaliation among residents, one representative spoke about the importance of no or minimal as possible use of agency staff, 'I think that with a strong Administrator and a strong Director of Nursing, that comes along with the well-trained staff, a facility that can retain staff so they can get to know residents and have some sort of comfort level because I have nursing facilities that management is not present. When you have 90% agency staff, there's no way to monitor, there's no way to educate, to train properly…there's just no way to know what's going on. I think that's the biggest difference that I see when you have strong management that you're open with your staff, they talk about things, they talk about issues…that really. And you can tell the nursing facilities…the ones that I work with that people have been there for a while, they have a good team as opposed to people that are non-present or they just rotate through administrators.'

When asked about the effect of staffing instabilities on residents, she said, 'A lot of residents say, 'Before this I knew so and so and they knew me and then I'll have a staff come in…I don't know who they are. I don't even know who to report it to. When I do report it, I feel like they're even more mean…nobody wants to work with me.' And residents know…staff are in and out and they'll say they don't pay them enough or management isn't very nice, people don't want to work here. I think if they feel that management doesn't care, why would their CNAs care how they're treated. If they'll say anything, they'll just get treated worse.'

A representative from another state shared this **story**, 'We have a home in our state that has gone 'agency-free' and that means they are no longer using any travelers for the care. They are using all *local* staff providing care to local residents or at least [de-identified name of area]…they might not be local to that town. I think the bigger corporations aren't going to take those efforts on. I think these smaller homes have or at least this particular one has made that commitment. They've put it out to the community. I think it will make a huge difference in their quality of care.'

She added, 'They are no longer employing staff that we call travelers or work for a staffing agency. They are only employing local people for their nursing and their [nursing assistant] positions. They are not using agencies at all. They are employing people directly. They're bringing them in, interviewing them for a position in their home. They are not using an intermediary in any way to hire their staff.'

When asked about characteristics of care homes with less or no fear of retaliation among residents, one representative spoke about not-for-profit ownership status, 'I would say the best providers in terms of resident-centered care and a culture of minimizing the fear of retaliation would be our non-profits, our faith-based non-profits, and our Continuing Care Retirement Communities [CCRC]. They are going to be our best environments because residents are their clients, they are their paying customers and so [missed words], they really need to please their clients and their residents, and it might be a part of their mission statement. They do the best at staffing, they do the best at training, they do the best at creating an environment that really reduces the fear of retaliation. They are more resident-centered in their whole approach, their whole business operation.'

She clarified, 'CCRC are for-profit but they are a different business model than for-profit corporate owned nursing homes that are primarily driven by Medicare and [Medicaid; de-identified state] so they are a completely different environment. Until you change that nursing home culture to be more like those others, I think it's going to be hard to really change much unless you just happen to have a good Administrator who is there for however many years that you can rely on to help resolve these issues.'

While recognizing that not-for-profit care homes also receive Medicaid and Medicare, the representative clarified, 'They are different by being the non-profit. So therefore, they have more money maybe to put into…reinvest into higher staffing levels even if it's just one person…even half-time position. Their mission statement also may gear them towards a more resident-centered type business model…even if they accept Medicare or [Medicaid; de-identified state] in their nursing home or whatever.'

A very experienced representative saw a lot of value in small not-for-profit homes as opposed to what she described as 'corporate owned facilities' (for-profit chains), 'The smaller non-profit facilities…there's two things there. One is the aspect that it is a non-profit. I think that changes their focus in that particular home. I also think that *small*…I think the size of a home makes a *big* difference in the quality of care. In a smaller home often all the staff know all the residents [and] all the residents know all the staff.'

An representative from another state said, 'We hear Mom-and-Pop nursing facilities, board-run, not part of a chain. I feel like those facilities have fewer complaints and happier residents, less fear of retaliation, less complaints in general. Oftentimes, we see that those are higher budgeted for PPDs…per patient day…so you see more staff with a fewer number of residents, which is helpful.'

Representatives thought that a good sign of taking care concerns seriously and cherishing these opportunities for improvement is when Administrators and managers welcome and appreciate the work of representatives and fully cooperate with them.

One representative said, 'Those facilities who welcome the Ombudsman, see us as a partner, and work together with us, I think those are the ones that are honoring their residents' rights much better than those who, 'Oh my gosh, the Ombudsman is here and we're going to withhold as much information as possible.' They are willing to work with us and they see that we're all in it for the right reason. I see those facilities who talk to the residents about us, point their residents to our information, they see us not as someone on their side, they see us as someone in it for the benefit of the resident. I think those have a lot less retaliation and probably a lot less concerns in general.'

When asked what she thinks these Administrators understand that others don't, she said, 'I think that they see value in us and they know that we are independent, we are always the resident's advocate, and that we are looking for solutions and resolution to the same issue that they've might have hit a dead end with. Sometimes it is tunnel vision for all of us…you just need a different idea from someone else who can bring a new perspective, bring a new idea that maybe no one else had thought of…and I think those facilities appreciate that and appreciate working with us.'

Finally, representatives spoke about care homes that work hard to protect residents' right for privacy whether it is in their bedrooms and bathrooms in general and during provision of personal care, whether it is their ability to have private in-person or phone conversations or any other forms of communication with family, friends, other residents, and the Ombudsman representative or during Resident Council meetings.

Residents' ability to have private and secure communication with the outside world is addressed in **Appendix 7** Assistive Technology.

Chapter 12

Characteristics of Administrators of Care Homes with Low or No Fear of Retaliation

Many representatives highlighted the distinction between Administrators' "30,000 feet" approach versus those who cherish and use the "on the floor" resident-directed approach. When asked about characteristics of Administrators of care homes where residents experience low or no fear of retaliation, one representative said, 'Solid administration who has been there and who understands residents' rights first and foremost.'

When asked the same question, one representative said, 'You have people with just built-in compassion and you have people who really want to do the right thing. Those that believe the residents and not poo poo them away because they have dementia or some cognitive challenge. Someone that is *present* in the facility. That is visible in the facility. That takes an *active* role in day-to-day residents' lives. They know their residents and they are involved.'

A representative from another state said, 'I think it all starts from the top. If you have an Administrator that actually cares and knows their residents and knows their staff and integrate…like talk to them and like really get to know the whole community within the building, I think you have a better outcome, better morale, the residents love their aides because the aides are more personable, they have these good relationships with the residents. And even when situations go south, like they'll have a bad aide, their own employees will report that that agency aide isn't doing good or they'll know that their co-worker isn't great so they'll report them and not just the resident reporting them. And when the Administrator knows these residents and has good relationships with the residents, the residents are not afraid to tell the Administrator…they'll say, 'Hey, I had a bad situation. Can you help me?' I had a building like that…it worked *very* well. It was more like a community…less like a job every day.'

Another representative said, 'Administrators who get it right are *hands on*. When the administration…whether that's Administrators, Directors of Nursing, Social Workers…when they are in the field, when they're out and about with the residents, the residents feel *so* at ease. I see my facilities. I see the residents so much happier…they're outgoing. There's really isn't fear of retaliation and it just works well when my administration is out there on the floor in the trenches with the staff, with the residents. They don't put themselves in a higher level like, 'That's not my problem.''

Quote
"*There's really isn't fear of retaliation and it just works well when my administration is out there on the floor in the trenches with the staff, with the residents*." – Ombudsman representative

She contrasted it with Administrators who are not hands-on, ‘One of my worst facilities that I had dealt with, the Administrator was a banker before he went into nursing home administration. When he was brought in…because we know a lot of facilities are closing and the finances…he was brought in to be the banker and he dealt solely with like the funding stuff and had *zero* interactions with the residents and it was *the worst* facility. It’s closed. It got closed. It's gone. It was a large nursing home that is now gone.’

One SLTCO said, ‘I think the role of the Administrator is they are the person that is *fully responsible* for the health, safety and welfare of all residents. They have a big job and I think that when an Administrator is successful at creating a good working environment and demonstrating the leadership with emotional intelligence and all those things and they are creating a safe space through active listening and welcoming concerns and grievances and actually have a Grievance Policy that's talked about regularly and that Administrator is meeting with residents individually…collectively and they're walking out and visiting with people…Those are the people I think are most successful…who set a high standard for professionalism, they want people to, ‘if they see something, say something,’ they want their staff to treat residents with respect and they put time and attention into training and promoting the well-being of their staff.’

Another said that homes with less or no fear of retaliation ‘have a very strong and present Administrator. It starts at the top. If you have an Administrator who is in the building and is walking in the halls and addresses every resident that they pass by first name and ask them how their family is and how are the grandkids and how's their dog doing…they’re present…they're out…they know their residents…they know what's going on.’ When asked what these Administrators understand that others don’t, she said, ‘It’s a corporation. Most of them are running via corporations, there’s numbers, there’s things that they have to do, but they see the human aspect side of it. They have empathy. They have compassion and that *shows* in their staff. If you have a strong Administrator who is empathetic, who is compassionate, who is there and present, your staff are all going to take that lead. Because if staff doesn't take that lead, the Administrator doesn't have them on their staff anymore.’

When asked about care homes that have low or now fear of retaliation, a representative from another state said, ‘It’s the management. Their style, that they are involved with the staff that they both show the staff that they care about their well-being but that they also are constantly doing trainings and they are very present for residents and staff, that they are communicative to residents about things, they’re communicative to us, they notify us when there’s *any* allegation at all…we’re out there all the time because of it…but they’re not usually substantiated but just if there is presence and active management through the Director of Nursing and the Administrator, it’s going to keep the floor staff accountable.’

One representative described the value she sees in Administrators that are on the floor visiting with residents and families on a regular basis and serving as role models to staff, 'If the Administrator and administrative staff are out on the floor, walking the floor, visiting with the residents, having face-to- face conversations, eye contact with them, eye contact with their family members, *that's* what's going to make the difference.'

She explained, 'Because then the staff see the main person out on the floor and they're talking to residents. They don't want those residents saying anything to administration because that administration is already out there talking to them. So they are going to be more 'on their game' because their administration is 'on their game' instead of that administration that's always in their office and they don't have contact with the residents. They have that friendship with that Administrator and so I think the staff are going to do better. Plus, if the Administrator is out on the floor and she is helping, you know, push Susie Q to the dining room or delivering a tray or just out and about, staff respect them more and they want to do a better job for someone that they see out there, 'She is just like us. I am going to do better.'' She added, 'That person is not untouchable. That person, if I have something to fuss about, she is going to come down the hall sometimes today and if I can see her, I can visit with her when she comes down the hall. She was friendly to me last time and asked me how I was doing that day so I am going to tell her whatever.'

By 'untouchable,' she referred to Administrators who are rarely on the floor, 'You can't access them to tell them what's going on. They are in their office all the time. We hear time and time again, 'We don't even know the Administrator. They don't even come out of their office. We don't know who it is. They've changed places so many times, we don't even know who it is.' Then you go into a facility that says, 'Oh my goodness, our Administrator is out and about and she visits with me. They sat and had a cup of coffee with us the other day. She asked if she could come to the Resident Council meeting so we invited her so she could talk with us about x, y, z. If you have an open door or an open communication where I am out and about, then they are going to be happier. I think the staff and the residents.'

Referring to 'the accountable Administrators,' her colleague said, 'They are held accountable. They take ownership in their facilities. They are part of their facility. They are engaged….and making a good example for others working in the facility.'

Another representative identified a trend, 'In my experience, there's a difference you can tell if the Administrator has a social work background or a business background…You can typically tell the difference if someone has a social work background. I hate to say it but usually in a positive way.' She said that she hates to say it because 'I have very good business-minded Administrators as well.'

Three representatives from different states thought that, in general, care homes run by seasoned Administrators tend to have lower rates of fear of retaliation among residents. One SLTCO said, 'The Administrators that don't allow retaliation are seasoned. The ones that don't know what's going on because they are new…for some reason or another, we've had a lot of Administrators that are changing rules and we're getting 'green ones' in or the recycled awful ones. If the person is seasoned and runs a good home, you don't have to worry about retaliation…unless you get an individual case reported to you that an aide was doing it or a med tech. But generally, if they run a good home, they'll turn around and they'll take care of it with you.' When asked whether she sees experienced Administrators that are also retaliatory, she said, 'No. Not the decent ones, the old timers, no.'

The second representative said, 'I believe that experienced Administrators are important in being a part of this role because we have a trend in [de-identified state] right now where we have a lot of very young inexperienced Administrators that *don't* understand resident rights and will support retaliation.'

She went on to share a **story**, 'Recently I had a case with a very very seasoned and experienced Administrator where two residents went on pass to a casino and had a great time. When they came back, there were no running cabs so they tried to get the cops to bring them back to the facility. Long and short, they got back to the facility safely and everything was fine.' The representative said that she told the Administrator, 'I am really glad that you were in charge of this ship because if it was one of the young guys, I could see where they would say, 'You guys are not going out on pass ever again.' Because of his experience in saying, 'Residents do have a right to leave the building and go to [de-identified name of casino].' I don't see that with the younger crew that manning a lot of these facilities in [de-identified state].' The third representative spoke about the importance of 'longevity' of Administrators and managers, 'When I talk about green flag facilities, I'll say, 'One of the benefits here are that the Director of Nursing has been here 20 years, the Administrator has been here 15 years, the social worker has been there 10 years. That's a *huge* benefit.'

When asked about Administrators that handle fear of retaliation well, one SLTCO said, 'The Administrator that deals with it well will go in and basically be there with the residents every step of the way. I see that sometimes. There are some good Administrators.' She went on to say that it is the 'same thing' with the assisted living managers in her state.

Chapter 13

Discussion

The report represents a comprehensive examination of Ombudsman representatives' strategies and barriers in addressing the issues of residents' fear of retaliation and actual retaliation against them when voicing care concerns in LTC homes. The quality improvement project generated a large body of knowledge that could be used in various ways to improve care practices, representatives' work to address these issues, and bring about needed policy changes. Ultimately, it could increase the likelihood that residents will be able to realize their right to report care concerns without fear of retaliation, threats of retaliation, and actual retaliation.

Thousands of paid and volunteer representatives across the country could now use the knowledge to strengthen their educational efforts, resident-driven advocacy, and systems advocacy to better address these issues. To accomplish it, the knowledge could be used to strengthen existing educational programs provided to representatives. Equipped with this knowledge, they could be more effective in detecting, investigating, and resolving these issues. The knowledge could also be used to improve educational programs provided by representatives and care homes to residents, families, direct care staff, nurses, social workers, managers, Directors of Nursing, Administrators, and grievance officers. State surveyors could also benefit from increased education on this issue (see below).

As importantly, the project raises awareness to the issue of residents' fear of retaliation, helps "de-stigmatize" it (Painter M. personal communication, May 23, 2023), and calls for a more meaningful action from all stakeholders to address it.

This chapter provides a high-level summary of the main findings of the report, including:

- The interviews with 50 Ombudsman representatives (with an average of 12.4 years of experience in this role) from 32 states (with a good mix of urban and rural regions) revealed that the scope (range of manifestations) of residents' fear of retaliation is significantly broader and thus more concerning than reported to date. It showed that this issue is real, longstanding, multifaceted, challenging, harmful, and prevalent. It is also considered underreported and not centrally tracked nationally.

- Interviews with the representatives suggest that, in general, residents' fear of retaliation may be more prevalent in urban care homes than in rural ones (though some variation was reported and not all representatives shared this view). Research studies are needed to shed light on this issue.

- As reported in prior research (Caspi, 2024), the fear of retaliation was found to be a strong barrier for reporting care concerns, rights violations, and mistreatment. Many representatives believed that residents' experience of this fear often means that care concerns are not voiced, mistreatment complaints are not filed, neglect of care and abuse continue, and perpetrators and care providers remain unaccountable. Fearing retaliation, the voice of many residents often remains silenced.

- While not the primary focus of the project, family fear of retaliation was found to be a significant factor limiting reports on care concerns, neglect of care, and mistreatment. Research is urgently needed to examine this issue but also staff fear of retaliation from supervisors, managers, and co-workers (Berklan, 2023).

- The report identified dozens of forms of retaliation. A portion of these acts were not reported publicly until now. These forms of retaliation manifested verbally, non-verbally, physically, or through retaliatory discharges. They spanned a wide range of care-related situations and circumstances. Retaliation often meant that residents' right for dignity and respect were violated and their emotional security and safety were compromised. While the spectrum of severity of retaliatory acts varied, many were disturbing, scary, and deeply traumatic. The project also generated an in-depth body of knowledge on the important but often overlooked distinction between subtle and blatant / obvious / evident retaliation (though the distinction may not always be straightforward). Preliminary evidence from this project suggests that subtle retaliation may be more prevalent than blatant retaliation. Together with findings from previous studies (Robison et al. 2007; 2011; Caspi, 2024), this knowledge could be used to raise awareness to this largely invisible form of abuse and improve different educational efforts (e.g., delivered to residents, families, care staff, managers, and representatives), detection, resident empowerment, resident-driven advocacy, investigation, and resolution. It could also serve as a foundation for future efforts to map the territory and establish an evidence-based typology of staff retaliation against residents in LTC homes.

- Consistent with prior research on residents' lived experience of fear of retaliation in nursing homes (Caspi, 2024), the power imbalance between residents and staff / managers was found to be an underlying thread. Residents' physical dependency on staff for meeting their basic care needs (e.g., assistance with showers, toileting, changing soiled adult depends) often places them at risk of being fearful of retaliation when they consider whether to voice care concerns. One can only imagine how excruciating this dilemma may be for many residents.

- The project identified characteristics of residents more and less fearful of retaliation. It also identified characteristics of residents at higher risk of being retaliated against. While research is needed to examine this issue more rigorously, the preliminary knowledge generated on these issues could be used by representatives in early detection, education efforts, resident empowerment, and resident-driven advocacy. Care providers could also use this knowledge to educate staff about it to improve detection of vulnerable residents in need of increased attention and proactive protections.

- Representatives identified a series of signs (verbal and non-verbal) indicating that residents may be fearful of retaliation when voicing care concerns (i.e., when they did not explicitly say that they are fearful of retaliation). These signs could be incorporated into educational and training programs provided to representatives, residents, families, direct care staff, and managers.

- The report identified a series of factors contributing to residents' fear of retaliation and actual retaliation (such as institution-centered care practices, poor leadership practices, poor staffing levels, inadequate staff training, and the fact that direct care staff are often treated 'like dirt'). These could be used to inform efforts to improve care practices, representatives' education and advocacy, and policy changes.

- The report identified a series of challenges and barriers in representatives' efforts to address residents' fear of staff retaliation and actual retaliation. The challenges and barriers identified operate both inside and outside the care home. Inside the care home, representatives believed that the very nature of residents' fear of retaliation (resulting in their reluctance to give representatives consent to intervene), the burden of proof ('It happens in private'), and an institution-centered culture of care (led by Administrators, corporate offices, and owners that disregard residents' care concerns) often limit their ability to resolve this issue. With varying degrees of magnitude, many of them also saw a relationship between poor staffing levels and

residents' fear of retaliation and actual retaliation (with staff burnout, high staff turnover, heavy reliance on agency staff, and inadequate staff training as factors). Key mechanisms underlying this relationship were identified. Unique challenges in advocating for residents from a tribe in a very rural nursing home were also identified. Outside the care homes, beyond the impact of the workforce crisis on the topic at the center of this project, representatives identified a series of barriers stemming from weak federal and state oversight and enforcement of residents' rights and protections related to fear of retaliation and actual retaliation in nursing homes and assisted living residences (major concerns were voiced about limited protections in the latter care sector). Increased awareness of these internal and external barriers could stimulate discussions about ways to address them and/or reduce their impact.

- Representatives also identified unique challenges primarily related to residents living with dementia but also those with serious mental illness. For example, beyond memory-related challenges and the common dismissal of care concerns voiced by residents with dementia, representatives also identified important misconceptions about this population. In addition, representatives recognized what CMS describes as 'Reflexive' retaliation (i.e., verbal and physical abuse of residents in advanced stages of dementia in response to their rejection of personal care such as during showers) as a major and daily challenge warranting increased attention in education provided to direct care staff and managers but also to representatives.

- The report identified things certain staff and managers do to compromise representatives' work in resolving residents' fear of retaliation and actual retaliation. Examples include instilling a culture of fear of retaliation, denying retaliation (e.g., 'They're in denial about it;' 'That doesn't happen. We don't do that. You know we wouldn't do that'), dismissing care concerns, not cooperating with representatives, poor, incomplete, and unreliable documentation of incidents internally and externally (e.g., 'He refused'), compromising the role of the Resident Council (e.g., not respecting residents' right to hold meetings privately; interrupting, controlling, and influencing; taking minutes in ways that do not reflect residents' care concerns; and not following through on concerns and suggestions; 'Yeah, yeah, we're working on it' or as described by one representative as 'the endless loop of B.S.'), monitoring representatives' visits with residents, confronting, questioning, and making threats against residents reporting care concerns, and compromising the functionality of cameras installed by families in bedrooms. Being aware of these practices could assist representatives in proactively identifying and addressing them.

- Representatives described dozens of strategies they use to address residents' fear of retaliation and actual retaliation. Select examples include being present in care homes ('Our presence is our super power'), using the "masking" strategy, meeting in private, educating residents about their rights (including demonstrating to them how their rights can be realized) and the grievance process, breaking residents' isolation ('There is power in numbers' and identifying an 'internal advocate'), cultivating trust with residents (being honest with them and never making promises one cannot keep), acknowledging their fears, empowering them 'to be their own advocate' and to speak up about their care concerns, strictly meeting consent requirements (e.g., 'We can't go back on consent because that's just like what our makeup is. We can't have trust without that'), respecting residents' wishes / adhering to resident-directed advocacy ('I work for you'), pursuing resident-specific complaints versus General Complaints, exercising patience, following up, and striving to work collaboratively with care homes (with exceptions). Other strategies identified included harnessing the power of individualized Care Plan meetings and Resident Councils (though, as noted earlier, a series of challenges related to these councils were identified), conducting thorough investigations (e.g., using the 'magnifying glass;' identifying gaps in communication), advocating for staff reassignment, identifying violations in discharge notices (retaliatory discharges were a major concern), and escalating issues to entities outside the care home (e.g., corporate office when one exists or to the SSA) when staff and managers do not address ongoing care concerns despite repeated requests and/or advocacy. In addition, representatives described numerous successful interventions resulting in full or partial resolution but also incidents challenging and complex to resolve. Residents' approaches considered by representatives as effective were also identified. Taken together, the series of strategies identified represent a treasure trove that could be opened and used by representatives and other stakeholders across the country.

- Lessons learned by representatives in their efforts to address residents' fear of retaliation as well as advice for new representatives were described (these are presented in appendices). These knowledge gems could be used to educate new representatives and affirm and reinforce practices used by more experienced ones.

- Many representatives highlighted the critical importance of the education they provide to residents and families, care staff members, managers and Administrators (e.g., representatives reported that a subgroup of care staff members may not be aware that certain things they say or do to residents are perceived as retaliation). Education to residents was considered integral to empowering them to voice their

care concerns while staff education was seen as key to improvement in care practices (e.g., awareness, prevention, recognition, reporting, and response). Areas in need for improvement in the education provided to representatives on fear of retaliation and actual retaliation were also identified (several representatives saw a need to develop educational materials such as videos and a stand-alone training program / curriculum on these issues). Insights from this report could also be used to educate state surveyors to improve their ability to build trust with residents fearful of retaliation, give more weight to their input, and enhance their interviewing and investigative skills. Some residents are reluctant to speak with surveyors about their care concerns and mistreatment due to fear of retaliation. One resident living in a nursing home in Minnesota told a state surveyor, 'I am literally afraid of her. She intimidates. Are you sure nothing is going to happen to me?' Another resident living in a nursing home in Illinois told a surveyor, 'What am I supposed to do when you leave? I still must live here. I don't want to talk anymore' (Caspi, 2024).

- Representatives identified areas in need of legislative changes including the need for all states to consider adopting Connecticut law requiring annual In-Service on retaliation in nursing homes (the law needs to be expanded to assisted living residences). To my knowledge, no other state requires such stand-alone training. Representatives saw a need for stronger federal and state oversight, protections, deterrence, and enforcement of residents' rights related to fear of retaliation, threats of retaliation, and actual retaliation. They also recommended bridging major gaps in state regulations governing the assisted living sector. In the words of one representative, 'What is the role of enforcement around this particular issue?'

- Representatives made recommendations related to Ombudsman-to-LTC bed ratio in general and in rural regions. This issue represents a longstanding concern. It is also timely given the recent introduction of the *Strengthening Advocacy for Long-Term Carte Residents Act* to improve the LTCOP. In addition, the need for centralized tracking of residents' *fear of* retaliation in the National Ombudsman Reporting System (i.e., NORS; Complaint Code D06) was identified. Such tracking is essential for improving understanding of the scope of fear of retaliation and policy changes needed to address it. The issue is timely given the current call for public comments for changes in NORS complaints data. It is important to recognize that nursing home residents not only have the right to be free from retaliation when voicing care concerns, but they also have the right to voice care concerns without *fear of* retaliation. Left untracked, their fear of retaliation will remain largely invisible and important practice and policy opportunities to address it will continue to be missed.

- With the eyes into the future, numerous representatives identified characteristics of care homes with 'less or no' resident fear of retaliation as well as characteristics of Administrators of care homes with low or no resident fear of retaliation (referring to leadership, one representative said, 'It all starts from the top and filters down.'). Representatives can use this knowledge to strengthen their efforts to educate Administrators, Directors of Nursing, other managers, and direct care staff about measures they can proactively implement to reduce the fear of retaliation among their residents. Care providers committed to delivering person-directed care practices and creating fear-free care homes could benefit tremendously from implementing the protective factors outlined. As importantly, residents and families can be informed about what they should expect from care providers when it comes to the highest professional care standards. A roadmap is now publicly available.

- Special attention was dedicated by representatives to the role of assistive technology in addressing residents' care concerns, fear of retaliation, and actual retaliation (though a series of barriers to implementation were also identified). While what is needed first and foremost in care homes is the 'low-tech' (i.e., close trusting relationships and meeting residents' care needs and enhancing their dignity, well-being, and safety), representatives made a strong case for using existing assistive technologies and developing new ones to empower residents, strengthen their voice and self-advocacy, and enable representatives to better advocate for them. To give one example, representatives saw a need to ensure that residents will have easy and affordable access to private and secure ways to communicate with the outside world, including with representatives. In the words of one resident in early-stage Alzheimer's, 'Why can't our voice be heard outside the walls of this building?'

The report includes over 130 real-life stories about residents' care concerns, fear of retaliation, actual retaliation against them, and the strategies representatives use to address them. Collectively, these stories shed light on residents' experience of these fears and form of abuse and they demonstrate the preventive and protective value of LTCOPs.

Numerous compelling and inspiring quotes, reflection questions, findings from studies, newspaper articles, experts' views, helpful resources, and calls for research – highlighted throughout the report –reinforce key messages and insights shared by the representatives.

The circumstances surrounding residents' experience of fear of retaliation and actual retaliation are often unique and complex. Obviously, not all scenarios can be addressed in a single report. That said, the project enabled to capture varied, complex, and nuanced situations representatives deal with and the strategies they use to resolve them.

The report provides a detailed account of the hard, challenging, and frustrating but also rewarding work of representatives and how they often have to 'walk a tight rope' – skillfully 'juggling multiple balls in the air' while trying to maintain a delicate balance – as they cultivate trust with residents, educate and empower them, follow *their* direction, deal with unhelpful forces (e.g., severe staffing shortages, marginally trained care workforce, and institution-centered culture of care (often for-profit) that instills fear in residents and dismisses their care concerns), and advocate for realizing their right for dignity, quality of care and life, and safety. It provides a window into their craft and the level of dedication required to fulfill their role despite many barriers. As stated by a very experienced Ombudsman, 'My role…I take it very seriously because we're dealing with folks' lives here.'

The report demonstrates the key role representatives play in addressing one of the most concerning and prevalent issues in the lives of residents, that is, their ability to voice care concerns without fear of retaliation and without retaliation against them. Thus, the report could be used to advocate for increased funding to the LTCOP (referring to inadequate Ombudsman-to-LTC bed ratio, one representative said, 'That is a huge barrier'). No matter how passionate, compassionate, skilled, and effective representatives may be, if the funding provided to their program is inadequate, they will not be able to be sufficiently and meaningfully present in all care homes in their region; even if they do meet the required number of visits, depth will likely suffer. And as this report showed, beyond specialized knowledge, experience, and professionalism (one very experienced representative said that it takes 5 to 7 years to learn the role), it is often the depth and patience that are key to resolving care concerns to a resident's satisfaction. In the words of Mairead Painter, Connecticut SLTCO, 'Without our eyes and ears in these facilities, residents are at risk of abuse, neglect, and exploitation, and any number of rights violations.'

Building trusting relationships with residents is critical and it often takes time. There is no way around it. Referring to this issue, one representative said, 'There is no other shortcut that I've been able to figure out.' Empowering residents and getting them to the point where they feel safe and comfortable speaking up and giving representatives consent to intervene may take hours, days, weeks, months, and in some cases years. Sometimes, despite all efforts, residents choose not to file a complaint. It is their right and it must be respected as it lies at the heart of the Ombudsman program.

Without their 'superpower' (i.e., frequent presence in care homes), representatives' ability to empower residents to speak up about their care concerns, fear of retaliation, neglect, abuse, and retaliation will be limited and many residents will continue to suffer in silence.

In addition, without adequate funding to hire enough representatives, LTCOPs' ability to engage in systems advocacy in general and related to residents' fear of retaliation and actual retaliation (such as through legislative changes) may not realize its full potential.

Beyond resident and families' education on fear of retaliation, my hope is that the report will increase care homes' awareness to this issue, encourage them to establish zero tolerance policies for retaliation, educate all their employees about it, and implement meaningful measures to prevent, identify, report, investigate, and promptly address it.

I hope that care homes will see fear of retaliation as a barometer of care quality and as a precious opportunity for improvements. LTC trade associations such as LeadingAge, American Health Care Association, and Argentum should take a lead role on this front.

Some industry representatives state that staff retaliation against residents doesn't take place and certain Administrators report that they are not aware that residents are fearful of retaliation. For example, in one nursing home in Florida, more than 15 residents were fearful of retaliation when voicing care concerns. They said, 'They make you pay,' 'They get back at you,' 'They sweep things under the rug,' 'No point reporting,' and 'Don't write down our names.' Referring to staff who were mean to them, one resident said, 'Can't say their names. Don't want to pay the price.' Despite these widespread fears, the Administrator said, 'I am surprised that this is the culture. I am not aware that residents are afraid of voicing concerns. My door is always open' (Long Term Care Community Coalition, 2023).

Taken together, the quality improvement project described the varied ways in which representatives serve as 'a bridge over scary water' for vulnerable and frail residents whose care needs are not met but they are reluctant to report it due to fear of retaliation. Skillfully building that bridge – and diligently maintaining it – often enabled these professionals to alleviate their fears, speak up, and seek resolution to their care concerns.

When asked whether she sees her role as a bridge for residents, one experienced representative said, 'Absolutely. I mean, quite often I make the bridge. That's my biggest thing…is I want them to be empowered. That fear of retaliation will keep them silent but when you *empower* them, they are more *open* to speak on those concerns, they are more open to address an issue and stand up for themselves. My goal is to build that bridge.'

When asked if there's anything I didn't ask about that she'd like to recognize, one representative said, 'I think we've covered it all but if we were in an elevator and I had to answer you, I would say, it happens. People live in fear. Not in every facility but a lot more often than we think but there *is* hope and we *do* have much work to do. It's real, it happens but we have much work to do. One of these days I might find myself in one and I've had many people loving them and I want every person to have a good life and they *deserve* it.'

References

Acero et al. (2024). The role of social workers in long-term care for older adults: A mixed-methods systematic review in Europe and North America from 2000 to 2022. *International Social Work*, published online ahead of print. https://journals.sagepub.com/doi/abs/10.1177/00208728241269670?journalCode=iswb

Allen, K. (May 19, 2021). Arrest warrants issued for 2 former Colorado police officers involved in violent arrest of elderly woman. *CNN*.

Karen Garner arrest: 2 Loveland, Colorado, police officers involved in violent arrest of elderly woman with dementia subjects of arrest warrants | CNN

Altimari, D. (February 2, 2023). State report on a CT nursing home details alleged problems that included patients in urine and feces-stained diapers, delayed food and missed showers. *Hartford Courant*.

https://www.courant.com/2023/02/02/state-report-on-a-ct-nursing-home-details-alleged-problems-that-included-patients-in-urine-and-feces-stained-diapers-delayed-food-and-missed-showers/

Archibald et al. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods, 18,* 1-8. https://journals.sagepub.com/doi/full/10.1177/1609406919874596

Atlanta Long-Term Care Ombudsman Program (2000). The Silenced Voice Speaks Out: A Study of Abuse and Neglect of Nursing Home Residents. Atlanta, GA: Atlanta Legal Aid Society; Washington, DC: National Citizens Coalition for Nursing Home Reform.

Barrick A.L. et al. (2008). Bathing without a battle: Person-directed care of individuals with dementia. Second edition. Springer: New York. https://www.springerpub.com/bathing-without-a-battle-9780826101242.html

Berish et al. (2019). The impact of long-term care Ombudsman presence on nursing home survey deficiencies. *JAMDA, 20*, 1325-1330. https://pubmed.ncbi.nlm.nih.gov/30922864/

Berklan, J.M. (2023). Many nursing home staff fearful of retaliation by superiors: Study. *McKnights Long-Term Care News.* Many nursing home staff fearful of retaliation by superiors: study - McKnight's Long-Term Care News (mcknights.com)

Brod et al. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life Instrument (DQoL). *The Gerontologist, 39(1)*, 25-35.

Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL) | The Gerontologist | Oxford Academic (oup.com)

Buckley, C. & Estrin, J. (June 12, 2009). All night care for dementia's restless minds. The New York Times: Dusk-to-Dawn Therapy for Dementia's Restless Minds - The New York Times (nytimes.com)

Caspi, E. (2024). Residents' fear of retaliation in America's nursing homes: An exploratory study. *Journal of Applied Gerontology, 43(5)*, 497-514.

Residents' Fear of Retaliation in America's Nursing Homes: An Exploratory Study - PubMed (nih.gov)

Caspi, E. (November 13, 2023). Privacy violations and elder mistreatment. Staff misuse of social media in nursing homes. Webinar. Hosted by Elder Voice Advocates. https://www.youtube.com/watch?v=2NJIztfwR08&t=2s

Caspi, E. (April 16, 2019). 20 reasons why we need to know the early life history of people living with dementia. Guest Blog Post. *ChangingAging*:

20 Reasons Why We Need to Know the Early Life History of People Living With Dementia - ChangingAging

Cohen-Mansfield et al. (1996). Wandering and aggression. In: Carstensen LL, Edelstein BA, L, eds. *The Practical Handbook of Clinical Gerontology*, 375-397. Sage Publications.

Cohen-Mansfield J. & Golander, H. (2012). Analysis of caregivers' perceptions of "hallucinations" in people with dementia in institutional settings. *American Journal of Alzheimer's Disease and Other Dementia, 27(4)*, 243-249. Analysis of caregiver perceptions of "hallucinations" in people with dementia in institutional settings - PubMed (nih.gov)

Curtin, L. (October 11, 2016). Dumped: When nursing homes abandon patients to the hospital. *American Nurse*. https://www.myamericannurse.com/dumped-nursing-homes-abandon-patients-hospital/

Dean et al. (2023). Labor union and staff turnover in U.S. nursing homes. *JAMA Network Open, 6(10)*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10576215/

Dunlap et al. (2021). Background checks and the health workforce: Practices, policies, and equity. Center for Health Workforce Studies. University of Washington. https://familymedicine.uw.edu/chws/wp-content/uploads/sites/5/2021/11/Background-Checks-FR-2021.pdf

Edelman, T. (July 3, 2024). Court affirms ruling that New York nursing homes must spend 70% of revenue on direct resident care and limit profits to 5%. Center for Medicare Advocacy.

https://medicareadvocacy.org/ny-nursing-home-spending-rule/

Fenster, J.N. (December 17, 2023). Cruel social media posts target nursing home residents across U.S., CT research shows. *Connecticut Insider*.

https://www.ctinsider.com/connecticut/article/nursing-homes-social-media-mistreatment-18516763.php

Gebeloff et al. (December 9, 2021): How nursing homes' worst offenses are hidden from the public. *The New York Times*. https://www.nytimes.com/2021/12/09/business/nursing-home-abuse-inspection.html

Gross, R.E. (March 13, 2024). 'Failure to thrive,' or failure to investigate? *The New York Times*:

https://www.nytimes.com/2024/05/13/science/medicine-geriatrics-failure-thrive.html?smid=nytcore-ios-share&referringSource=articleShare&sgrp=c-cb

Grosz, P. (Producer). (March 11, 2024). Stop Retaliation in Illinois Nursing Homes. Pass SB3559. [Film]. Roustabout Media: https://vimeo.com/922142641/5ffd88a8bf

Harrington et al. (2016). The need for higher minimum staffing standards in U.S. nursing homes. *Health Services Insights, 9*, 13-19. https://pubmed.ncbi.nlm.nih.gov/27103819/

Harvard Law Review (May 2019). Wetzel vs. Glen St. Andrew Living Community LLC: Seventh Circuit holds landlords may be liable for tenant-on-tenant discriminatory harassment.

https://harvardlawreview.org/print/vol-132/wetzel-v-glen-st-andrew-living-community-llc/

Henreckson, J. (March 18, 2024). Lawmakers plan to expand whistleblower 'retaliation' protection for nursing home residents. *McKnight's Long-Term Care News*.

https://www.mcknights.com/news/lawmakers-plan-to-expand-whistleblower-retaliation-protection-for-nursing-home-residents/

Human Rights Watch (February 5, 2018). 'They want docile.' How nursing homes in the United States overmedicate people.

"They Want Docile": How Nursing Homes in the United States Overmedicate People with Dementia | HRW

Kasper, J.D., Freedman, V.A., & Spillman, B.C. (2014). Disability and care needs of older Americans by dementia status: An analysis of the 2011 National Health and Aging Trends Study. U.S. Department of Health and Human Services.

https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//44491/NHATS-DS.pdf

Kauffman, C. (February 19, 2024). Whistleblower lawsuit alleges nursing home fired aide for reporting abuse. *Iowa Capital Dispatch*: https://iowacapitaldispatch.com/2024/02/19/whistleblower-lawsuit-alleges-nursing-home-fired-aide-for-reporting-abuse/

Kusserow, R.P. (1990). Resident abuse in nursing homes: Resolving physical abuse complaints. Office of Inspector General. Report.

https://oig.hhs.gov/documents/evaluation/1478/OEI-06-88-00361-Complete%20Report.pdf

Lawrence, B. (July 17, 2024). Family fears retaliation by nursing home. *The Laurinburg Exchange*. Family fears retaliation by nursing home | Laurinburg Exchange

Liu, P.J., Caspi, E. and Cheng, S.W. (2022). Complaints matter: Seriousness of mistreatment citations in nursing homes nationwide. *Journal of Applied Gerontology, 41(4)*, 908-917. https://doi.org/10.1177/07334648211043063

Logan, L. (April 23, 2024). Retaliation against abused adults in RPAs. *Queens Citizen*.

https://queenscitizen.ca/retaliation-against-abused-adults-in-rpas/#google_vignette

Long Term Care Community Coalition (June 2023). "They make you pay": How fear of retaliation silences residents in America's nursing homes. Report. "They Make You Pay": How Fear of Retaliation Silences Residents in America's Nursing Homes - NursingHome411

Louisiana Long-Term Care Ombudsman Program (2022). LA PEER – Louisiana's Program for Empowering Every Resident. [Video] https://www.youtube.com/watch?v=l1A6fLusNFc

Magan, C. (2023). Caregivers allege 'harassment and retaliation' at Hastings veterans' home. *Pioneer Press*.

https://www.twincities.com/2023/03/05/caregivers-allege-harassment-and-retaliation-at-hastings-veterans-home/

Marselas, K. (December 13, 2017). Jury awards $5.2 million to nurse fired after reporting abuse.

https://www.mcknights.com/news/jury-awards-5-2-million-to-nurse-fired-after-reporting-abuse/

Michael, J. & Lyden, T. (January 4, 2021). Hidden epidemic in Minnesota's assisted living facilities: More regulation coming, but when? *FOX 9*. TV segment:

Hidden pandemic in Minnesota's assisted living facilities: More regulation coming, but when? (fox9.com)

Miles, M.B., Huberman, A.M., and Saldana, J. (2014). Qualitative data analysis: A methods sourcebook. 4th edition. Qualitative Data Analysis: A Methods Sourcebook: Miles, Matthew B., Huberman, A. Michael, Saldaña, Johnny: 9781506353074: Amazon.com: Books

Miller, M. (November 18, 2016): No rest at rest home: Fighting bias against gays and lesbians. *The New York Times*. https://www.nytimes.com/2016/11/19/your-money/lgbt-senior-housing-case-fight-bias.html

Minesota Office of Ombudsman for Long-Term Care. 2023 Annual Report.

https://content.govdelivery.com/attachments/MNOOLTC/2024/05/03/file_attachments/2867321/OOLTCAnnualReport2023.pdf

Mor et al. (2004). Driven to tiers: Socioeconomic and racial disparities in the quality of nursing home care. *Milbank Q., 82(2)*, 227-256. https://pubmed.ncbi.nlm.nih.gov/15225329/

Myhre et al. (2020). Elder abuse and neglect: An overlooked patient safety issue. A focus group study of nursing home leaders' perceptions of elder abuse and neglect. *BMC Health Services Research, 20(1)*, 199. https://pubmed.ncbi.nlm.nih.gov/32164695/

National Center on Elder Abuse (2023). Mistreatment of people with dementia. Research Brief: NCEA_RB_Dementia_2023.pdf (usc.edu)

National Consumer Voice for Quality Long-Term Care (June 2024). Addressing concerns about retaliation. Fact Sheet.
https://theconsumervoice.org/uploads/files/long-term-care-recipient/CV_Retaliation_Handout_web.pdf

National Consumer Voice for Quality Long-Term Care (September 8, 2022). High staff turnover: A job quality crisis in nursing homes. Report. https://d.docs.live.net/6b6aa27a66d54ea4/Desktop/High_Staff_Turnover-A_Job_Quality_Crisis_in_Nursing_Homes.pdf%20(theconsumervoice.org)

National Consumer Voice for Quality Long-Term Care. "Difficult" is not a diagnosis. What to do when your loved one is pushed to take antipsychotic medications. Fact Sheet.

https://theconsumervoice.org/uploads/files/general/CV_DifficultDiagnosis_AdvocateFS_web.pdf

National Long-Term Care Ombudsman Resource Center (2018). Responding to allegations of abuse: Roles and responsibilities of the Long-Term Care Ombudsman Program.

https://ltcombudsman.org/uploads/files/support/ane-no-consent-ref-guide.pdf

National Long-Term Care Ombudsman Resource Center (January 2022). Module 3 (page 27). Trainee manual: Initial certification training curriculum for Long-Term Care Ombudsman Programs.

National Long-Term Care Ombudsman Resource Center. State Long-Term Care Ombudsman Program: 2019 Revised Primer for State Agencies. https://www.advancingstates.org/sites/nasuad/files/State%20Long-Term%20Care%20Ombudsman%20Program%202019%20Revised%20Primer%20for%20State%20Agencies.pdf

Nelson et al. (1995). The relationship between volunteer long-term care Ombudsmen and regulatory nursing home actions. *The Gerontologist, 35(4),* 509-514. https://tinyurl.com/yfxucr78

Nerayo et al. (2023). Racism and discrimination experiences among staff in long-term care homes. *Innovation in Aging, 7(1)*, 1106-1107. RACISM AND DISCRIMINATION EXPERIENCES AMONG STAFF IN LONG TERM CARE HOMES - PMC (nih.gov)

Power, G.A. (2017). *Dementia beyond disease: Enhancing well-being*. Revised edition. Health Professions Press: Baltimore, Maryland.

https://www.healthpropress.com/product/dementia-beyond-disease-revised-edition

Richmond et al. (2020). Ability of older adults to report elder abuse: An emergency department–based cross-sectional study. *Journal of the American Geriatrics Society, 68(1)*, 170–175. https://doi.org/10.1111/jgs.16211

Robison, J. et al. (2007). Connecticut long term care needs assessment: Connecticut Long-Term Care Ombudsman Program. University of Connecticut's Health Center. https://health.uconn.edu/dev-aging/wp-content/uploads/sites/102/2017/03/ombudsman_program.pdf

Robison, J. et al. (2011). Community-based versus institutional supportive housing: Perceived quality of care, quality of life, emotional well-being, and social interaction. *Journal of Applied Gerontology, 30(3)*, 275-303. https://journals.sagepub.com/doi/10.1177/0733464810369810

Serres, C. (November 16, 2017a). Senior home residents risk eviction when they speak up. The *Star Tribune*:

https://www.startribune.com/senior-home-residents-risk-eviction-when-they-speak-up/450626083

Serres, C. (November 12, 2017b). Abused, ignored, across Minnesota. *The Star Tribune*:

https://www.startribune.com/senior-home-residents-are-abused-and-ignored-across-minnesota/450623913

Shieu, B.M. et al. (2021). Younger Nursing Home Residents: A Scoping Review of Their Lived Experiences, Needs, and Quality of Life. *Journal of the American Medical Directors Association, 22(11)*, 2296-2312. https://pubmed.ncbi.nlm.nih.gov/34265269/

Skeldon, L. and Jenkins, S. (2023). Experiences and attitudes of the LGBTQ+ community on care / nursing homes. *Homosexuality, 70(13)*, 3075-3107. https://pubmed.ncbi.nlm.nih.gov/35816357/

Somboontanont et al. (2004). Assaultive behavior in Alzheimer's disease: Identifying immediate antecedents during bathing. *Journal of Gerontological Nursing, 30(9), 22-29.* https://pubmed.ncbi.nlm.nih.gov/15471060/

Span, P. (July 21, 2017). Another possible indignity of age: Arrest. *The New York Times*.

Another Possible Indignity of Age: Arrest - The New York Times (nytimes.com)

Stannard, C. I. (1973). Old folks and dirty work: The social conditions for patient abuse in a nursing home. *Social Problems, 20(3)*, 329-342. https://psycnet.apa.org/record/1973-29687-001

Stepick, L. et al. (2024). Rising reliance on contract CNAs in nursing homes: Unveiling the impact on care quality and workforce stability. PHI in partnership with UCSF Health Workforce Research Center.

https://www.phinational.org/rising-reliance-on-contract-cnas-in-nursing-homes-unveiling-the-impact-on-care-quality-and-workforce-stability/

Texas Long-Term Care Ombudsman Resident Council Toolkit (2023).
Texas Ombudsman Resident Council Toolkit - 2023.pdf

Thompson, C. (November 22, 2022). As police arrest more seniors, those with dementia face deadly consequences. *The Marshall Project*.

Arrests of Seniors Are Up. For Those With Dementia, It Can Be Deadly. | The Marshall Project

University of Wisconsin Oshkosh (2016). Facilitator's Guide entitled Fear of Retaliation.

https://wss.ccdet.uwosh.edu/stc/CAREGIVER/_WebRedesign/Documents/Retaliation/FearofRetaliation-FacilitatorGuide.pdf

U.S. House of Representatives (July 30, 2001). *Abuse of Residents is a Major Problem in U.S. Nursing Homes*: https://www.cbsnews.com/htdocs/pdf/waxman_nursing.pdf

U.S. Senate Special Committee on Aging (May 19, 2023). *Uninspected and Neglected: Nursing Home Inspection Agencies Are Severely Understaffed, Putting Residents at Risk*.

UNINSPECTED & NEGLECTED - FINAL REPORT.pdf (senate.gov)

U.S. Government Accountability Office report (2024). *Long-Term Care: Information on the Ombudsman Program*. GAO-24-107209: https://www.gao.gov/products/gao-24-107209

Williams et al. (2009). Elderspeak communication: Impact on dementia care. *American Journal of Alzheimer's Disease & Other Dementias*, *24(1)*, 11-20. https://pubmed.ncbi.nlm.nih.gov/18591210/

Williams et al. (2003). Improving nursing home communication: An intervention to reduce elderspeak. *Gerontologist, 43,* 242-247. https://pubmed.ncbi.nlm.nih.gov/12677081/

Williams et al. (2009). Elderspeak communication: Impact on dementia care. *American Journal of Alzheimer's Disease & Other Dementias, 24(1)*, 11-20. https://pubmed.ncbi.nlm.nih.gov/18591210/

Wood, S. & Stephens, M. (2003). Vulnerability to elder abuse and neglect in assisted living facilities. *The Gerontologist, 43(5)*, 753-757.

https://academic.oup.com/gerontologist/article/43/5/753/633894?login=false

Yeung, P., Rodgers, V., Dale, M., Spence, S., Ros, B., Howard, J., & O'Donoghue, K. (2016*).* Eden Warmth Survey--Residents (EWR-R) *APA PsycTests*. Eden Warmth Survey--Residents (apa.org)

Zhang et al. (2020). Elderspeak to resident dementia patients increases resistiveness to care in health care profession, *Inquiry, 57*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7425308/

Appendix 1 – Project Overview – Used for Recruitment to Project's Interviews

Quality Improvement Project

Ombudsman Program Strategies for Addressing Residents' Fear of Retaliation in LTC Homes

The phenomenon of residents' fear of staff retaliation when voicing care concerns has been shown in research to be common in LTC homes (e.g. 23% of residents in nursing homes). A report entitled "They Make You Pay: How Fear of Retaliation Silences Residents in America's Nursing Homes" – based on a study in 100 nursing homes – has demonstrated the serious negative emotional and physical consequences experienced by residents impacted by this issue.

National Long-Term Care Ombudsman Resource Center states, "Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity."

Furthermore, investigative journalist Chris Serres wrote, "The threat of retaliation not only terrifies residents…, it discourages them and their families from taking steps that would protect their rights or enforce public regulations."

This project aims to learn from Long-Term Care Ombudsman Programs' (LTCOPs) efforts to address this issue through their educational efforts, resident-directed advocacy, and systems advocacy. With their specialized knowledge, Ombudsman representatives and State Long-Term Care Ombudsmen are in a unique position to improve understanding of this issue.

This is a Quality Improvement Project, not a research study. The new knowledge about Ombudsman's strategies and the barriers they face in addressing this issue could help strengthen LTCOPs' practices and educational initiatives as well as inform policy changes. Ultimately, such knowledge could increase the likelihood that LTC residents will receive high quality, safe, and dignified care without fear of retaliation.

The data collection method planned to be used in this project is semi-structured interviews. We plan to interview Ombudsman representatives and State Long-Term Care Ombudsmen from at least 30 states. We anticipate that each interview would take up to 1 hour. The interviews will be video recorded (using Zoom videoconferencing platform) and transcribed verbatim in preparation for qualitative analysis. The interviews will be confidential. The final report (September 30, 2024) will not include any information about you, your representatives, and your Ombudsman Program.

The Connecticut LTCOP is the project's funder.

We hope that you'll be willing to participate in this project.

Please let us know if you have any questions,

Eilon Caspi PhD Gerontologist. Email: eiloncaspi@gmail.com

Mairead Painter Connecticut State LTC Ombudsman Department of Aging and Disability Services Email: Mairead.painter@ct.gov

Appendix 2 – Interview Guide – Ombudsman Representative Version

Introduction

Previous research has shown that many residents in long-term care homes are afraid of retaliation if they speak up about right violations, care concerns, and make mistreatment complaints (23% of nursing home residents). Family members are also afraid of retaliation when advocating for their loved ones' rights, dignity, care, and safety. Residents' fear of staff retaliation and actual retaliation against residents can result in serious emotional/psychological harm (frustration, distress, anxiety, fear, depression, emotional trauma, and de-humanization) and physical harm. Many residents are physically frail, cognitively disabled, and dependent on staff assistance in meeting their basic care needs. It is within this power imbalance that residents' fear of staff retaliation often develops.

The National Long-Term Care Ombudsman Resource Center states, "Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity… It is critical that Long-Term Care Ombudsman Program representatives understand how fear of retaliation influences a resident's or another complainant's choices regarding complaint reporting and resolution."

In the 2017 *Star Tribune* series *Left to Suffer,* journalist Chris Serres wrote: "The threat of retaliation not only terrifies residents, it discourages them and their families from taking steps that would protect their rights or enforce public regulations."

This interview aims to learn from *your* experience in addressing this issue in your educational efforts, resident-directed advocacy, and systems advocacy. Your thoughts are invaluable.

This is a Quality Improvement Project, not a research study. The goal is to generate knowledge about the strategies you use and the barriers you face in addressing this issue; knowledge that could then be used to improve Ombudsman programs' practices. Ultimately, it could increase the likelihood that residents could report on rights violations, voice care concerns, and make mistreatment complaints without fear of retaliation.

The interview is confidential. The final report (due September 30, 2024) will not include any information about you, your representatives, and your Ombudsman program.

To protect their privacy and confidentiality, I ask you to refrain from mentioning any names of residents, family members, care staff members, care homes or any other information that could be used to identify these individuals.

The goal of this project is learning and improvement in Ombudsman program practices, policies, and procedures related to residents' fear of retaliation; not criticizing you or your program.

While I prepared a list of questions, feel free to skip any questions you're not in a position to answer or that you don't feel comfortable addressing. Okay?

Is there anything about the project you'd like me to tell you before we begin?

Background questions:

What is your current role at the LTCOP?

Overall, how many years have you worked as a LTC Ombudsman?

In what other roles did you work at the LTCOP?

1. _____ / number of years: ____

2. _____ / number of years: ____

3. _____ / number of years: ____

Program Characteristics

The following questions have to do with the characteristics of your LTCOP. This information will only be used at the aggregate level; no information will be used at any point to identify you / your LTCOP.

Is your LTCOP considered (circle the response):

- Urban / Rural [Question regarding Ombudsman Representative's specific region]
- Centralized / Decentralized

Other than nursing homes and assisted living ("residential care communities"), what other care settings your LTCOP serves?

_____

Note: Separately, State Long-Term Care Ombudsmen of the 32 LTCOP participating in this project were asked via email to compile and send the following two figures (for FY 2023):
1. FTE Ombudsmen-to-LTC bed ratio. 2. Total Ombudsman volunteer hours.

These figures are not presented in this report. They were shared with Mairead Painter, Connecticut State Long-Term Care Ombudsman.

Interview Guide

Representatives of the Office of the State Long-Term Care Ombudsman

(i.e. Ombudsman program representatives / regional / local ombudsmen)

1. Briefly, what are your general thoughts about residents' fear of retaliation in long-term care homes?

2. In your experience, would you say that there are certain resident characteristics that determine whether they are more or less fearful of staff retaliation?

3. In your experience, what are some common ways in which staff retaliates against residents?

4. If a resident does not mention that they fear retaliation, are there signs you look for that show they are fearful?

5. While recognizing that every situation and circumstance is different, could you walk me through the general process you go through when addressing residents' fear of retaliation or allegations of retaliation once you become aware of them?

6. In your experience, what do you find as effective practices and strategies for alleviating and resolving residents' fear of staff retaliation? In your response, please use as much detail as you can.

6.1. Can you share an instance where you successfully dealt with (ideally resolved to a resident's satisfaction) a resident's fear of retaliation or actual retaliation? If so, could you share a bit about it and what you think made the intervention successful?

7. What advice do you have for residents who fear staff retaliation when voicing care concerns? In other words, what do you think residents can do to alleviate their fear of retaliation when considering reporting rights violations, voicing care concerns or making mistreatment complaints?

7.1. Do you recall a situation where a resident's approach in dealing with her/his fear of retaliation or actual staff retaliation stood out to you as particularly effective? If so, can you tell me more about what the resident has done?

8. What role, if any, do you play in addressing family fear of retaliation (against their loved one or themselves) when voicing care concerns and making mistreatment complaints? The emphasis in this question is on residents who are unable to advocate for themselves such as due to advanced Alzheimer's disease.

8.1. Do you recall an instance when you successfully dealt with family fear of retaliation when voicing care concerns? If so, can you tell me about it?

9. In general, what do you see as the role of the Resident Council in addressing residents' fear of retaliation?

9.1. In the context of residents' fear of retaliation, how can you help residents ensure that the Resident Council is operated as intended?

10. Have you worked to reduce residents' fear of retaliation by providing training to care staff, consumer education, sharing information with Administrator and LTC home's leadership, or other collaborative efforts? Yes / No. If so, please describe that work, and share links / documents.

11. What do you see as some of the main challenges and barriers when it comes to addressing residents' fear of retaliation?

12. Do you recall an instance when a resident's fear of retaliation prevented you from intervening due to lack of resident permission (consent) and that due to the lack of intervention there was a negative outcome for the resident? Looking back, was there anything you or your Ombudsman program could have done differently?

13. Thinking about residents your program assisted, in the context of fear of retaliation, can you recall a situation that stood out as particularly complex and difficult to resolve? If so, can you describe it briefly and what made it challenging?

14. Many residents live with a cognitive disability due to Alzheimer's or other forms of dementia. What do you see as unique challenges in your efforts to address fear of staff retaliation among and actual retaliation against residents with dementia…especially those in mid-to-late stages?

15. Looking back at your efforts to address this issue, are there any important lessons learned you can share? Any insights you think would be invaluable for other LTCOPs to know about?

16. What strategies do you use, if any, to reduce the likelihood that after your visit with a resident, staff will retaliate against her/him?

17. To what extent do you feel that your current training adequately addresses how to respond to residents' fear of retaliation?

18. Can you think of things – such as resources, protocols, procedures, policies, regulations, laws – that do not currently exist in your state or at the national level that, if existed, would have helped your Ombudsman program in better addressing this issue? Anything comes to mind?

19. Can you think of an existing law or regulation that prevents or limits you from fulfilling your role in addressing this issue of residents' fear of retaliation? Yes / No. If so, do you think it needs to be changed? If so, how?

20. Do you think that assistive technology has any role to play in assisting LTCOPs in better addressing this issue / phenomenon? Yes / No. If so, in what ways?

21. With an eye into the future…and perhaps with a more positive note…as we are about to wrap up this interview… What would you say are key characteristics of LTC homes where residents have significantly less (or no) fear of staff retaliation? Please share examples, if applicable.

22. Anything I didn't ask about you think is important to recognize about this issue?

Appendix 3 – Review of Ombudsman Trainee Manual (10 modules)

A review of *Trainee Manual: Initial Certification Training Curriculum for Long-Term Care Ombudsman Programs* (2022) developed The National Long-Term Care Ombudsman Resource Center indicates that it explicitly refers to the issues of residents' fear of retaliation or actual retaliation against them (including terms such as reprisal) approximately 25 times – though these mentions consist of about 13 times when considered as a unit of meaning (i.e., when more than one of these terms are used in a single paragraph addressing a particular aspect of these issues).

Specifically, the 10 modules (for the most part briefly) address different aspects of these issues. That said, these issues may be indirectly addressed in other parts of the 507-page trainee manual.

Selected examples are described here for illustration:

- In the context of Ombudsman representatives not being Mandatory Reporters and the tension this may create between the LTCOP and others not familiar with the program, it encourages Ombudsman representatives 'to talk to the resident about their situation and the consequences of reporting or not reporting the alleged abuse, including any fears of retaliation. Educating the resident allows for the resident to make an informed decision.' [Module 1; page 29]

- A brief mention that fear of retaliation as well as fear of getting someone in trouble and being treated differently for complaining are barriers that may influence a residents' sense of empowerment. [Module 3; page 26]

- Recognition that retaliation is 'one of the most common reasons expressed by residents for not seeking resolution to their concern. It may be real or perceived, but in either situation, it is frightening to residents.' [Module 3; page 27]

- A distinction between subtle and obvious retaliation (with examples for illustration). [Module 3; page 27]

- The need to educate residents about their rights 'including their right to present grievances without fear of retaliation.' The paragraph includes steps to empower residents (not necessarily specific to fear of retaliation though they could apply to it) such as by encouraging them to participate and address their concern in a Care Plan meeting and Resident Council meetings. It also states, 'Talking about which staff member may most effectively address the problem' and 'Explaining how to file a complaint with the state agency…and the pros and cons of doing so.' [Module 3; page 28]

- It cites a video titled Residents' Rights Month, which 'summarizes the information discussed on empowerment and retaliation.' [Module 3; page 28]. The video is private and thus its content could not be reviewed.

- Under a segment 'Exercise of Rights,' it states, 'A facility must ensure the resident can exercise rights without interference, coercion, discrimination, or reprisal.' [Module 4; page 24]

- Under a segment titled *Grievances*, it states, 'The resident has a right to voice grievances to the facility or other agency or entity that hears grievances without discrimination or reprisal and without fear of discrimination or reprisal.' [Module 4; page 31]

- A brief Right Violation story about 'Connie' is included under the segment titled *Grievances*. In the story, Connie says that after she asked for the Ombudsman's help, staff treats her differently when they are being 'rude and ignore her requests for help.' The advocacy example provided is: 'Explain Connie's right to present complaints without the fear of retaliation. Offer to talk to staff about the recent concern and offer to provide staff training about residents' rights and retaliation.' [Module 4; page 31]

- A paragraph titled 'Unvoiced Concerns' states, 'Problems sometimes exist in a facility without anyone complaining to the LTCOP. One unique role of the LTCOP is to determine when and where there are problems experienced by residents, even when residents don't express them. An absence of complaints may not mean that all residents are receiving quality care or experiencing an acceptable quality of life. There are many reasons why residents are reluctant to voice concerns, including fear of retaliation, as well as the issues related to trust.' [Module 7; page 13]

- Under 'Tips for effective note taking,' it advises Ombudsman representatives, 'If you will be taking notes in person, explain the reasons why to relieve any anxiety or fear on the part of the person being interviewed.' [Module 7; page 28]

- A paragraph on the need to determine the root cause of a complaint. It lists a series of causes, including, 'Was there deliberate retaliation against the resident?' [Module 8; page 10]

- 'Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity. Since residents live in the facility and rely on staff for their basic needs, their fear of retaliation cannot be overemphasized. It is critical that LTCOP representatives understand how fear of retaliation influences a resident's, or another complainant's, choices regarding complaint reporting and resolution.' [Module 9; page 20]

- In a segment titled *If you witness abuse*, suggestions are made for Ombudsman representatives as to how they should handle these situations. In a part titled 'Following the incident,' it states, among others, 'Speak with the resident (or residents) about the incident; explain the role of the program; ask the resident if he/she wants to report the incident to the

investigative agency; and inform the resident of the facility staff's responsibility to report the incident and conduct an internal investigation. If the resident does not want to report to the investigative entity, the LTCOP representative should explore the resident's concerns, address any fear of retaliation, and discuss what steps can be taken to keep the resident safe (e.g., the advocacy strategies in the above scenarios in which the resident does not provide consent).' [Module 9; page 23]

- The initial certification training also cites and links the video titled *Voices Speak Out Against Retaliation*. In the video, five nursing home residents speak about their lived experience of fear of retaliation and actual retaliation. The video also includes their advice for overcoming fear of retaliation (e.g., finding and telling someone a resident trusts; the importance of being heard; participating in a Resident Council including the creation of a paper trail of ongoing concerns, which could be shared with Ombudsman representatives and 'other agencies' when they remain unaddressed; the Bill of Rights including 'the right to respect and dignity' and 'the right to raise grievances without fear of discrimination or reprisal;' and, Ronnie's words, 'It behooves a facility to create an atmosphere of open communication where residents can speak their mind because when people speak their mind, they become confident and empowered and when they're empowered, their quality of life improves').

Taken together, while a series of very important messages are contained in the Trainee Manual, it appears on the face of it that the training curriculum could be strengthened when it comes to the issues of residents' fear of retaliation, threats of retaliation, actual retaliation, and the potential consequences of these on residents. Topics that could be added or strengthened in the Trainee Manual include, among others, how to recognize fear of retaliation, additional examples of subtle versus blatant / obvious / evident retaliation, case studies, representatives' strategies and barriers in addressing these issues, ways to empower residents to self-advocate when fearful of retaliation, the role of Resident Councils and Family Councils (including how to address situations where staff and managers compromise the intention of Resident Councils), and findings from recent research, and new fact sheet developed by the National Consumer Voice for Quality Long-Term Care.

Appendix 4 – Lessons Learned

Ombudsman representatives reflected and shared lessons learned from their work over the years in the context of residents' fear of retaliation and actual retaliation against them.

One representative said, 'I think just keeping an open mind…knowing that each situation is going to be different due to the setting of the situation, due the resident, due to the facility staff. Each setting is going to be different so just keeping that open mind and taking it case by case.'

Another representative said, 'I think the single biggest thing in the work that we do that's most critically important is that we carefully listen to the voice of the person we serve.'

A representative from another state said, 'You just have to listen to the resident and family members and just deal with caution because you don't want to do anything to make it worse for the resident who has to live there.'

An experienced representative said, 'I think just simply taking in every concern of the resident whether you think it *sounds* far-fetched or not. There may be some kind of truth in there. You know, looking at the disease process of someone with dementia or someone with a mental health disorder. Just knowing that they *may* be something going on and not to just assume that 'I see purple dinosaurs going across the ceiling and they keep messing with me.' If you look into it and find out those purple dinosaurs may be bed bugs. Just to not ignore some of the things that may sound strange but just kind of dig into it to see if they didn't know how to explain it…verbalize or had the ability to verbalize what those complaints were. I think that would be the biggest thing. It's just taking the time to listen to the resident and realize that oftentimes it may be a communication issue whether it's communication from the resident expressing it or communication from the breakdown in staff *understanding* what a complaint is or understanding what is considered retaliation.'

One SLTCO said, 'The most important thing is that you have to always…even when you're frustrated about the situation, you have to always take direction from the resident. It's not about *you*. It's about what they want. I think that's especially hard when the resident won't let you do anything and you see things continuing to get worse and or it's the family member you're working with because of that person has advanced dementia. I think that sometimes Ombudsmen overstep their bounds and don't follow direction from the person they're taking direction from. I find that with my staff. One of the things we're working on a *lot* is consent…making sure that we're *always* getting consent and we get consent *every* time we can see the person…especially because of fear of retaliation.'

When asked what makes it so that sometimes representatives overstep their bounds, she said, 'That and they're lazy. It takes more time to get consent. You have to go back to the resident every time you go see them. You have to know *specifically* what consent means and who they want you to talk to…especially in those cases…it's more important than any other…this and abuse cases. These kinds of cases…anytime there's fear associated with it, you have to make sure that you are honoring what the resident wants and in order to do it the right way, that takes a lot of work and a lot of time and often multiple visits and the Ombudsmen are running around…because they've got 5 million things to do that they take shortcuts.'

She added, ‘Some Ombudsmen really like the facility staff and get a little too close. And that’s a problem.’ When asked what can happen when they become too close with care staff, she said, ‘Well, number one, they’re not free, they’re violating conflict of interest standards but also they won’t address the residents’ needs properly. And who are they really serving? They’re not resident-centered and if I find that staff are in bed with the facility, they’re not going to be Ombudsmen too long. They’re really not fulfilling our role. I have great relationships with facility staff but the residents are who I honor.’ When asked about potential consequences when representatives take shortcuts and not properly pursue a consent, she said, ‘The resident will suffer. They could be retaliated against, they’re not going to get the care they need, their wishes aren’t going to be honored. They’re also not going to trust the Ombudsman anymore.’ She added, ‘We do have residents that when this happens, they get *hurt*, physically hurt. They go to the hospital. So it can have really *bad* consequences.’ She said that they could also experience neglect, ‘Okay, well, we’re just not going to care for you tonight’ and close the door and, ‘We’re not going to feed you.’ A tray is forgotten…that kind of thing.’

Another representative made this suggestion to Ombudsman representatives, ‘Educate yourself. If you don’t have the knowledge, you can’t educate other people on it. This representative also encouraged other representatives to have realistic expectations about changing the whole system and to cherish those small wins, ‘You’ve got to be okay with knowing that you’re not going to fix the system. I mean, you just *have* to be. You have to be able to take your small wins…that one person who finally said, ‘You know what, you can help me, and we’ll take whatever comes and we’ll deal with it together.’ You have to be able to take the small wins. We can bring small change but as it is right now, we’re not going to…just the Ombudsman alone…fix the system.’

An Ombudsman representative from another state said, ‘After doing it for so long and being in healthcare for so long…I think I realized…it took me a while but I realized that systemic change is *really, really* hard. As an Ombudsman, I sometimes feel stifled in being able to do systemic change because the real systemic change comes in the form of regulation…federal, state whatever regs that hold the provider accountable. I as an Ombudsman don’t have the ability…unless I run for Office. I am happy to educate those people, but I don’t have the ability to enact that. I think what I have learned is that if I can make it better for just one resident on a given day, if we can improve the delivery of services to them or the way it’s delivered, then that is an accomplishment, that is a positive, that is an outcome that we should be very satisfied with.’

She added, ‘I had the pie in the sky when I graduated from college that I was going to change healthcare and right the wrong sort to speak and maybe the older I get, the more cynical I get. I realize that really. I am *just* as impactful by helping one person every day with their individual concerns as I would be in rewriting healthcare [laughs] and changing the dynamic or the delivery of service. It took me a while. I beat my head against the door or wall quite often but I have come to peace with knowing that if I have given the residents the tools, the information, the resources to help themselves, to empower themselves, or I did it on their behalf and we did see the facility respond and do change things and improve things for them, that’s really where the power is…in that individual person that you have helped.’

Appendix 5 – Advice for New Ombudsman Representatives

Ombudsman representatives were asked if they have advice for new representatives when it comes to addressing the issues of residents' fear of retaliation and actual retaliation against them.

Their responses are presented here:

One very experienced representative said, 'It takes about 5 years to understand the dynamics of an Ombudsman role. It doesn't happen overnight. You have to formulate ways to understand your role as an Ombudsman. In order to understand your role, it takes about 5 maybe 7 years to understand what the role of the Ombudsman entail.'

An Ombudsman representative from another state said, 'I think what is so valuable is number one, you have to really know what work that you're getting into…who you're serving…you're serving a population that is vulnerable whether it will be children, elderly…individuals who are in a nursing facility, you know, you have young people in there too. To keep in mind and to educate yourself that these are vulnerable people. You are the voice of these individuals. It is *your* responsibility to do whatever you can. Don't just take any situation or any complaint even from family members as a grain of salt. Your role as an advocate for that resident. You're doing your due diligence to, first, assess because that is what you're there to protect that resident. Always assess, don't assume and do your due diligence in being able to resolve, look at the source of the situation or the incident. How can we resolve? How can I protect this resident? And to act. I think that is sometimes the failure of many…especially young people going into social work or as an Ombudsmen. They really don't realize the vulnerability of the population that they are serving. So education plays a part particularly with individuals with mental health disorders or dementia. You really have to know who you're working with…the population and how to advocate.'

Other representatives spoke about the importance of triage. One SLTCO said, 'The first thing that we tell them is if they're getting a complaint, then contact us in the office first to see if it's a complaint that they can handle or they need a senior Ombudsman. I've had that happen with one of my employees where, yes, the facility did smell like urine, but she walked in and said to the Administrator, 'It smells like piss here' and I said, 'That's not how you handle this.' I don't want them to get into a situation where they don't want them back in there again or they give them a hard time. So what I do is I have them call me and if I think I should handle it, I handle it.'

Another SLTCO said, 'One of the things that I set up is…number one, that the volunteer Ombudsmen know how to recognize something like that they are reaching out to their Ombudsman supervisor *immediately*…not only when the fear of retaliation is expressed or the threat of any kind of abuse…anything related to abuse. I have a requirement…they are *immediately* to tell their Ombudsman supervisor because they have more experience typically, have more training and expertise to guide them so that we have some consistency there in how to handle that. I think that a *seasoned* volunteer that's a whole another story but a lot of programs around the United States have short term volunteers so you're training volunteers *all the time* and onboarding them. It's hard

to get every single scenario worked in and even if you did, they're not going to *remember*. You lock it in when you've experienced and you've worked through it. Then you have that to build off of.'

An experienced representative said, 'I think people coming into the Ombudsman program, they're kind of shocked by all the confrontation that we do have to come up against. We not only have to come up against it with the nursing home staff but even the residents' families. There's a lot of confrontation that a lot of people just can't do. I think it takes a very unique person to be an Ombudsman.' Her colleague said, 'I am not a very confrontational person.' She added that confronting an Administrator (such as about retaliation) 'is basically something that is learned. That's learned over time.' She added, 'I could gladly sit in the background and listen, but this job makes me have to sometimes go toe to toe with an Administrator and I have to do what I have to do when I am advocating for a resident.'

When asked what she wished she'd known when she started working in this role, another representative said, 'I didn't know…my role as an Ombudsman was to not only be an advocate for residents but a part of it is also educating staff and facilities and reminding them. Without education or if reminders stop, they don't think about it, they don't act on it. I wish that in the beginning I did more trainings, participated more in Resident Councils, talked to residents in general about their rights, their concerns and even their fears. I think once COVID came, my focus switched because people lost that connection, but I wish it didn't take that long. It wasn't a big part of what we did…and I think for me, I'm bringing that back up…with the shortage of staff they're trying to get people in and out and they're losing a *big big* component and if the nursing facilities can't educate staff or train them, then I'll take that role on.'

A representative from another state highlighted the importance of representatives knowing the regulations governing the LTC settings they serve. She said, 'I don't want to say that the staff aren't willing to work with us but they ultimately know that the Ombudsman program a lot of time doesn't have the teeth…and so if you're well-spoken and well versed and knowledgeable about the regulations and the rights and those types of things, then you are able to kind of hit them a little harder because they recognize that there's another piece of that.'

Other representatives wanted to remind new representatives that 'consent is a must' and highlighted the importance of 'Not taking shortcuts, being patient, and taking as much time as needed to building rapport and trust with the resident.' A very experienced representative said, 'There will be many things that come along that upset you in a day…you will see things…residents will tell you things…but consent is a must…so that is my standard in regard to retaliation and other complaints, that is my standard. But I think in helping with retaliation and other complaints, the most important thing you can do as an Ombudsman is…be there, listen, and build rapport. Do what you say you're going to do, let them know that somebody believes them, somebody is willing to help, and all they have to do is use *their* power and give us the word.'

A very experienced representative said, 'It is just important to know…it is not one and done. We can't just go in and expect with one little thing that things are going to be resolved…that there aren't going to be any future issues or that there's not going to be retaliation because we're involved…it

sometimes increases the likelihood of that. There's always something more and we have to be following up and we have to continue our involvement and go back. It is never a one-time solution and it is all perfect and we can put a little bow on it. It doesn't work that way.'

When asked what advice she has for new representatives with regards to residents' fear of retaliation, another very experienced representative said, 'I would say to listen, to develop honest relationship with the resident and their family members.' She added, 'I'd like to throw in that caution that I've always felt is a core piece for me around this topic…is don't promise that nothing will happen because we don't really know that and I think sometimes [those] new to the job think the best of things and can't imagine that something really bad could happen and I think we don't really know that because we're not going to be there to see or feel or help the person.'

When asked the same question, another representative said, 'I would tell them retaliation is real and it is not always what some may perceive as significant or obvious…going back to the subtle things. I think it's important to listen to *everything* the resident is telling you because you're going to pick up on things that they might already been experiencing retaliation without them saying it. If it's just them telling you why they're not going to file a report…they might not say, 'Because someone took it out on me' but they might say, 'Well, I don't…in case they don't give me care' and things like that…so you might need to dig a little more in to get more information.'

One representative said, 'Patience. You *have* to be patient because it can get trying at times…I am not going to even lie. If you're trying to deal with an issue that the resident has expressed or the family has expressed to you that's happening, and you're trying to convince them that you're *on their side* and that you're going to speak up for them, they are only seeing up until now the facility side of it and how severe the retaliation is going to depend on how quickly they may turn around and understand that we are truly here and start to build that trust process. It can be a couple of days, it can be a couple of weeks, it can actually go on a few months before they are finally like [said with a big sigh], 'Okay, I'm beginning to trust you.' So patience is a big thing.'

Another representative said, 'It's trying and it's time consuming. They could call today and they don't want to do it and then they'll call back Friday and they still want to reiterate what's going on and we're asking for consent and they still don't want to do it and it could be weeks, it could be months that this is ongoing until you've developed that *trust* with them that they know that they can trust you to do something about it.'

A representative from another state said, 'I think when we all get those complaints, we all want to put our caps on, we all want to jump in, we all want to save the day.' She went on to suggest, 'Take your time, build that rapport, and ensure everyone's comfortable. I remember as a very young Ombudsman, I'd get calls and I'm like, 'Okay' and I am out the door and I am like wanting to save the day and it was another Ombudsman that was like, 'You need to take a breath. Take a minute…think about what they're asking you and what your role is.' I think that's important.'

One very experienced representative said, ‘Looking back at my career…I don’t know if it was worse for the resident but…not going to the resident first. I know that that is a mistake that I made in the past because I want to protect the resident and not upset them for what family members are calling about.’ She shared this **story**: ‘They’re getting ready to be discharged because the family member hasn’t paid their bill…and that was a situation that was very uncomfortable for me because I feel like the resident should not have to deal with, ‘Oh, I am here.’ The family is not paying the bill. I know I’ve done that because I am doing it out of protection of the resident, but this is the resident who lives there, and they really have the right to know what’s going on. Sometimes we want to protect them and we’re really not protecting them if we don’t share with them what’s going on.’

An experienced representative said, ‘I think that having the long history at some of my buildings that I do have has been *really* helpful. I know some of the managers professionally. Knowing and being able to identify a good manager to communicate issues and concerns with…sometimes that’s not possible as they change in and out…but definitely having that communication with them, utilizing corporate contacts if you have them and then if management aren’t kind of reining in the troublesome staff that are retaliating or doing things that seem like retaliation, you don’t have a choice but to go to the survey agency and try it and see if that helps.’

She saw these working relationships with managers as an asset, ‘It’s something that I’ve been really trying to do. Our program as a basis is a little borderline offensive to most facilities’ staff because they feel like our program exists means they’re doing something wrong at baseline. They would need to be educated on their rights if the facility wasn’t upholding them. If the facility was educating them on their own rights, which they’re supposed to do by regulation. I think a lot of people automatically think negative of our involvement and that if we cultivate better working relationships that kind of really explain or talk through what the issues are…the staff issues with us, it helps.’

Another spoke about maintaining professional boundaries with staff and managers, ‘When I first started, it was a place where I grew up and lived and knew everybody in town. Knowing where those boundaries are between staff and us would have been helpful. Knowing that the Administrator was my neighbor and that we had to have two separate relationships…professional and personal…and making those boundaries loud and clear, that would have been helpful in the beginning.’

One representative said, ‘I will never forget it. I think it was two days into the job after training. I worked at a human service center. I just had an office there and one of the workers came down with a vulnerable adult protection report. Someone came up to me because the former ombudsman held a dual role of a vulnerable adult protection worker and the ombudsman…totally different dynamics…and came up to me and said, ‘Here, you will want to read this.’ I started reading it and realized, ‘Oh, wait a second. I don't have the permission of the resident to even read it.’ I started reading it…I didn't know what I was looking at and then finally I said, ‘I can't look at this because I have to have the resident’s permission.’ The other Ombudsman did.’ I said, ‘I understand. Maybe she would be looking at it from a Vulnerable Adult Protection point of view or maybe she was looking at it as an Ombudsman. I am only the Ombudsman. I can't look at this.’ I should have said, ‘What am I going to be reading? Is it resident related?’ Never forgot it.’

Appendix 6 – Issues Related to Residents from a Tribe in a Very Rural Nursing Home

At the suggestion of one SLTCO, one informal and short interview was held (without an interview guide) with an Ombudsman representative who works with residents from a tribe in a very rural nursing home (information was deleted from the summary below to protect the identity of the representative, the residents she is serving, the nursing home, and the tribe; the de-identified content presented below was reviewed and approved by this representative).

Background. This new representative said that the nursing home she oversees is the only one on the reservation and that 'a lot of the residents there are wheelchair bound.'

She said that 'a lot of the staff are from the community' and that from the reports she receives 'it looks like the staff are more local. Many of them are [de-identified name of tribe], which is great. They do speak [de-identified name of tribe's language] with the elders but we also do see traveling nurses that come in who are non-native.'

The representative said that there hasn't been a [de-identified name of tribe] Ombudsman covering the nursing home for several years until she started covering it. She said that prior to her role, Ombudsman representatives had to drive 4 to 5 hours to do a routine visit at the nursing home.

She said, 'Coming into the facility brand new without having rapport, that has been hard for residents so til this very day, I am still building rapport with them, making them comfortable enough to trust me and talk to me…so that is ongoing…because working with tribes coming from a government entity, there is that *mistrust*…you have to really build a good relationship…get that down…climb that wall…it takes some time. I understand that and I am still working on that.'

While she said, 'I haven't had a confirmed case of fear of retaliation,' she shared, 'In meeting with the residents there, some of them will talk about how they have encounters where staff were mean like, 'They're mean to me' or 'They're mean to others.' They may say mean things or they are rude and, 'I didn't like that they said that but I didn't say anything.' I hear some of that…more than one resident disclosed that…so I'd listen and take notes and when it comes to resolving it, I'll ask, 'Do you need help with it? Would you like me to do something? Everything is confidential. If you don't like your name mentioned, we don't need to do that. Have you spoken to your family?' It is always like, 'No, let's not do that. We're not going to move forward.' They would just say, 'I don't want to do anything.' And when it comes to family, they'll say, 'No, I don't want to tell family. I don't want them to worry about me.' I've encountered a lot of that. They don't want to move forward with it.'

When asked about situations where residents want to complain about care when most of the staff are from their tribe, she said, 'I haven't encountered that but I don't think it is going to be very good.'

She went on to give an example, 'There was one thing that happened when I first came on board as an Ombudsman. A staff had taken money from a resident…the resident gave it willingly but it is against their policy, but they took it still…and when they got caught, when they finally gave it back, the story was, 'Oh, I was just borrowing it. I didn't ask for it' and nothing was done about it and the resident didn't want to do anything about it. The representative couldn't go in and help alleviate

anything so we left it up to the facility and based on the policy, they aren't allowed to do it. Nothing was ever really done about it. It was kind of just swept under the rug it felt like.' She added, 'In talking to the resident afterwards, I sensed that there was no fear of retaliation.'

She said, 'I think based on my personal opinion, when you are [de-identified name of tribe] you are more than likely going to know a lot of people or be related to a lot of people…it is not always through blood.' She spoke about family lineage and the community one originates from as very important for people from this tribe. She explained, 'We carry these with us and that is how we identify ourselves and that is how we relate to others. So when you go into that facility, the elders are going to ask you [questions that may reveal whether the person is from their family lineage or community origins; original words de-identified] and, 'Oh, you're my relation by this.' I think that is what plays a role into elders wanting to help out other people including staff.'

When asked if some of the staff are from the residents' family lineage and community, she said, 'Yes. I think that opens the door for being taken advantage of for elders. A lot of cultural aspects I think play a role in how this long-term care facility is operated and why fear of retaliation may be occurring. I think it is there…I just don't have any confirmed cases to really prove it but yeah.'

She added, 'It is not just [de-identified name of tribe] elders but also tribal elders everywhere. We all get raised with the sense of 'it's not just you,' like yourself, but it is everything, it's you, your family, your community, and your Tribe. You have to think like that and carry that with you…so our elders have done the same.'

She went on to say, 'We're supposed to think of our elders as respected…we're supposed to cherish them and take care of them…that's our worldview on elders. It feels like abuse, neglect, all that stuff, fear of retaliation is a very *private*…let's keep it, no one should know about it and there is that shame attached to it like, 'Oh, that has happened to me…I wonder why.' It's a lot…there are a lot of things attached to that…to make our decision.'

When asked if she sees that as a barrier for reporting or resolving issues to the resident's satisfaction, she said, 'I believe so. I think that is definitely a barrier. Just being on the reservation here…growing up and now as an Ombudsman…it is always like if something bad happens, what would others think, 'Oh, I don't want that.''

She added, 'Then as an elder, they want to take care of their loved one in the community so if something happens to them either by family or someone who is supposed to take care of them, they are afraid of how it is that going to look if it gets out and that person being impacted, 'I don't want that to happen. I don't want anything negative to happen."

When asked about potential consequences for the resident when this cultural barrier comes into play, her response was, 'I think for this particular facility, the fear of 'if I speak up, they may ask me to leave,' comes up 'and where do they go?' Hours away to [de-identified state].'

She said that the closest nursing homes to the one she oversees are hours away and that families want to keep their relatives 'on the reservation around [de-identified name of tribe]-speaking staff

and families as opposed to having them go off.' She believes that 'residents and families are concerned about it' and about whether people in the far away nursing home will not speak their tribe's language and won't engage with them. She provided context, 'Everything is far out of reach for us. We travel a lot for everything…school, medication, healthcare, shopping, necessities' and 'transportation is always an issue on the reservation.'

When asked about the consequences for residents when they don't pursue a complaint due to these cultural factors, she said, 'I think so personally…I really do…a lot of tribal elders, that sense of myself only isn't really there so from growing up here with elders, working with them, they are always making whatever they are going through…health conditions that they have…smaller than it is.' She gave an example, 'When they go to the hospital and you can see they're in pain but when the doctor asks, they'll say, 'No, no, I am fine.' That is what a lot of elders do, 'Oh no, I am fine, it's okay.' They don't want too much attention drawn onto themselves…and they are just going to deal with it…whatever is going on until…I don't know…wherever it leads them.'

When asked what she thinks might work in addressing these issues given these unique cultural factors and challenges, she said, 'I think a whole series of education needs to be done here.'

She said that the education needs to be done 'with everyone, especially the elders.' From Ombudsman's perspective, I think starting with the elders is best because we do grow up with these [said while making a hand gesture by her head indicating beliefs]. It's stuck in our heads but sometimes a little shift in perspective is what we need to make a change.'

She added, 'When I first got there, I felt really down about…something is going on but why won't they speak to me about it. I want to help…I want to do something. We could do something but it wasn't happening so I just kept going back, handing out brochures, going through every resident right with them…educating them, 'It is your home and you can still enjoy what you like' and 'If you don't want someone to speak to you rudely, then that is something that we can change and you can speak up. You have your meetings with the staff…you can say something.''

She went on to share a **story** about a resident who is using a wheelchair, 'I was so proud of her. She went to her meeting with the staff one month and she addressed it. She didn't want to be spoken to in such a way, 'I have rights.' They made changes and they spoke with the staff. And when I visited her next, she was more happy. We talked a lot. That little piece of education with her, I think it opened *so much* and I think that's the best."

She described the incident, 'The staff actually came in during the night and threw her clothes on her bed and said, 'I am tired of helping you, you can dress yourself now.' And the resident, she noted the time and who the…she didn't know exactly who that staff was but there were only a few that night but she made sure that she remembered and during that meeting, she brought it up. She said that the staff was suspended ('during the investigation, they made sure to remove the staff from the resident') and that they might have terminated their employment.

She added, ‘My goal is to hopefully work with more families because there is so much education lacking here. I think once we notify the families about what they should be looking out for when they visit the elders and when the elders mention that someone was mean to them, question them more, figure it out.’

She went on to say, ‘I think the staff needs to be educated as well like take those breaks when you’re feeling frustrated, what are signs of abuse, we may be doing something that we don’t know is considered abuse. Let’s educate everyone. There are a lot of community-dwelling elders here…so I think getting into this population is another good idea but yeah, definitely starting with the elders and the residents.’

Towards the end of the interview, I asked: Is there anything else you’d want to highlight? Anything else you’d like to add in the context of fear of retaliation in this community?

Her response was, ‘The only thing I want to mention is I am bringing all these cultural things up…I am really not trying to bash my own culture. It is beautiful and a lot of these things that we have received from our other generations, it kept us going, it really has but whatever resolutions other people are thinking about, just try to keep these into consideration because if you just *dive into* a tribe and start yanking stuff, it is not going to be a good turnout. Sensitivity and slow pace is key. That is what I want to say.’

She added, ‘We are taught, cherish our elders but it seems like we’re kind of moving away from that. There are a lot more issues…abuse…exploitation is huge here. I don’t understand why…we’re holding on to all these cultural norms but not that one.’

Referring to financial exploitation of elders in the tribe, she added, ‘It’s everywhere here. In the community especially but that case in the facility that I mentioned where staff “borrowed” that, I would consider that exploitation but in the community it is prevalent here. A lot of people are using their elders for money. It’s not great. It’s frustrating to work in that field and see that…where with our cultural norms we are supposed to cherish them. There is this high pilar in the community and yet they are treated this way. Yeah, it’s frustrating.’

She said, ‘I think APS are aware. I don’t know what the solution is. I don’t think anyone really found out what is the thing that changes it all but I do believe it needs to be talked about more.’

Appendix 7 – Assistive Technology

A series of technological devices were identified as those that have the potential to assist residents, families, and Ombudsman representatives in addressing the issues of residents' fear of retaliation and actual retaliation against them in LTC homes. The devices identified include existing technologies and those that representatives thought need to be developed in the future. They also identified various barriers in using these devices.

When asked about the role of assistive technology in addressing residents' fear of retaliation, a very experienced representative said, 'I think this is a question for *residents*.' This response identified a need to conduct a survey among residents to seek out *their* input on this front. That is, what types of assistive technologies *they* would like to have access to; ones that would assist them in realizing their right for dignified and quality care, improving their independence and safety, alleviating their fear of retaliation when voicing care concerns, and preventing actual retaliation against them.

A representative from another state said that during COVID-19 when she wasn't permitted to go and visit residents, some nursing homes had an iPad 'where they would bring it to the person's room if they were able to communicate and I would talk with them, and I actually got more information from people that felt safe in their space in their room. I think it was really helpful. We have never done that before.'

She went on to talk about the affordability issue, 'There are a lot of people who can't afford it.' She said that in her state 'if you're in a nursing home, they take all of your money and you're left with $40 a month so that probably wouldn't even pay for the Internet.' The issue of affordability of assistive technologies is addressed in more detail below. She added that a lot of older people 'don't have the knowledge of technology so they need someone to teach them.'

She said that assistive technology 'would also connect them to family members that may not live close so they have a connection so they can have another advocate. They could reach out to us. Some don't want us to go meet with them in person because they feel like the Ombudsman walks in and they're gonna know that I made a complaint so that's another difficult piece. Maybe if there was another way for them to talk to us and see us without that concern that 'if you come in, then things are just going to get worse or they're going to be mad at me.'

She concluded, 'Now that's available, I think it would be better connected to families, to providers. There are some people that just can't get out of bed. I think there's a lot more that can be done that just hasn't been tapped into.'

Another representative said, 'I am not as familiar with assistive technology as probably some are but I certainly think that any capability you can give to a resident who has diminished capacity physically or communicatively could benefit.'

As noted earlier in this report, several representatives saw a need to improve residents' access to a secure private way to communicate with the outside world including with representatives.

When asked about the role of assistive technology in addressing residents' fear of retaliation and actual retaliation, a very experienced representative said, 'Every resident needs a phone.'

Referring to residents who can operate a phone, she added, 'Every resident needs a way to reach someone outside the facility at all times.' She added, 'I would love it.'

When asked the same question, a SLTCO spoke about the need to enable residents the ability to communicate with the world outside the care home, 'I think the nice thing that folks that have access to is they're able to communicate with people easier.' When asked to clarify what devices she referred to, she said, 'Tablets, any type, anything that they can make the 'equivalent' of a phone call with or an email or FaceTime…that kind of thing, that's very helpful.'

She spoke about the value she sees in residents having access to recording devices, 'We find sometimes when people have recording devices…whatever that means…Alexa or a camera or other things like that, that sometimes they have records of things that have happened.'

Representatives said that some residents advocate for improving their care by using their cell phones to video and/or audio record staff to generate evidence in support of their care concerns.

When asked what other things residents who have a phone can do beyond calling someone outside the care home, one representative said, 'They could take a video or record.' She added that she sometimes receives pictures and sometimes audio recordings but 'most often not a video.'

After saying that she sees value in use of cameras, she went back to speak about devices that enable residents to communicate with others outside the care home, 'I think it has been very beneficial because it has given the residents access to people outside…their families, us, others and then also a way to have a record of something. Those are the things.'

Quote
"Why can't we make our voice go through the walls of this building?" – Older person living with early-stage Alzheimer's disease in an assisted living residence Source: Caspi, E. (2010). Preventing agitated behaviors and encouraging positive emotions among elders with memory-loss in an assisted living residence. Doctoral dissertation study. UMass Boston.

She identified a couple of barriers related to the use of these devices, 'The issue we have is there's not enough available for people. Also, for people with disabilities, making sure that somebody can assist them with the technology. We have some people that either can't learn or can't physically manipulate [the device] or something else that limits their ability to use those types of things. So that's a barrier.'

She confirmed that residents having a secure way of communicating with her representatives is an asset for her Ombudsman program. She added, 'We have some programs that bought residents some tablets and we help people get cellphones. If somebody else isn't helping them get cellphones and stuff like that.'

Another representative said, 'COVID was really horrible in a lot of situations but one of the things that COVID really did in the positive was it really pushed us to look at things like people communicating more frequently via e-mail, via phone, and FaceTime. During the height of COVID, we had these funky robots that could go into facilities when we couldn't go into facilities. A robot is pretty in your face…it's as if we would walk into the building…people are interested in what a robot would be doing.'

She went on to highlight the importance of assistive technologies that enable residents to discretely contact Ombudsman representatives, 'If a resident is fearful of retaliation, having them reach out to the Ombudsman almost on the sly to share their concerns, it really does take away that fear because let's be honest, when an Ombudsman walks into the building, everyone is like, 'Oh, what's the Ombudsman doing here?' They all kind of follow around and things like that so if a resident can share those things without the Ombudsman being in the building, it often makes them less nervous that I am going to alert everyone that you're here.'

When asked about situations where staff stand by the door and listen to the resident's phone conversation with an Ombudsman representative who is *not* in the building, she said, 'That's a great question. My initial thought is residents have the right to privacy so if we want them to have a private conversation…like we could maybe shut the door, go to another room to have those conversations so that it's not broadcasted. You're right. No matter what happens, staff could be lurking outside the door hearing what you're saying and then it kind of defeats the other purpose of that.' This issue is addressed below and under barriers related to the use of assistive technology.

When asked about the role of assistive technology in addressing residents' fear of retaliation, another representative said, 'During COVID, we received funding through the CARES Act and were able to provide facilities with iPads. We were able to provide our volunteer advocates also with iPads so that the advocate and residents could communicate independently and privately. One of our advocates was not doing in-person visits and he was at home with his iPad and had the Activities Director put the iPad on a cart and she rolled it down the hallway so that he could see the environment, he could see residents in real time, and he could communicate with them. The iPads were *super* helpful and continued to be helpful in communication privately between even our staff…our staff had iPads as well so that we could communicate.'

When asked how privacy can be protected, she said, 'That wasn't done privately, no. The Activities Directors [are] in charge of making sure the iPads stay in a space…that it doesn't get stolen. Then we or the advocate is making contact with the Activities Director that we want to speak with such and such resident and they'll bring the iPad to the resident and then the staff person will leave the room and the resident is left with the iPad.'

When asked if residents have a secure and private way to reach out to him, one representative said, 'It depends from resident to resident but I would say the majority of people that I am encountering in long-term care at this point they seem to have a cell phone so they're able to reach me directly by cell phone and I think we're seeing an increase in that to some degree.' He added, 'There's an obvious gap here. You have to be able to use the cell phone, you have to have a cell phone.'

It is important to recognize that in a significant number of states residents can anonymously reach out to the Ombudsman program. For example, when asked if residents can securely reach out to her and privately reach out to her electronically in a confidential way, one representative said, 'Yes. They could call us anonymously. They can make a complaint anonymously. They can. We have our posters around and every month we try to get as many people as we can to talk to.'

When asked about the role of assistive technology in addressing residents' fear of retaliation and actual retaliation, an experienced representative said, 'I would love cameras but also telephones. I think the assumption that everyone has a cell phone…cause not everyone has a cell phone. There are residents who do not have cell phones and they have a right to use a telephone privately. But so many just have an old cordless phone. I think focusing on residents' ability to communicate with outside agencies when they're needing help where they have access to telephones, where they can speak privately…access to information where they can contact appropriate agencies. I just think needs to be better than what it is.'

She added, 'It is assumed that everyone has a cell phone or access to a telephone, and I don't feel that that is always true. In many cases, the residents who do not have access to a cell phone, they don't have families that are willing to pay for the service for them to have a cell phone…so they are reliant on a phone available at the facility. And sometimes that access is *really* not as accessible as it should be.' She was referring to situations where a resident does not have a landline in their bedroom and the phone of the care home is located at the nurses' station.

She added, 'Many' care homes 'have a cordless phone where a resident can take it to their room and then the phone gets lost and then nobody else has access to it because they have to find the cordless phone or it dies. So there's a *limited* access and limited *focus* in making *sure* that all residents have access to outside support.'

When asked who will pay for these phones, she said, 'Right. That's an issue. If someone doesn't have the finances to pay for a cell phone or to pay for a landline in their room, that's a concern.'

Policy Recommendation

Given the critical need to ensure that residents have an affordable, secure, and private way to communicate with the outside world, care advocacy organizations, policymakers, lawmakers, and federal and state regulators may want to consider passing legislation requiring nursing homes to provide a private landline phone (elder-friendly, disability-adapted, and dementia-friendly device) in the bedroom of each resident who wishes to have it and has the cognitive ability to use it (for information about residents' right to have "reasonable access" to use a phone and other forms of communication in nursing homes, see the Federal requirements under Ftag 576 titled Right to Form Communication with Privacy).

Assessment of residents' cognitive abilities and physical disabilities (such as the ability to operate the phone) needs to inform and guide these decisions to increase the likelihood that the resident would be able to use the phone effectively. The phone will need to adapted to the unique physical disabilities of the person using it.

Many residents in advanced stages of Alzheimer's may experience significant challenges using a phone and thus they may not be able to benefit from it (a subgroup of these individuals may experience distress as a result of unsuccessful attempts to use it). By contrast, many people in earlier stages of Alzheimer's disease are capable of using and benefiting from using a phone when the right dementia-friendly conditions are created and when the phones are dementia-friendly. Ongoing cognitive assessment will be key to optimal usage of the phone and to ensure minimal frustrations for the individual using it as Alzheimer's disease and other forms of dementia are progressive and over time the person may not be able to use it effectively.

For examples of elder-friendly and dementia-friendly phones, visit this webpage of *The Alzheimer's Store*.

It is important to recognize that even if each resident had access to a private cell phone, a series of issues may still need to be addressed. Examples are provided here for illustration:

The phone could be lost (e.g., misplaced, taken by other residents or stolen), it could break, it may need maintenance service, batteries may need to be charged daily, and residents may have difficulty operating them (such as due to vision loss, hearing loss, physical disability, or cognitive impairment). In addition, personal and private information stored on the cell phone could be accessed by others without the resident's permission.

In addition, even if all residents who were physically and cognitively able to use a phone had access to one in their bedroom (either a cell phone or a landline), other privacy concerns may remain. For example, a resident considers calling the representative to reporting a care concern they believe is ignored on an ongoing basis, but the resident is reluctant to make the call because in the past they've seen staff members standing right outside their bedroom listening to their private conversations. One representative recognized this concern and confirmed that all the aforementioned issues (i.e., pertaining to a resident's ability to use a phone) need to be addressed.

Consistent with other representatives quoted earlier, this Ombudsman spoke about WiFi problems (described below under the segment titled *Barriers and Challenges Related to Use of Assistive Technology*) and the need for a more meaningful, sustainable, private, and secure way for residents to express their voice outside the walls of the building in general and in rural areas.

The same representative spoke about assistive technology when she suggested, 'Make it access for vision loss. Knowing their rights. Access to information to those who are visually impaired. Sometimes in rural areas can be challenging with access to that information and services.'

A representative from another state also spoke about the importance of residents having cell phones, 'To ensure each resident has a phone.' She identified a related concern, 'They have the right to have a phone but if it's in a nursing home and that phone is located at the nurses' station, how private are there conversations even if they go to their room because now they have their roommate listening. So I would say being able to empower them with a phone to be able to have those a personal phone to be able to have those conversations…to be able to call us and not from the nurses station…to be able to call their family members.'

Her colleague added, 'A lot of the insurance companies will cover for them to have a phone but it's just making them aware that they are allowed that and that way they can have a peace of mind.'

When asked what makes it so that the phones are at the nurses' station, she explained, 'Most of our nursing homes removed the resident room [landline] phones unless the resident pays for them.' She added, 'If the resident pays for that phone in the room, then they can have that phone in their room. Otherwise, if you call to speak with somebody, it's up at the nurses' station. And it maybe a cordless phone that they can…or even a cell phone that they can walk away [with] but you can't walk too far because you're going to have reception issues and then what type of privacy do you have?'

She explained, 'Because we call all the time and they are not to ask who is calling if we ask for a specific resident but I can pretty much tell you, it's probably 60:40 when I call a facility and they ask, 'Can I ask who is calling please?' And my comment is, 'Yeah, now I need to talk with your Administrator…don't worry about the resident because I need to have that too because you can't do that.' They need open lines of communication. It could be another form of retaliation. If the receptionist knows that whatever resident is having a continuous issue and now you have people calling for them, they conveniently questioning and they want to know who is calling.'

She reiterated the value she sees in residents' having phones, 'That would make a huge difference. Because they *know* that it would be more of a private conversation and they're more apt to talk to us. And when you call a resident at a nursing home even if they do have a landline phone in their room, they will tell you they're still not sure it's a private conversation.' She explained, 'They think the facility is listening. If it's an individual phone line, is it a phone line that's maybe the nurses' station can pick up and listen in on their conversation?' Her colleague added, 'They think the facility is recording them.'

Residents' need for private and secure ways to remotely communicate with representatives was illustrated in another representative's statement, 'I just got an email this morning, 'I am emailing you because I am afraid to call you because this is going on.' The resident expressed concerns about understaffing, not receiving assistance with showers, and the food. They used email because they were fearful that they'd be overheard by staff if they were to use the phone.

Some residents use Alexa (virtual assistant technology) to call for staff assistance, call their family and the Ombudsman representative (they use it also for other purposes). One representative said, 'Alexa is a good communication piece for residents. I have a resident who communicates via Alexa. She has everything in it. She can use her call button with Alexa. It's a technology that she uses. She tells Alexa what she wants and Alexa alerts folks for her. She tells Alexa to call the Ombudsman [and] Alexa calls me and she is on the line. She has no use of her hands or her legs but she is very cognitive. It's like a microphone that is connected to Alexa. And it's a wireless piece that she is able to use and she speaks through the piece that is attached to Alexa.' She added, 'When Alexa calls me and if I am not here, it is the resident's voice that comes on my phone leaving me a message to call her.' The resident is 'totally dependent on the facility to assist her and because Alexa gets them to her ('she tells Alexa and her call system will ring'), she doesn't have any problems because she is very vocal, and Alexa is very beneficial to her because that's how she communicates.'

A representative from another state spoke about how she uses text to send residents and families useful information. She said, 'I think the use of technology to send information quickly to residents or families so that they can do their own due diligence or prepare themselves is huge.' She explained, 'I can send a text to somebody with a link or something for them to research a facility if they're looking at a new facility or they're wanting to see about moving someone to a new facility, I can send them a link that has the state survey report on it and they can read about that facility…what was their last survey report and so using that. A lot of residents have cell phones now where they're able to use [it].'

When asked if she uses it for existing or prospective residents, she said, 'I would say both. If a resident is unhappy in a facility and wants to move across town or something, they may not have the ability to go and tour it or visually see it so we can provide them [with] these resources via the internet and text messaging where they can read about these things before they decide to make that move…whether they are coming from their home in the community or from nursing home A to nursing home B. So that's been great.'

Resource Box

Residents and families can get a crude sense of the quality of care provided in an individual CMS-certified nursing home by visiting CMS Care Compare website.

However, they also need to be aware of the flaws and limitations of the information displayed on the website. A review of Care Compare's 5-Star Quality Rating System is available from the author of this report upon request.

For an example of an innovative website that allows the public to quickly access completed and de-identified state investigation reports in assisted living residences and other long-term care settings in Minnesota, visit Elder Care IQ (launched November 29, 2022).

Elder Care IQ is the winner of the 2023 John R. Finnegan Freedom of Information Award from the Minnesota Coalition on Government Information. For additional information about Elder Care IQ, see this article:

Caspi (2023). Elder mistreatment investigations buried no more: 50 reasons why Elder Care IQ is needed.

Another representative stated that she and her colleagues would like to see 'a tablet type device in every room so the residents could easily complete an anonymous report either to us or to the facility of to the Department of Health so that it wouldn't pinpoint who they were but it would say whatever grievance they have. In being anonymous, it's so much easier for people to complain. They're not as worried about it…like when they're in a group and they talk about something because it's not just them.' She said, 'In a perfect world, it would be an anonymous website or something that they can access where it wouldn't be 'Mavis in room 103.' It could be anybody in the building said…really how grievances should work where they don't have to put their name on it but in most facilities there's, 'What's your name?' Someday that would be a really good option.'

A representative from another state said, 'We live in such a world where iPhones, iPads, Laptops, phones…the technology is there…even in ways to call for help. If I can't speak, I might use a tablet that Speech Therapy has put together for me and it helps me communicate my needs to the staff members or anyone who might be visiting.'

When asked how this assistive technology works, she said, 'You might have a tablet that has icons on it or that tablet might have a picture of a toilet and the person pushes the toilet and it says, 'I need to go to the bathroom.' The device itself is speaking for the person…the person is able to push the button and it says, 'These are my needs,' 'I am hungry,' 'I am thirsty,' 'I want to go outside,' 'I need to go to the bathroom.' It kind of helps the care when there's communication barriers but also empowers the resident to let them know you can in a way communicate your care needs, which should hopefully, create a better environment for the staff and the resident.'

She added, 'Normally, what we see is…it's an iPad that's attached to a wheelchair and so wherever the staff is around or if a family member is around, they are right there communicating with that person…so they would push the button and it would let the person know what they need.'

Another representative said that one resident who was physically paralyzed ('He had a stroke and had some bad outcomes related to it') used a computer device that enabled him to "type" and form sentences on the screen using eye movements. She said, 'One of the first residents I met in this job. He was unable to use his body from the neck down and he had a computer system that he used with his eyes and he was able to communicate with us…he was able to type on a screen to communicate with people. It was like a keyboard computer screen that he had to focus on. It was tiring. It would wear him out if he talked to you very long, it wore him out.' It was connected to his call lights system. That is how he got the staff to know he needed help. He connected to the internet with it. He had a Facebook account. He sent emails. He emailed us on a fairly regular basis.' She concluded, 'I have *never* seen a device like this in a facility before. It was an *amazing* thing he had.'

When I shared this story with a representative from another state, she said, 'Oh my goodness. That's amazing. Wow. That's amazing. I'll share that with everybody today.' When I shared it with an experienced representative from another state, she said, 'Wow. I don't think I've ever seen that.'

A representative from another state said, 'I have some residents that the only communication they have is using their computer. I can think of two gentlemen right off the top of my head…one has to use…what are they called a pick…where they can't use their hands but they have a wand that that's how they type on their computer.' When asked to elaborate, she said, 'This gentleman has it wrapped around his hand and that's how he uses the keyboard.' She said that the resident is unable to use his fingers so he uses a wand that is attached to his hand to press the keyboard.

Some residents who are paralyzed in their hands use their mouth to hold a stylus pen with which they type on their touch-screen devices (tablet or iPhone mounted on a phone stand) to communicate with others outside the care home.

Another innovative approach was described by Connecticut SLTCO Mairead Painter (this information was shared during a Zoom interview held several months prior to this project):

Some residents who are bedridden are able to participate remotely in a Resident Council meeting when it is projected on the wall inside their bedroom. When this idea was shared with a representative from another state, she said, 'That's *amazing*.' A very experienced SLTCO from another state reacted to it by saying, 'Yeah, that's an idea.' She added, 'I am writing it down.'

Mairead also shared that in her state residents are using their iPhones to swipe a QR code that enables them direct access to the Ombudsman Program. In a subsequent Microsoft Team call (held on March 18, 2024), she provided additional details about the way the QR code is used. She said that her representatives give residents a Palm Card with information about the Ombudsman program and a QR code. This Ombudsman program is moving away from giving residents business cards (residents may more easily lose them). Instead, they are now using Palm Cards (3x the size of a business card) which are harder to lose. The Palm Cards include the picture of each Ombudsman representative and their contact information – so when an Ombudsman hands it to residents, it can help them identify the Ombudsman when they are visiting the building. Currently, the Palm Card is in English and Spanish versions. In case of emergency, residents are encouraged to call 911.

Swiping the QR code on the Palm Card 'takes them to our webpage.' From there, residents need to click a couple of times and scroll down to see the phone number of the Ombudsman program. Clicking on the phone number calls the Ombudsman program (there is no need to type up the whole phone number). The phone call will be answered during working hours. Residents also have the option of filling out an online form on any day of the week. Forms filled and submitted online during the weekend will be read on Monday. A note on the webpage says, 'If you want to file a complaint, click here' (an online form will then open). The online form allows residents to quietly type up and submit a complaint without being overheard by others such as care staff. Families can also use the online form.

Representatives from several other states shared that they do not use a QR code for this purpose and that they see a need to implement it in their state. Examples of representatives' reactions when they learned about it: 'Oh, wow;' 'Wow. We need that in [de-identified state];' 'That's a good idea;' 'That's a great idea;' 'That's amazing' (this representative cautioned that many residents with

dementia will not be able understand how to operate it); 'I love it. What a great idea. Sometimes we'll stumble across that resident and I am always like, 'How do you communicate with them? How are you communicating with them when there's a language barrier or they are blind or they're deaf?' So that's a great idea. No. We don't have any of that. I wish we did.'

A very experienced representative said, 'We have a QR code but it just gives the information about the program. I don't think that there's a way…other than they can email us. It is not like a fillable form that they can shoot off.'

One SLTCO said, 'We have a QR code that is on our poster in the facilities. That takes them directly to the online Complaint Form. And staff use it too. It's a nice way…if you're passing by our poster in the hallway and you see that QR code…we have had…it seems like in certain areas…more staff who are calling us with a complaint because they can very discretely walk up to a poster, hover over the QR code, and send in a complaint.' They can do it anonymously.

One representative said that during COVID when they were wearing masks, she realized how much she relies on lip reading (e.g., 'I did not realize that I read lips so much'). She added, 'You had to have a mask…I can't understand anything.' She then shared how she often uses a headphone microphone with residents who have difficulty hearing. She said that 'it's like a speaker. You talk into it and it makes your voice louder.'

When asked about the role of assisted technology in addressing residents' fear of retaliation, a representative from another state said, 'I think anything that's going to help us better communicate with residents.' She described a device she and her colleagues use during in-person visits with residents, 'We just bought pocket talkers for people that are hard of hearing. It's headphones and then you can talk into the device and they can hear if they are hard of hearing. If they are completely deaf, obviously no but if they are hard of hearing, it makes it easier for them to hear versus to have to write stuff down on a piece of paper or a white board. I think that can help with increasing the communication to understand what they're trying to convey in the first place.' The device amplifies the sound so residents can hear the Ombudsman representative better. The device is maintained by Ombudsman representatives and handed out to residents to put on during visits.

The representative's report on this device may suggest a need to provide these residents access to a similar device during routine times – not only when representatives visit them – but also during their daily interactions with staff as well as during visits with their family members and friends.

When asked about the role of assistive technology in addressing residents' fear of retaliation, a very experienced SLTCO said, 'A lot of times, if someone is unable to speak, I tell them to take a legal pad in and write the question out. If someone is unable to answer that way…like nodding their head, I ask them to squeeze hands…so yeah, we do have this technology. We use that technology.' She said that she was referring to that yellow pad lawyers use and added, 'We bring that in because that seems to be big enough.'

Another SLTCO said, ‘My policy and procedure says that you make every attempt to use what we call the Language Line if there is a language barrier. I think it's called the TTY for people who are deaf and hard of hearing’ [i.e., a device used to type messages back and forth]. She added, ‘We do have some of our materials…like our Resident Rights are in braille.’

One representative expressed a concern about representatives using their laptops when speaking with residents such as in their bedrooms. She explained, ‘It kind of makes it less personable. It’s less genuine.’ She added, ‘I like to sit down next to a resident or meet that resident where they’re at and I don’t want anything between us.’ She said that if representatives were to come in with a laptop, ‘I don’t think that they are going to trust us.’

When asked whether assistive technology has a role to play in addressing residents’ fear of retaliation or actual retaliation, a representative from another state said, ‘I have been communicating with people who are deaf or hard of hearing.’ Referring to people who have language barriers, she said, ‘I was thinking about people who have Autism that communicate more like with iPads or something…point different things…and the cameras’ that her colleague mentioned earlier. When asked whether she meant that she wished there would be a technology that could help residents who are deaf or hard of hearing better communicate and understand, she said, ‘If that is something they are able to do…I have [had] in the past where people are writing [gestured writing] back and forth…and that’s kind of…you know, you’re switching back and forth so if there is something that is a little easier.’

One very experienced representative said that they would like to see an Online Ombudsman Portal developed consisting of an electronic list of residents with their bedroom numbers and possibly their photo in each care home, ‘I would say and I think it’s probably could solve more problems than I am able to articulate here but one thing is I always feel like sometimes we have trouble finding a resident so if a resident calls us, we set up a time we're going to go see them, they even tell us their room number but then we go to their room and they're not in their particular room or maybe when we enter the building maybe we don't have their room number. I would like it if there was some way we could have access to an electronic list of the residents within a facility and to know where their rooms are so that we’re not…even though we look around and try to physically find them we might still be left with their only choices to ask a staff member ‘Where is Mrs. Smith? I'm trying to find Mrs. Smith’ and you're then identifying a person and of course we avoid that at all costs but it's very hard sometimes for us to make that connection. If we had a list of residents maybe with even a photo so I know who I'm looking for. I don't know where HIPAA falls within all of that. I know we have access to a lot more information about facilities than we tend to maybe take advantage of but I wish there was some way to identify a resident that we might be trying to seek out.’

She added, ‘It would be nice if I could just go online and have like an Ombudsman Portal or something and then I see a list of all the residents in the home and I know in residence on Wing C Room 19 is where Mrs. Smith lives and I'm going to go try to see her this afternoon. She might not be in the room. I don't think we should be implanting chips in people or put a device on their wheelchair so that we can try to look at a map and find them in a facility. That's probably a little too

intrusive but I think something that would at least allow us to be targeting the right wing without having to ask a lot of questions of staff that could set up off their concerns.'

One very experienced representative said, 'When we think about assistive technology, we have to think outside the box.' She went on to share an idea about an assistive technology she thought needs to be developed, 'The police have this little camera…a little body camera. Body cams can be very effective…so assistive technology in that way, residents can have something that is not really visible. That technology could capture…and residents could be among staff without the knowledge of staff. If there's something that is a little *subtle*. If it's something like a lapel pin and they'll admire the pin thinking it's a pin and it's not really a pin.'

She had another idea for an assistive device for residents who are hearing impaired, 'Something that you can wear in your ear that looks like a hearing aid, but it would be by way of technology that protects the resident.' She said that it could serve a dual purpose – improve a resident's ability to hear and capture audio and/or video of what's happening to the resident.

Installing Cameras in Bedrooms

Ombudsman representatives spoke about the importance of residents and families installing cameras – either hidden or in plain sight – in bedrooms (after meeting all applicable regulatory requirements such as those related to informed consent (from the resident and their roommate(s) if they share the bedroom with other residents), notification of the care provider, and privacy and dignity protections).

When asked whether assistive technology could play a role in addressing the phenomenon at the center of this project, one representative said, 'Cameras would help significantly if everybody got them.' She explained, 'There's such a power struggle with the staff who obviously have the power versus a resident having a camera. Something that records black and white what happened I think really supports the resident and takes away the 'he said, she said.''

When asked the same question, another representative said, 'I think for [de-identified name of colleague] and I, the first thing that came to our mind [when reviewing the question prior to the interview] was audio and visual surveillance.' We are seeing them in some facilities. There's the posting on the door, there's 'This room is under monitoring.' I think in the majority of situations, that type of assistive technology can be so beneficial. It lets the resident know my family member can "drop in" or I can use Alexa to call my family member and we can communicate when maybe I can't use my hands or I'm not able to push a call light and I need something. I see it as helpful in the care. There's always the privacy concern with that.'

When asked the same question, a very experienced representative said that 'everybody has a cell phone.' She then went to speak about 'catching people' through video recordings that people take, 'We're seeing a lot more videos…systems in people's rooms…where it catches people where they're not getting good care, which sometimes is retaliation. I think just that modern technology is contributing to hopefully protecting residents in some ways. Residents protecting themselves.'

Another representative said, ‘I am all for monitoring devices if a resident wants to have them in their room. Because I think…I don’t know if it’s necessarily would help us to better address it but I think it can cut down on some of it because if you see a staff member go into a room and angrily putting down their meds, you see that, then you can show them…you can address, you can use that as a teaching moment. I am all for it. I do think it will cut down on some of it.’

During a separate forum dedicated to residents’ fear of retaliation, one representative said, ‘Here in [de-identified state] we’ve been encouraging people to put video monitoring in their rooms because that will show what exactly happened inside the room. In most cases, I am not saying in all, but in most cases when there’s video monitoring, the staff is cognizant of being videotaped and so they would not do some of the things that they would do without the monitoring. We do encourage them to…whenever they can…to put video monitoring in their rooms.’

She went on to recognize the need to meet state regulatory requirements before installing the camera in a resident’s bedroom, ‘They have to display that the room is being monitored so they do know that they are being video recorded. They have to get permission…if they have a roommate. [De-identified state] has a lot of things in place before installing the video monitoring. Yeah, it is evident that the room is being surveilled and it does make most people cognizant of their behaviors when they are in the room.’

Another representative said, ‘I think every family should have that right to be able to place the camera there and a care bear if you will…a nanny cam to monitor what's happening but also need to be mindful of the resident's dignity and if that resident would not change clothes in front of you prior to going into a facility, then you need to make sure that that camera is in a place where you're still maintaining that dignity.’ She added that consideration for residents’ dignity and privacy (including roommates) is very important.

Quote
“I can’t depend on the assistive living provider to provide quality accurate documentation of historical fact. Assistive technology will provide me crystal clear audio and video facts.” – Ombudsman referring to families installing cameras in the bedrooms of their loved ones

Another representative said, ‘I encourage every family, every resident who is willing to accept this, to put a camera in their room. Put surveillance in your room because it helps mitigate care…when the building says, ‘Well, we were there every hour,’ well, the surveillance show that you were here once in the whole shift or even how you are cared for. The surveillance is there.’

When asked about their state law and issues of consent and confidentiality, her colleague said, 'We have documentation that residents have to sign off on whether they want the camera in their room. That's legislated already. We were talking about this prior to this interview that cameras actually benefit the residents regarding fear of retaliation because a lot of times the staff forget that the camera is in the room…because if you're nasty and mean and that's part of your character, it's going to show up when you least expect it. You can't put it away. So a lot of times these same aides or administrative staff are coming into the room and forgetting the camera is there because they're so upset and we get all of that. So that has been great.'

The representative said that they were able to pass a camera bill during COVID 'so nursing homes are now required to allow residents to have cameras. Assisted livings always had cameras because it is individualized apartments, but nursing homes are now required to allow the residents to have cameras and residents can record. You know, every time something is happening, people record it in the community? That's their home. They can record. Residents are utilizing that tool now and most residents have phones now.'

Resource Box
Camera Bill
Camera Use in Long-Term Care and Resident Right to Use of Technology (Connecticut Public Act No. 21-55).

When asked whether they have other thoughts about assistive technology, the first representative said, 'I feel like surveillance is the biggest piece on it. I feel like with the population that is entering the nursing homes now, a lot of them are technology savvy so they have their tablets, their phones. When they have situations like this, they are recording the incidents and honestly, I am glad that they do.' Her colleague confirmed that the use of assisted technology consists not only of stationary cameras installed inside bedrooms but also 'any device of their choosing' that has recording capabilities (such as an iPhone or tablet).

The first representative cautioned that in some situations when a camera is used by a resident, staff may retaliate against them. She said, 'I've noticed that in retaliation to that…I had a resident recently this last year she was having issues with one of the aides and so she began to record the situation and because of that, the building retaliated by putting a sign on her door and letting everyone that goes in know that she records. Not that she has a recording in her room. No, just basically saying she will record you.'

A representative from another state spoke about the value she sees in using cameras in the context of staff 'reflexive' retaliation against residents in advanced stages of dementia who verbally or physically reject personal care, 'That would be a perfect spot for cameras…and on the facility side to be honest with you because it would…twofold…it would help us prove that this retaliation did in fact happened but I think it would also hold the staff more accountable.'

She recognized that there could be serious privacy and dignity issues involved as a lot of personal care takes place inside bedrooms and bathrooms and added, ‘Maybe in the hallways because it always seems to be a build up as you’re walking to the shower room…you’re going to be apprehensive coming up the hallway…so yeah…with respect to privacy and dignity.’

A representative from another state shared a **story** about an incident that occurred in a ‘memory care’ home, ‘One resident was getting confused as to which room was his and he would enter the other gentleman's room and that other gentleman would become agitated and then they would both become agitated.’ In a video sent to the Ombudsman representative by a family member, staff members were seen standing and watching it happen without intervening. One was saying (something along the lines of): ‘Oh, look how agitated he is.’

The representative said, ‘I was watching the staff [and thought], ‘What are they doing to alleviate the situation?’ Where are they? It was almost I felt like they were antagonizing the gentleman instead of the training would have taught them to redirect that gentleman and if they had that, then the situation…because the police would end up being called. It turned into a whole situation that it didn’t need to be if the staff had received that training.’ She added, ‘The staff were leaning against the wall and just kind of giggling. It was just like a smirk. And the family member was like, ‘See, see what he is doing to my dad?’ [and I said], ‘Yeah, I see what he is doing but I also see staff not trying to prevent him from doing anything.’ There are situations like that.’

She said that she believed that what the staff did was retaliation ‘because the one resident that kept going into the gentleman's room…who was confused…for whatever reason, these particular staff members had issues with that resident prior…so to me it was a form of retaliation.’

One representative who spoke about the dismissal, marginalization, and dehumanization of residents with dementia said, ‘The biggest thing that I have found to be extremely invaluable is the installation of camera and electronic monitoring. Not necessarily hidden. I don’t even advocate for covert surveillance. I even discourage that because I am like, ‘If you put a camera in there today and they know it, let’s hope they give him quality of care or quality of care the minute the camera goes in.’ We’re not here playing cops and robbers at the Ombudsman Office. Now, if the Department of Health wants to get into that, that’s fine…that’s up to them, which they don’t really review any of the videos most of the times anyways…but with regards to getting immediate response and improvements, putting it right there out front and center is gonna hopefully support us in that process.’

When asked about her views related to the role of assistive technology in addressing residents’ fear of retaliation, another representative mentioned the installation of cameras in bedrooms. She added, ‘Maybe not even hidden. I think this camera should be everywhere where it is supposed to be…not in the bathroom…and there’s buttons you can turn off when you’re changing someone or doing personal care. But I think staff should know the cameras are there.’

One representative said that for educational purposes, Artificial Intelligence (AI) could be used on footage generated by cameras installed in public spaces (she said that she is not aware of care homes using AI for this purpose). Specifically, when asked about the role of assistive technology in addressing residents' fear of retaliation, she said, 'Video cameras, cams in the halls and things like that. I would be nice instead of just during an abuse allegation…I hope…and we're seeing that a little bit more…like live cameras now going and the Administrator can pull up…I guess AI…the staff are entering…are we assessing that dignity and respect, good customer service? Can we see the level of care? From leadership perspective too. My thought is using AI every once in a while, to assess what the actual care is going on if they don't see that person going down the hall, they don't see the Admin or the Ombudsman there but someone else is watching those interactions. What's really going on?' She added, 'I am sure they're going to find a lot of positive things to talk about as well. Then there's ways of change.'

Another representative identified a concern related to the affordability of using cameras inside bedrooms. She said, 'Because the cost of the camera is on the resident, those who are on Medicaid can't afford it.' She said that she'd like to see 'a provision that was paying for a camera in those cases so it won't be limited just to those who have the means.'

Use of Surveillance Cameras in Public Spaces

One representative spoke about the importance of surveillance camera footage in the public spaces of the care home, 'In some cases, it can prove to be useful especially for those abuse cases or what not. Again, the surveillance cameras have been very effective especially when you're having to investigate whether it'd be myself or the Administrator [where] they have to go to those meetings to investigate and see what happened. In some cases, I feel that they are very useful.'

The representative gave an example, 'If a resident has been neglected…let's say…has been on the floor…say, 'My mom says she has been on the floor for four hours or five hours. No one came to her aid.' I have had some instances where an Administrator was able to look at the camera and they can look at the time and see, 'Well, you know what, I am able to substantiate that argument.' We're looking here on the camera and the time and I see a CNA didn't come into the facility until 2 or 3 hours later. The CNAs didn't do the 2-hour checks. So that's an example that sometimes those surveillance cameras serve to be very useful especially in those particular cases.'

Barriers and Challenges Related to Use of Assistive Technology

The inability to afford different assistive technologies / devices was identified by several Ombudsman representatives as a barrier. For example, One representative working in a very rural area said, 'There are a lot of people who can't afford it. My residents can't afford a phone' and 'the thing is, if the resident can't afford the iPhone, the facility isn't going to buy them for everybody.'

A representative from another state said that Legal Aid has a program [name de-identified] that offers a free phone…so many minutes a month to people with low income but there are issues with that in nursing homes so 'it's not just as easy as you think.'

Examples of such issues include the fact that residents may lose the phone, other residents with dementia may take it and misplace it, and staff may steal the phone.

Another representative said that some residents are 'not tech savvy' and thus it may be challenging for them to use certain devices. For example, a representative who recommended that more residents would have access to phones 'to make it easy for residents to contact us' added, 'But honestly, residents don't contact us because phones are hard for them to navigate at this point. Seniors have hard time with phones.' She saw a need to simplify ways in which residents could contact the Ombudsman representative such as by clicking on a single button on a phone or other device. She said, 'That would be amazing. *Yeah*. If that existed, that would be oh my gosh.'

In addition, residents' physical disability, cognitive disability, visual and hearing impairments may limit their ability to use certain devices. Related to it, a representative from another state said that someone will need to teach residents how to use certain devices and that some residents need hands-on assistance in real time (which may introduce logistical issues but also privacy issues when the person assisting them is standing by them during the call to assist them if needed).

Beyond empowering residents in other ways (regarding their rights and how they can support each other in realizing them), residents trained in the LA PEER program assist their peers in using assistive technology. During an online forum dedicated to the issue of residents' fear of retaliation, one representative said, 'We push residents learning and embracing technology…iPads, Zooming, group texts, and emails. We actually have volunteers and Ombudsmen who train interested residents in doing that. And what's happened, and this is also part of the LA PEER program, it has given them purpose, it has given them confidence.'

Her colleague added, 'You have residents that are technology-wise. Those residents are encouraged to assist other residents with *their* cell phones or their iPads. To set those devices up for them. They appreciate someone who is in the facility whom they trust…like another resident…to assist them with setting up *their* technology on *their* devices.' She added, 'I encourage that because you have residents that were in this field prior to coming to a nursing home. It's very good assistance that's internal in a facility…that if they don't want staff to assist them with their devices, they always have a resident who is savvy about setting up those things for them.' Another representative said, 'We had one of our LA PEERs actually help us with our Zoom presentation' [a LA PEER training] at [de-identified name of care home]. It was pretty amazing. We're turning to the resident because he had the expertise and it was really nice.'

As noted earlier, several representatives identified the challenge that may occur when residents use a device (e.g., iPhone) to communicate from their bedrooms with the Ombudsman or others outside the care home and staff may be standing by their door listening to the conversation. One representative said, 'It happens all the time.' This practice is concerning because it is a violation of residents' right for privacy but also because it may result in residents' reluctance and fear of having these conversations when they want to express their care concerns with an external advocate.

Representatives greatly appreciated that they could communicate with residents using iPads and tablets during COVID-19 lockdowns and thereafter. However, they recognized the concerning possibility that care staff may be listening to residents' conversations with them and others (whether by standing by the bedroom door and listening or being present inside the bedroom).

One representative said, 'I would say that COVID really forced the hand of technology and using FaceTime and Zoom and various things to communicate face-to-face with people. It's not a perfect system because we saw this trend of COVID where unfortunately a lot of residents don't know how to do Zoom or Teams or FaceTime and so a staff person has to set it up for them and connect you with an X entity whatever that was and then the staff would stay in the room to make sure that the technology continues to work…and while I appreciate that…I do, it doesn't allow the resident to have a private conversation. It doesn't allow the resident to voice their concerns and if they do, there's that fear that that person who is there to help with the technology is the one who is going to report back to that staff person, 'Hey, Mary Johns said that you were mean to her.' It sets up that paradigm again.'

She added, 'Then there was this issue…we saw this in the pandemic…especially with the iPad or the device was owned by the facility….therefore, they were very protective of it, and I get it, they don't want it dropped and broken, I get it, I understand that.' She recommended, 'Devise a system where it's on a table, you know, the resident is not holding it…where they could lose grip on it and it could fall or somehow project it on the TV. There are ways around that that you can protect the device from being damaged. There was a lot of concern about that because sometimes we would talk with the resident and we didn't know that somebody else was in the room and therefore, we're not having a private conversation and not knowing that. That is *huge*. That's the *basis* and the *foundation* of our program, the confidentiality, and the right of the resident to contact us without any strings attached sort to speak. That was *really* frustrating to us. I guess we had not perceived it. It was our first pandemic, a lot of us never [been in] anything like that so it never occurred to me to ask the resident, 'Are you alone in your room or is somebody there with you?' Just start asking that question when we did a phone call, a Zoom face-to-face.'

She said that she'd like to see a technology that is secure and private that residents can use to reach out to her 'because the regulation does say that they have to provide a phone for a resident to use to make a phone call but again, the regulation doesn't say that it has to be in a private room or a private space.' Her concern was that the nursing home often places the phone in the nurses' station or in the hallway. When asked if she'd like to see Federal regulation that requires nursing homes to provide a private landline inside residents' bedroom, if the resident choose to have it, she said, 'Oh yeah, that would be huge.'

She added, 'Also that the facility will not be in control of it…so what I am saying is how do I get to that resident on the phone in room 205 without going through the front receptionist or the switchboard person and saying, 'I need to talk to the resident in 205.' Let's say I call them twice in a given day because we're having a discussion about things. All that receptionist has to say is, '205 has gotten a lot of phone calls today' and so, again, there's never that true sense that they can talk

with us without being noticed that they are calling or who is calling. We have staff now that will say, 'Can I ask who is calling?' And I'll say, 'No, I am sorry. I can't disclose that.' And they'll say, 'You know, this is the cordless phone at the nurses' station. We can't tie it up for long cause I am going to need it.' And I'm like, 'Well, I am sorry. The resident has the right to talk to whomever calls.' If this is the phone that's available to all residents because it can be moved room to room, you can't tie it up because you need to call a doctor. They need to have a separate line or a phone system where they can conduct *their* business on. But yes, staff will say, 'How long are you going to be on the call cause I need this phone to be able to do whatever task.'

Representatives spoke about Wi-Fi / Internet connectivity / reception issues in general and in rural areas in particular. One representative who works in a rural area spoke about issues with Wi-Fi and internet access in rural areas. She said, 'That was something that we ran into with COVID. We provided tablets to each facility but some of the issue was the internet…either they had a slow connection and their internet was just limited to management and it was not accessible to residents. I guess assistive technology is having appropriate internet access.' She added, 'We had that in our facilities, we had it in our schools, in the homes during COVID when things kind of shut down. Accessing any internet was an issue particularly in rural areas.'

Regarding the ability to use wireless communication devices, a representative from another state said, 'We still have facilities that don't have Wi-Fi. So residents…even if they had a tool to access, you know, computer or smartphone, if they don't have Wi-Fi, that becomes a [problem].'

She added that many residents can't afford to have Wi-Fi services, 'The PNA [Personal Need Allowance] is so low, $50 a month. It's either you get a phone or you get underwear, it's one of those things.' She added, 'If they have a question, they want to find [missed word] units, they want to do things for themselves to try to get themselves out of the situation, technology is the answer but only if they have the devices, and only if they have a broadband.'

Another representative said, 'Most of our buildings and older buildings are using cinder block and they don't get good reception. That's a huge barrier for us.' She said that this problem prevents residents from being able to communicate with her electronically. She added, 'If they had Phones, they probably could but they're not going to be able to get the reception in those cinder block buildings. The Wi-Fi systems in these facilities are not good at all.'

A related issue has to do with the burden of setting a camera inside a resident's bedroom as 'it is passed to the family member because of the facility's Wi-Fi.' One representative explained, 'It'll be an invasion of privacy for a family member to tap into a nursing facility's Wi-Fi' ('Due to HIPPA, we can't connect you to our Wi-Fi.'). Families need to obtain their own provider to install the Wi-Fi. She added, 'It's an invasion of privacy' as the care home 'would have access to that camera that is in their loved one's room.'

The problem that could be created by 'throwing it back' on the resident and the family when asking them to obtain their own Wi-Fi provider may be exacerbated by the facts that some residents don't have a family to assist them with this process and some can't afford to pay for the Wi-Fi service.

Another problem identified by representatives consists of call light logs that don't capture certain staff members' practice where they come to a resident's bedroom in response to a resident's call for assistance using the call bell, turn it off, not provide the requested care, and leave the bedroom. When asked about common ways in which staff retaliate against residents, one representative said, 'It's not answering the call light, it's also removing a call light from the resident's reach. It's answering the call light and saying, 'I'll be back in 10 minutes,' and they don't return or answer an hour later.' She added, 'Sometimes I ask my residents, 'Time it. How long has it been? 'Put your call light on again.''

She described the problem with the call light tracking system, 'Because a lot of the facilities also have monitoring systems and they can know how long that call light goes on. It becomes a problem if staff member comes in [and] turns it off because it looks like it's answered. Sometimes I have to tell the Administrators, 'Look, this is what's happening…they're turning it off [and] say they'll be back in 15 minutes. It looks like it's answered in a timely manner but it's not so you need to be aware that this is happening.''

Another representative said, 'Anything involving call bells is tough because call bells are often timed and they often run on a system so it notes when your call bell goes off and how long it's audible until it's answered. That's what facilities typically will use to determine if they waited a long time or they didn't wait a long time. So when the nurse comes in and turns off the call bell, it shows on the system that care was provided even though it might not have been provided. Sometimes that's a really difficult situation to go up to bat against because it's a nurse and reporting system versus me and a resident saying it wasn't provided….so that is a really tough situation.'

The need to address this issue stems from a statement made by another representative who described a staff practice where they 'turn off your call lights and say they'll be right back and they *never* come back.' She said, 'We hear this *every* day several times a day.'

Some care homes do not have a tracking system for the call light system. As one representative described it, 'If there's no internal computer program that does what I would call Call Light Audit, you know, you're looking at a database that says during this hour, we had this many call lights on. If there is nothing like that, then staff know, 'Well, there's nothing for me to get in trouble for.''

Another representative identified the same problem in some care homes, 'These call lights aren't tracked resulting in the resident not getting the needed care. There's no tracking system for these call lights and their needs are just not being taken care of.'

Finally, some representatives were not aware of assistive technologies used by residents and representatives in other states. This may represent a missed opportunity when it comes to efforts to alleviate residents' fear of retaliation and empower them to voice their care concerns with an advocate 'outside the walls of the building.'

Appendix 8 – Ombudsman Representatives' Words of Appreciation of the Project

The most experienced Ombudsman representative interviewed for this project said at the outset of her interview, 'I think when I was presented with the opportunity to speak on a fear of retaliation, it sort of brought a general fresh awareness to this topic. I think I've done the work for so long and it's part of the fabric of what we deal with on everyday basis when we work with complaints, and I may have gotten to the point where I just sort of saw it as one of the many barriers we deal with in getting residents good quality of care and quality of life.'

She added, 'I didn't really separate it out and freshly think of it as something…as a problem to be solved or maybe we should bring fresh resources to it. By reviewing and preparing for this interview, I think it's just brought a new awareness to this particular aspect of long-term care and made me feel like maybe it deserves some more thought and creativity to try to address this pretty prominent problem.'

When asked about ways her representatives educate residents, families, staff, and Administrators about the issue of fear of retaliation, a SLTCO said, 'This interview and this exercise with you has really brought this to my own attention that we really need to make a stronger effort, which is why I was asking about what you're going to release in September. I want to put it front and center and I want to make this a requirement of the program to put even more attention to this this issue.'

At the end of an interview, one Ombudsman representative said, 'We know it's hard to capture so we do appreciate you talking about this very important topic because it's not black and white and it's subjective in terms of what someone's sees as being retaliated against.'

Another said, 'What you're dealing with this very issue is just core to everything though. If you don't have a staff and you don't have people expressing their concerns or because they fear retaliation or actually have been retaliated against, it's just a recipe for disaster and has been.'

At the end of another interview, a very experienced representative said, 'I think everything that was discussed here is crucial, is crucial for the betterment of this phenomenon.' I know this phenomenon is widespread. It's all over the place and you were really excellent in delving into it a little bit deeper to understand how we can make it better for our residents in any healthcare facility.'

One representative said, 'Thank you for doing this…looking at the retaliation…because it is something we deal with and that the residents deal with daily.' Her colleague added, 'The residents thank you. It may seem that they don't but they truly do.'

Another said, 'If your project leads to some kind of change, then God bless you…seriously.'