Voices Forum 2024

Voices United, Empowering Choices: Strength in Advocacy







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VOICES FORUM: Voices United, Empowering Choices: Strength and Advocacy

October 4 .2024

<u>Agenda</u>

Arrival and Registration

Pledge of Allegiance

Professor Moore | Council President from Sgt. John Levitow

Welcome

Mairead Painter | State Long Term Care Ombudsman

Opening Remarks

Amy Porter | Commissioner of the Department of Aging and Disability Services

Presentation – Money Follows the Person

Christine M. Weston

Director of Community Options at the Department of Social Services

Raffle

Presentation - Moving Forward Resident Council

Mairead Painter | State Long Term Care Ombudsman

Presentation – Fire Through Dry Grass

Reality Poets

Alhassan "EL" Abdulfattaah Peter "Pete" Yearwood Shannon Nelson Vincent "V" Pierce

Presentation Resident Rights to Essential Caregivers

Irma Rappaport – Essential Caregivers Movement

Award Presentations

Carol Rosenwald Spirit of Advocacy Award – Irma Rappaport
Brian Capshaw Rock Star Award - The Realty Poets/ Fire Through Dry Grass

Legislative Update

Daniel Beem | Long Term Care Ombudsman Program

Lunch and Raffle
Open Mic & Panel Discussion
Closing Remarks

Presentation Money Follows the Person Christine Weston

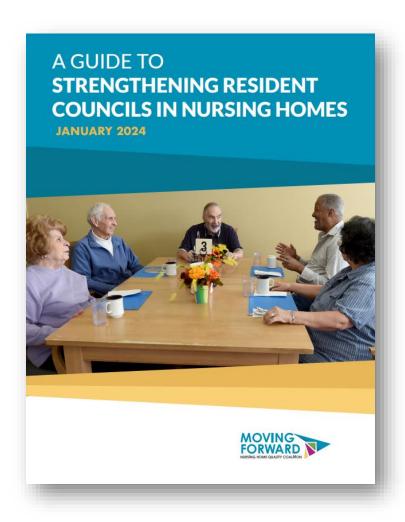


Christine Weston is the Director of Community Options at the Department of Social Services (DSS)

Christine Weston is the Director of Community Options at the Department of Social Services (DSS). Christine has been with DSS for 14 years and has served the members of CT receiving Home and Community Based Services (HCBS) for over two decades. Her experiences range across direct care, care/case management, program oversight, system, program and policy design and development as well as management across multiple DSS programs.

Community Options is a large unit responsible for all the HCBS supports and services provided by DSS. These services include Medicaid Waivers, like the Personal Care Assistance, Acquired Brain Injury, Autism, and Home Care Program for Elders Waivers. The unit also covers state-funded come care services and state plan services, like Community First Choice. Money Follows the Person, CHESS and the HCBS ARPA projects are all managed from this unit.

Moving Forward Coalition Strengthening Resident Council Guide



The <u>Moving Forward Coalition</u> has developed a <u>Strengthening Resident Council</u> <u>Guide</u> to enhance the effectiveness of resident councils in all nursing homes. These councils play a critical role in ensuring residents' voices are heard, but some homes may lack the standardized practices needed to fully support them.

The guide offers a structured approach to creating and sustaining inclusive, resident-directed councils in compliance with CMS Federal Regulations (CFR 483.10(f)(5)). It provides resident councils and those who support them with tools to foster engagement, address grievances, and maintain effective council activities.

This resource empowers residents to take the lead in shaping the culture and care within their community.

Presentation Essential Caregivers Act 2024 Irma Rappaport Essential Caregivers Movement



Irma Rappaport is a prominent figure in the Essential Caregivers National Movement. A passionate advocate, Irma became involved in the movement after witnessing the negative impacts of visitation restrictions on her mother in a nursing home, who died of malnourishment and dehydration because Irma could not assist her. Her personal experience galvanized her to take action, leading her to work tirelessly to ensure that others would not have to endure the same trauma of watching from afar as their loved one dramatically declined or died of "failure to thrive".

Irma's advocacy has been instrumental in raising awareness of the critical role that Essential Caregivers play in the lives of nursing home residents, within the state of Connecticut and also nationally. She has spoken at numerous events, engaged with legislators, and collaborated with various organizations to push for the passage of essential caregiver laws. Her dedication and leadership have made her a respected and influential voice in the movement.

The Essential Caregivers National Movement continues to grow, as more people recognize the importance of maintaining strong connections between nursing home residents and their essential caregivers. With advocates like Irma Rappaport leading the charge, the movement is making significant strides toward ensuring that the rights and well-being of nursing home residents are protected, even in the face of future public health challenges.

Essential Caregiver Resources and Further Reading

ESSENTIAL SUPPORT PERSONS - CONNECTICUT (PA 21-71)

(<u>DPH</u>) April 1, 2022 | Policies and Procedures - Essential Support Persons, and State-wide Visitation for Residents of Long-Term Care Facilities.

(<u>DPH/LTCOP</u>) August 15, 2022 | PowerPoint Slides From Presentation Regarding Essential Support Persons.

(CGA) June 21, 2021 | Public Act 21-71 : AN ACT CONCERNING ESSENTIAL SUPPORT PERSONS AND A STATE-WIDE VISITATION POLICY FOR RESIDENTS OF LONG-TERM CARE FACILITIES.

FEDERAL ESSENTIAL CAREGIVERS ACT of 2024 (H.R. 8331 in the House and S. 4280 in the Senate)

(<u>JOINT PRESS RELEASE AND SUMMARY</u>) Joint Press Release and Summary of Essential Caregivers Act of 2024.

(<u>BLUMENTHAL/L</u>ARSON) May 8, 2024 One Page Summary of The Essential Caregivers Act of 2024

(BLUMENTHAL/LARSON) Full Bill Text of The Essential Caregivers Act of 2024.

(CAREGIVERS FOR COMPROMISE) April 17, 2024 webinar recording outlining the bill provisions.

(CAREGIVERS FOR COMPROMISE) April 17, 2024 webinar presentation slides.

(<u>CAREGIVERS FOR COMPROMISE</u>) 30-minute video entitled "50 States/50 Stories" with testimonies from one constituent from each of the 50 states during the COVID pandemic lockdowns.

*If Interested in Signing an upcoming petition in support of this legislation, sign up for LTCOP emails by <u>clicking here</u> or contact Irma Rappaport at <u>irappapport@gmail.com</u>

Carol Rosenwald Spirit of Advocacy Award

"You Must Hold onto Your Ideals and Always Have the Courage to Speak Your Mind" ~ Carol Rosenwald



History of the VOICES Forum

In September of 1996, nursing home resident and activist Carol Rosenwald, with assistance from the Ombudsman Program, began organizing residents across the state to advocate for improvements in the long-term care system. Carol envisioned a time when the "VOICES" of nursing home residents could be heard "beyond the walls" of their facilities. She became the founder of the Statewide Coalition of Resident Councils and the driving force behind the first "VOICES" Forum in 1997. As a large group of voting constituents, residents were able to speak directly with political leaders and public officials about important issues affecting their quality of life.

VOICES 2019 marks the 26th anniversary of Carol's vision and of this historic event. Our heartfelt thanks to the many courageous residents who have attended VOICES over the years and to all of you attending today who inspire systems change in long term care. You have our deepest admiration and respect.

~The Long-Term Care Ombudsman Program

This Year We are Pleased to award the Carol Rosenwald Spirit of Advocacy Award To

Irma Rappaport
Essential Caregivers Movement



Irma Rappaport continues to be a leading advocate for the Essential Caregivers movement in Connecticut and Nationally. Her personal experience during the COVID-19 pandemic, when her mother suffered severe neglect in a nursing home due to visitation restrictions, fueled her dedication to this cause. Her mother's death in February 2021 underscored the critical need for essential caregivers.

In Connecticut, Rappaport's advocacy was instrumental in the passage of the Essential Caregivers Act. Signed into law in June 2021 by Governor Ned Lamont, this legislation ensures that designated caregivers can access long-term care facilities during public health emergencies, providing consistent care and emotional support to residents.

Irma Rappaport's relentless efforts to secure caregiver access and improve resident well-being at the state level make her an exemplary candidate for the Carol Rosenwald Spirit of Advocacy Award.

Brian Capshaw Rock Star Award



The Coalition of Presidents of Resident Councils and the Long-Term Care Ombudsman Program are pleased to announce the Brian Capshaw annually award recipient. Brian is remembered for his incredible advocacy both in Connecticut and at the national level. In 2012, Brian participated in the Consumer Voice Conference in Washington, DC. He represented Connecticut nursing home residents with a strong voice and with the incredible advocacy that only one who has "walked the walk" can bring to the conversation. He was the resident representative on the Long-Term Care Advisory Council, he testified at countless hearings and he went door to door at the capitol talking with legislators about all the issues so important to quality care and services for nursing home residents: improved staffing levels, video monitoring, personal needs allowance, to name just a few. Brian also worked on national advocacy: he was appointed to be the Chair of the Leadership Council of the Consumer Voice, he was interviewed numerous times by the national media and participated in a wide variety of state and national workgroups. Brian was invited to the White House to participate in the 2015 White House Conference on Aging.

Brian loved sports, his family and friends, getting into his van to meet friends for concerts and various activities. He thoroughly enjoyed his rock music! Brian, in every fashion, was an inspiration and a joy to all who knew and admired him. We miss him dearly.

This Year We are Pleased to award the Brian Capshaw Rock Star Award To

OPEN DOORS / Reality Poets "Fire Through Dry Grass" Protagonists



"<u>Fire Through Dry Grass</u>" is a documentary film that uncovers the devastating impact of the COVID-19 pandemic on residents of a New York City nursing home. The film is notably brought to life by The Reality Poets, a group of young Black and brown disabled artists. These artists use their poetry and art to document their experiences during the lockdown, highlighting the dangers they faced and their feelings of imprisonment. The film sheds light on the neglect they endured and their refusal to be marginalized or erased. The Reality Poets, many of whom are survivors of gun violence, represent a unique and powerful voice, providing an intimate look at a community often overlooked during the pandemic.

"Fire Through Dry Grass" is a profound commentary on resilience, visibility, and advocacy for marginalized communities, particularly those with disabilities. It underscores the necessity of acknowledging and addressing the systemic neglect and marginalization faced by disabled individuals, particularly in crisis situations like the COVID-19 pandemic. The film, through the voices of The Reality Poets, highlights the importance of self-expression, community solidarity, and the power of art as a tool for

advocacy and change. It serves as a call to action for greater inclusivity, respect, and care for all members of society, especially those who are often overlooked or forgotten. View the Full Documentary Film at https://www.pbs.org/pov/films/firethroughdrygrass/.



Alhassan "EL" Abdulfattaah EL was born and raised in Fort Greene, and spent his childhood between Brooklyn and the Bronx with his parents and siblings, with whom he is very close. In a case of mistaken identity, El was shot in a drive-by shooting in 2012 that left him paralyzed from the waist down. Today, El is a core member of the OPEN DOORS Design Team, using bold graphics to creatively inspire and uplift the community.



Shannon Nelson The first woman to join the OPEN DOORS Reality Poets, Shannon Nelson was a dental assistant before the swimming pool accident that left her paralyzed. She's been a quadriplegic for 27 years, and identifies as a wheelchair warrior, disability rights advocate, social justice activist and animal lover. Shannon once escaped from a nursing home in Maine and arrived in New York seeking freedom. She lived in South America for a year while escaping homelessness in the United States. She leads the OPEN DOORS Instagram series, The Movement, which spotlights past and present events in different rights movements that deserve more attention.



Peter "Pete" Yearwood Having contracted polio as an infant in Belize, Pete has lived with a disability all his life. In 1970 he immigrated to Brooklyn and met the mother of his children. After that relationship ended Pete got into the street life—using and selling drugs. In 2015, many years sober, he moved into a long-term care facility on Roosevelt Island, where he met his OPEN DOORS brothers, aka the Reality Poets. Pete is a member and manager of the group and played the narrator in their original play FADE, which premiered at the Main Street Theatre in 2019. He has led poetry

workshops for youth and people with disabilities, and co-led the creation of a community archive called Pandemic Island. Pete is an associate impact producer on the forthcoming documentary film Fire Through Dry Grass.



<u>Vincent "V" Pierce</u> Born in Newburgh, New York, Vincent Pierce is a music producer, gun violence survivor and community organizer. At the height of the pandemic he founded <u>Nursing Home Lives Matter</u> to protect the lives and freedoms of the primarily Black and brown residents of the facility where he lives on Roosevelt Island. He envisions NHLM growing into a national movement. Vince is a Reality Poet and the Director of the arts-and-justice initiative OPEN DOORS, an artist collective who, prior to the pandemic, traveled around the city sharing their poetry and stories. They continue to do so through virtual events. In 2019, Vince produced his first hip-hop album, <u>OPEN DOORS Reality</u>

<u>Poets Vol.1.</u>, and with a grant from the Center for Cultural Innovation launched the music program <u>ZING!</u>, aimed to keep kids off the streets and in the studio. In 2020, Vince was the only nursing home resident invited to speak before the New York State Joint Hearing on Residential Healthcare Facilities and COVID-19. In 2021, Vince presented before Congressional staff to introduce federal legislation and the following year, the Reality Poets received the New Mobility Magazine "People of the Year" award.

PANEL CONTACTS



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The Executive Board of the Statewide Coalition of Presidents of Resident Council members would love for you to join us.

Reach out to <u>LTCOP@CT.GOV</u> to confirm how to attend our bi-monthly SPCRC meetings!



Are You a Nursing Home Resident Interested in Making a Difference?

The Coalition is Seeking New Members!

You Will:

+ Be a voice for nursing home residents

SCPRC SCPRC WAGISTA TO

- Represent your peers in the nursing home
- Advocate for resident rights and interests

To our Resident Advocates who selflessly volunteer their time advocating on behalf of nursing home residents.

Thank You!

<u>Volunteer</u>	<u>Facility</u>
Carolina Diaz	Parkville Care Center
Javier Vargas	Trinity Hill Care Center
Doreen Near	Mystic Healthcare
Jennifer Glick	Chelsea Place
Joyce Werden	Norwich Sub-Acute (Norwichtown)
Kevin Place	Candlewood Valley Nursing Home
Richard Steele	Beechwood
Susan William	Touchpoints at Chestnut
Joann Seraphin	Douglas Manor
Allan Johanson	Wadsworth Glen Health Care and Rehab

Contact The Long Term Care Ombudsman Program:



1-866-388-1888



Email Us: ltcop@ct.gov

Follow us on Facebook: www.facebook.com/CTLTCOP



Mission

Coalesce and leverage a multi-disciplinary, statewide group of private and public stakeholders to prevent elder abuse and protect the rights, independence, security, and well-being of vulnerable elders.

Our Coalition

The Coalition of Elder Justice in CT ~ A multi-disciplinary, statewide group of private and public stakeholders working together to prevent elder abuse and protect the rights, independence, security, and well-being of vulnerable elders."

Our History

The Coalition for Elder Justice in CT was formed by the State Department on Aging in 2013 to lead and convene public and private stakeholders addressing elder justice issues in Connecticut. Governor Dannel Malloy recognized the Coalition and authorized the active participation by various state departments to collaborate and protect elders from multiple forms of elder abuse as illustrated in Executive Order 42. Since that time, the Coalition has hosted annual Seminars and Coordinating Council sessions and our partners have increased two-fold. A number of Action Teams have also been working on such issues as Financial Exploitation, Bank and Faith-Based training, and partnering with AARP Fraud Watch. With the recent award of an Administration of Community Living grant, support will be provided for Conservator Web-based Training, Law Enforcement training, and Elder Abuse Awareness.

Steering Committee

While the day to day coordination and operations are executed by Co-Chairs, presently State Unit on Aging lead staff, the Steering Committee is comprised of five key, member

organizations with distinct expertise in elder abuse. Together they provide support, guidance and oversight of progress on behalf of the Coalition.

Coalition Members

The Coalition is a multidisciplinary, statewide network of agencies and organizations that are partnering to achieve the vision and goals of the Coalition. Membership is open to all interested stakeholders at no cost. Members receive information and updates and have opportunities to attend seminars and the annual meetings and participate in Action Teams.

Interested in joining the Coalition

Please Visit

http://elderjusticect.org/

Click on Join the Coalition tab and fill out the membership form.

Coalition For Elder Justice In Connecticut

Co-Chairs

Lara Stauning, Staff Attorney, Aging and Disability Services, State Unit on Aging Mairead Painter, State Long-Term Care Ombudsman



Medicare Coverage for Nursing Home Care

Medicare doesn't generally pay for long-term nursing home care. Medicare Part A covers medically necessary, short-term care in a skilled nursing facility (SNF) under certain conditions. Part A covers a semiprivate room, medical supplies used in the facility, meals, and other items.

To be eligible for nursing home coverage, Medicare requires you to meet certain criteria such as, but not limited, to:

- You have a qualifying inpatient hospital stay of at least three days before entering the SNF.
- You stay at a Medicare-certified SNF.
- Your doctor orders and you receive inpatient skilled nursing or rehabilitation services on a daily basis. The daily skilled care you need can only be provided in a SNF on an inpatient basis because it is not available on an outpatient basis in the beneficiary's area or transportation to the closest facility would be an excessive physical hardship, less economical, or less efficient.
- You are enrolled in Part A with days left in your benefit period. (Note: If you are unsure of how many days you have left in your benefit period, call 1-800-Medicare.)
- You need treatment for a medical condition treated in the hospital or for conditions, such as bed sores, you develop in the SNF.

What are Examples of Medicare Nursing Home Care Fraud?

- Medicare was charged for:
 - Services that were not deemed medically necessary by your doctor
 - Therapy services or visits that were billed to Medicare but were not provided
 - More expensive services than what you were provided
 - More therapy than what you were provided
 - Skilled nursing services for dates after you were released from the SNF
- You are forced to remain in a SNF until your Part A benefits have expired even though your condition has improved and you wish to change to home health care services.

What Can You Do to Stop Nursing Home Care Fraud?

- Read your Medicare Summary Notice (MSN) or Explanation of Benefits (EOB) to compare the services Medicare was charged with what you received.
- Be sure you work with <u>your doctor</u> to enroll you in any SNF therapy services you may need and to determine medical necessity for these services.
- Do not accept gifts (such as money, gift cards, or groceries) in return for choosing a nursing home in which to receive skilled nursing.
- Do not sign forms that you do not understand, including a Medicare Outpatient Observation Notice (MOON), an Advance Beneficiary Notice (ABN), or any form that is blank.
- · Report charges on your MSN or EOB for services or visits you did not receive.
- Report charges on your MSN or EOB for services that are different than what you received.
- Report quality-of-care complaints to your local SMP and the Beneficiary Family Centered Care
 Quality Improvement Organization (BFCC-QIO).

Differences Between Home Health/Skilled Care and Nursing Home Care

Medicare coverage for home health does not include round-the-clock nursing care or some services considered custodial in nature. Home health aides can, however, provide some personal care services, including help with bathing, dressing, hygiene, and feeding, as long as the patient also needs intermittent skilled nursing or therapy. These personal care services are not automatically covered just because you receive home health care services. A doctor must certify your need for them. Talk to your doctor about what services are necessary and right for you.

How Your Senior Medicare Patrol (SMP) Can Help

Your local SMP is ready to provide you with the information you need to PROTECT yourself from Medicare fraud, errors, and abuse; DETECT potential fraud, errors, and abuse; and REPORT your concerns. SMPs and their trained volunteers help educate and empower Medicare beneficiaries in the fight against health care fraud. Your SMP can help you with your questions, concerns, or complaints about potential fraud and abuse issues.

It also can provide information and educational presentations.

To locate your state Senior Medicare Patrol (SMP): Visit <u>www.smpresource.org</u> or call 1-877-808-2468.

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We are a national nonprofit law organization. We provide free assistance for residents of Connecticut.

We provide education, advocacy and assistance to help older people and people with disabilities get access to Medicare coverage and quality health care.



Contact us for help when Medicare coverage is unfairly denied.



MedicareAdvocacy.org



@CMAorg



@MedicareAdvocacy.org



Headquartered in Connecticut and Washington, DC. 1-860-456-7790

Toll free in CT: 1-800-262-4414



Because Medicare coverage is often unfairly denied, creating barriers to necessary care.