



State of Connecticut
Independent Office of the Ombudsperson for Developmental Services
460 Capitol Avenue, Hartford, CT 06017

2022 Report to The Public Health Committee of the Connecticut General Assembly

Overview of the Independent Office of the Ombudsperson for Developmental Services

The Independent Office of the Ombudsperson for Developmental Services was established on June 29, 2001, in accordance with Public Act NO. 99-271 (Sec. 17a-210a), which mandates an office within the Department of Developmental Services (DDS) that is responsible for receiving and making recommendations to the Commissioner for resolving complaints affecting individuals under the care or supervision of the department or of any public or private agency with which the department has contracted for the provision of services.

It is the mission of the Independent Office of the Ombudsperson for Developmental Services to safeguard the rights of individuals with intellectual and developmental disabilities (IDD), and to work in partnership with individuals, families, state agencies, municipalities, general assembly members and other stakeholders to help resolve their challenges with the Department of Developmental Services.

It is the responsibility of the Ombudsperson to communicate systemic concerns arising from complaints to the Council on Developmental Services, the state legislature, and the Commissioner of the DDS to better direct the resources of the department, and to improve services for individuals supported by the Department and their families. The Office is mandated to assist only individuals who are eligible for DDS services and is prohibited from addressing employee or labor grievances.

The Office is located within the Central Office of DDS at 460 Capitol Avenue in Hartford, Connecticut. This proximity and familiarity with DDS leadership and staff facilitates direct access to information and collaboration to achieve improved advocacy and outcomes for individuals and their families. The Office maintains a strong policy of confidentiality and individual protections and informs those seeking assistance of the role the Ombudsperson in resolving complaints and concerns with the department.

DDS supports are offered through three regional offices: The North, South, and West Regions, the DDS Public Division, and Southbury Training School. DDS provides approximately 16,000 individuals with supports and/or services. The Office of the Ombudsperson receives referrals from a variety of sources - through individuals and their families, DDS Councils and committees, legislative inquiries, DDS staff and Case Managers, the Council on Developmental Disabilities, advocacy organizations, and private providers to name a few.

Introduction to the Ombudsperson

As the niece of a strong willed, proud woman with IDD, I witnessed first-hand the struggles my aunt faced in obtaining the life she wanted due to a lack of support options and my family's well-intentioned but mistaken belief they needed to make decisions for, not with her. I am proud to say she never gave up on herself and was finally able to achieve her dreams with the support of my family and DDS. Among the many lessons my aunt taught me, the most important is that every person, regardless of their level of disability, deserves to feel valued and respected and to have as much control over their own life as possible.

Prior to serving as Ombudsperson, I had the privilege to work for and with people with IDD and their families as the Director of Advocacy and Public Policy of The Arc Connecticut. During my time at The Arc, I learned a great deal about the diversity of needs, the challenges, and the resilience of the IDD community. I worked with thousands of persons with IDD and their families, providing them with education and opportunities to obtain the supports they needed to build the lives they wanted. I developed strong relationships with countless individuals and organizations including DDS, other state agencies, non-profit community providers, and advocacy organizations. And through my work at the Capitol, I collaborated with legislators on both sides of the aisle to build bipartisan support for the IDD community and to promote good public policy for persons with IDD.

My experiences, as a family member and an advocate, have helped me to understand the challenges people with IDD have face in obtaining the support they need to live as fully and independently as possible in the community. As Ombudsperson, I am committed to maintaining my strong connection with individuals and families, and to broadening my work with them, DDS, and other stakeholders to remove barriers, increase opportunities, and make Connecticut a better place to live for people with IDD.

Ombudsperson's Office as Source of Information for Individuals and Families

One of the important functions of the Office is to help individuals and their families who are seeking information and assistance in solving problems. DDS is a complex system. Individuals, families, and other stakeholders are often unclear about policies and procedures and are unfamiliar with the resources available to them. The Ombudsperson is a source of information and can provide active assistance with navigating systems both inside and outside of DDS.

While the statutory mandate of the Office is focused on individuals with IDD and their families, a substantial number of inquiries received are from individuals with other disabilities and members of the public seeking information. It is the unofficial policy of this Ombudsperson to connect anyone who contacts this Office with a viable resource that can assist them with their issue.

Ombudsperson's Office as a Source for Complaint Resolution

Another important function of the Office is to assist individuals, families and other stakeholders with complaints related to services and supports offered through DDS. Complaints are handled by first gathering information from all parties and researching factors that may have bearing on a particular issue, such as policies, systemic issues, past practices, and laws regarding individual rights and protections. Once the Office has gathered information, the findings are communicated back to the individual who issued the complaint. The Ombudsperson will often take an active role in assisting all

involved parties with finding a resolution that meets the goals and the needs of the individual. This frequently requires collaboration with individuals, families, and others, including DDS central office staff, DDS regional staff, private providers, hospitals, and other state agencies that may be involved with the issues in an ancillary capacity.

The Office cannot:

- Address complaints that are part of formal litigation or formal grievance procedures or investigations already underway.
- Give formal legal notice to the DDS regarding grievances, complaints, or concerns.
- Address concerns from employees of the DDS.
- Testify in formal or legal actions.
- Conduct formal investigations.

Complaints can be made via:

- **Phone** - (860) 418-6047
- **Email** - shannon.jacovino@ct.gov
- **Mail** - Connecticut Department of Developmental Services, 460 Capitol Avenue, Hartford, CT 06106, Attn: Shannon Jacovino
- **In person** - by appointment

Issues addressed in 2022

The following is a sampling of issues addressed by the office during 2022:

- Multiple issues in all settings related to the staffing crisis
- DDS Eligibility
- Eligibility Hearing Process
- Abuse & Neglect
- System navigation
- Rights of individuals
- Rights of guardians
- Rights of parents and family members
- Sibling supports and questions
- Establishing Regional Center parent/guardian group
- Legislator constituent issues
- Transportation
- DDS waiver supports
- COVID policies
- Notices of termination by providers
- School supports
- Youth supports
- Community parenting & family supports for individual with IDD
- Access to healthcare
- Individuals with high support needs who do not meet DDS eligibility criteria
- Autism Waiver & supports for individuals with autism
- DDS Waivers
- ADA
- HIPAA
- IDEA
- ARPA
- Residential supports
- Day & Employment Supports
- Behavioral Support Program
- DMHAS Young Adult Services Program
- Transition from school to adult services
- Respite
- Family Support Grants
- DDS Waivers
- DMHAS, DCF, ADS questions
- Deaf and Hard of Hearing rights and supports
- Establishing eligibility and supports for individuals moving to CT

- Questions about benefits
- Difficulties finding programs and exercising portability
- Mediation
- Support for individuals & families seeking alternative, creative, person centered supports
- Complaints about fiscal intermediary
- Summer camps
- DDS Human Rights Committee
- Individuals in hospitals or long-term care facilities
- Employer complaints
- CMS Final Settings Rule
- Maintaining family connections
- Provider accountability
- Guardianship & Supported Decisions-Making
- Encouraging and protecting family and self-advocacy
- Bilingual supports
- Technology

Ombudsperson's Office as Advocate for System Change and Improvements

The Ombudsperson serves on numerous councils and committees, and engages in collaboration, consultation, and advocacy to promote progressive policies and systemic improvements.

To this end, in 2022 I did the following in my capacity as Ombudsperson for Developmental Services:

- Served as co-chair of DDS ARPA Individual & Family Engagement Committee.
- Served as a member of DDS ARPA Advisory Committee.
- Served as a member of the Council on Developmental Services.
- Served as a member of the Supported Decision-Making Coalition.
- Served as co-chair of the State Employee Leadership Network (SELN) Interagency Collaboration Subcommittee.
- Served as a member State Employee Leadership Network (SELN) Strategic Planning Steering Committee.
- Served as a member of DDS Diversity Equity & Inclusion (DEI) Committee and DEI Strategic Planning Committee.
- Met with and provided written and oral reports monthly to the Council on Developmental Services.
- Met with representatives from the State Department of Education and the Bureau of Rehabilitation Services to get a better understanding of interagency collaboration and the current path to employment for people with I/DD.
- Met with representatives from the Greater Hartford Transit District to discuss transportation options for people with I/DD.
- Met with families from Southbury Training School and DDS Regional Centers.
- Met with People First of Connecticut.
- Attended regular DDS state-wide and regional meetings including leadership meetings, incident command calls.
- Attended DDS Region Regional Advisory Council meetings.
- Attended Council on Developmental Disabilities Bridging the Gap between Aging and Disability Services conference and presentations.
- Attended DSS Long Term Services & Rebalancing Steering Committee Meetings.

- Attended DSS Autism Advisory Council Meetings.
- Completed Life Course Ambassador training.
- Attended the Journey to Independence ATECH Conference.
- Attended Raising Consciousness – Preparing for Change & Cultural Communication Training.
- Attended ACL webinar on How Blended, Braided or Sequenced Funding Can Help Drive Employment, Equity & Inclusion.
- Attended Autism Awareness Day.
- Toured Southbury Training School, DDS Regional Centers, group homes and Camp Harkness.
- Consulted with DDS leadership, staff, and Case Managers.
- Consulted with DDS Self-Advocate Coordinators.
- Consulted with advocates including WeCAHR, Disability Rights CT, CT Council on Developmental Services, The Arc Connecticut, Keep the Promise Coalition, NAMI, PATH CT, Connecticut Family Support Network, the Local Initiatives Support Corporation, and others.
- Consulted with the Council on Developmental Disabilities.
- Consulted with Dr. Gerard Kerins on a proposal for a Center for Older Adults with Intellectual Disabilities at Yale.
- Consulted with Council on Developmental Services subcommittee on DDS Abuse & Neglect process.
- Consulted with the Council on Developmental Disabilities and DDS Director of Diversity, Equity & Inclusion to discuss outreach to underserved communities.
- Consulted with the Connecticut State Long Term Care Ombudsman.
- Consulted with the Community Services Division, DMHAS Office of the Commissioner.
- Consulted with the Connecticut Department of Children and Families Office of the Ombudsman.
- Consulted with the DMHAS Community Services Deaf and Hard of Hearing Services.
- Consulted with CT State Independent Living Council.
- Consulted with the New Haven Department of Services for Persons with Disabilities.
- Consulted with the Office of the Childcare Advocate.
- Consulted with DDS and advocates on waiver amendments.
- Consulted with DDS on improving communications and information sharing with individuals and families.
- Consulted Massachusetts and New Jersey Ombudspersons for Developmental Services.
- Consulted with Massachusetts Disabled Persons Protection Commission.

2022 Observations and Recommendations

While there were many critical issues addressed by this Office in 2022, there were several themes that came up with frequency and were noted as areas of concern in monthly reports.

Staffing Crisis:

The historic struggle to hire and maintain staff and nurses, particularly for private providers who support more than 95% of individuals supported by DDS, is well known to lawmakers. The COVID-19 Public Health Emergency has exacerbated this problem to an alarming extent. In his testimony before the Human Services Committee on House Bill 5001, DDS Commissioner Jordan Scheff told legislators, “The workforce crisis is an issue topping the list of priorities for the sector at this time. Without enough direct

care, behavioral health, and nursing staff, our sector will not be able to sustain current operations or expand to offer supports to those individuals currently waiting for services.”

For individuals and families, the impact of this staffing crisis is felt every day and in many aspects of the services and supports they rely on. There are very few inquiries or complaints that come to this Office, that can't in some way be traced back to staffing.

I have received numerous calls from families who, despite having funding, cannot find programs that will support their loved ones due to a lack of capacity in the provider system. This includes individuals who have been unable to return to programs since the COVID-19 Emergency, and those who have been approved for emergency funding. Unsurprisingly those who are hit hardest are individuals who need nursing and medical care, and those who have high behavioral needs. This lack of access also impacts choice. I have spoken with individuals and families who are not satisfied with their current supports, who can't or won't exercise portability because they are fearful of being left without any access to supports.

I have also heard from numerous individuals who self-direct, or self-hire supports, who have had increased difficulty finding staff, nursing, and behavioral support services.

The staffing crisis has, in many cases, also had an impact on the quality of supports, which in turn has an impact on the quality of life for individuals receiving those supports. Abuse and neglect investigations are often not being completed on time, or in a reasonable time frame, because staff who are trained to conduct investigations are forced to cover direct support shifts. High turnover amongst staff contributes to a lack of knowledge and connection to individuals being supported and their families. In addition to high staff turnover, many agencies have also had high turnover amongst managers. This results in fewer managers overseeing more programs, with less time to monitor the quality of those programs, and to train and supervise staff. This also means managers and staff have less time and patience to communicate, collaborate, and follow up, as they should, with individuals, families, and legal representatives. In some cases, this has resulted in families and providers existing in a state of conflict. In others, it has resulted in providers terminating supports. In still others, it has had a chilling effect on advocacy, with individuals and families afraid that speaking up will result in the provider withdrawing supports.

DDS has taken steps on its own to address staffing for private providers within their ARPA HCBS implementation plan, setting aside considerable funding for providers to develop workforce hiring and retention programs. They have also used ARPA funds to enhance the current employment recruiting network for those who self-direct and are working on long-term solutions with the Department of Social Services. But DDS cannot end this crisis on its own.

I want to thank the legislature for the passage of HB 5001 which will establish a Human Services Career Pipeline program to ensure a sufficient number of trained providers are available to serve the needs of persons in the state with an intellectual disability, other developmental disabilities, physical disabilities, cognitive impairment or mental illness and elderly persons.

I would also like to make the following recommendations which I hope will be considered:

- Direct Support Professionals (DSP) must receive competitive, livable wages and benefits that are indexed annually to account for increases in the cost of living.
- The work of Direct Service Professionals must be recognized as professional work with a career path that recognizes and rewards education, longevity, and skills enhancement.
- Reimbursement rates must reflect actual costs, and there must be a standardized process for adjustments to reimbursement rates indexed to inflation.
- Connecticut must invest in behavioral health and nursing workforce development, to meet current needs and ensure ongoing support for those with behavioral needs, complex medical needs and autism.

Individual & Family Rights and Provider Accountability

In 2022, the families who approached this Office, The Arc Connecticut, the Council on Developmental Disabilities, and legislators seeking to establish a Bill of Rights for individuals supported by DDS, were looking to address the issues of transparency, accountability, predictable standards.

Many individuals and families who contact this Office, do so out of a sense of frustration when they believe a provider is overstepping their authority or failing to fulfill their responsibilities. In these situations, families often feel it is difficult to get clarification on the boundaries of DDS' authority, and what tools DDS has to hold providers accountable. In addition to this, many individuals and families feel, as consumers, that objective information on things such as outcomes, abuse and neglect substantiations, and consumer satisfaction surveys should be available to them when choosing providers.

HB 5001 requires the Commissioner of DDS, in consultation with the Council on Developmental Disabilities, the Autism Spectrum Disorder Advisory Council and the Commissioner of Aging and Disability Services, to review the rights of persons with IDD or other developmental disabilities, including, but not limited to, autism spectrum disorder, to determine whether (1) additions or changes are needed to section 17a238 of the general statutes concerning rights of persons placed or treated under the supervision of the Commissioner of DDS 383 and (2) additional statutory protections are needed to ensure the rights of all such persons and their ability to seek a remedy for violation of such rights.

I believe this provides an opportunity to address some, if not all the issues raised by families, and would ask the parties to consider the following recommendations:

- The current statute needs to be updated to reflect that most individuals receive supports in community-based settings, through Home and Community Based Waivers, not institutions. The rights afforded to individuals through CMS waivers and protections afforded by the Final Settings Rule should be reflected in CT statute.
- All institutional terminology should be replaced with person centered language.
- People with IDD and their families should have the right to know that the supports they receive will be effective in helping them to achieve their goals. Establishing mechanisms to measure outcomes and hold providers/contractors accountable must be included.
- The right to be offered alternatives to guardianship for people with IDD, should be clearly delineated in statute.

Support Options for Individuals with Developmental Disabilities

Connecticut General Statutes Sections 17a-210 limit DDS to “the planning, development and administration of complete, comprehensive and integrated state-wide services for persons with intellectual disability and persons medically diagnosed as having Prader-Willi syndrome,” and Section 1-1g defines intellectual disability as “an intelligence quotient more than two standard deviations below the mean...with deficits in adaptive behavior that originated during the developmental period before eighteen years of age.”

In 2022, this Office received many calls from families, advocates, and school systems desperately seeking information for individuals with developmental disabilities who had critical support needs, who did not meet the IQ criteria to be eligible for DDS supports. Unfortunately, in addition to being ineligible for DDS, many of these individuals also have difficulty accessing other supports available to people with disabilities.

Most states do not restrict eligibility for services based on IQ. Connecticut’s restrictions deny many individuals with developmental disabilities access to the services they need to live successfully in the community.

HB 5001 requires the Secretary of the Office of Policy and Management (OPM) to, in consultation with the Commissioners of Education, Social Services, Developmental Services, Aging and Disability Services and Public Health, the Council on Developmental Disabilities and the Autism Spectrum Disorder Advisory Council, develop and recommend new state statutory definitions for intellectual disability and developmental disability and identify related programs for persons with such disabilities that may need to be changed or redesignated in accordance with any new statutory definitions, evaluate whether an Intelligence Quotient should be a factor in such definitions, and evaluate the level-of-need assessment tool used by state agencies that serve persons with an intellectual disability or other developmental disabilities.

I agree with path laid out in the bill which requires OPM to:

- Examine statutory definitions for intellectual disability and developmental disabilities in states nation-wide.
- Analyze best practices for level-of-need assessment tools used by other states and services for persons with an intellectual disability or other developmental disabilities.
- Assess alternative tools, models, or ways to capture an individual's service needs.
- Evaluate how funding levels for services and programs are determined for each individual within the state and in other states.
- Determine best state service delivery models for allowing such persons, or their representatives, to direct services based on their needs.

Acknowledgements

The work of my office would not be possible without the partnership, collaboration, and leadership of countless others who are committed to improving the lives of people with IDD, including:

- Governor Lamont for honoring me with the privilege to serve as the Ombudsperson for a community that I care so deeply about and hold in the highest regard.
- The Connecticut General Assembly for the same, and for the passage of HB 5001, a piece of historic, transformative legislation that has the potential to have a profound and lasting impact on improving the lives of people with IDD. I would like to specifically thank Speaker Matt Ritter, for making this a priority for the 2023 legislative session. Thank you as well to Representative Jillian Gilchrest, Senator Matt Lesser, and the members of the Human Services Committee for listening to all stakeholders, particularly individuals and families. I would also like to give special thanks to Representative Jay Case, founding member of the IDD Caucus, and Representative Lucy Dathan for working together to ensure that HB 5001 had bipartisan support, and fully represented the needs and wants of the IDD community. You and the members of the IDD Caucus are champions for people with IDD and their families.
- DDS Commissioner Scheff and Deputy Commissioner Velardo for their leadership, vision, and commitment to partnering with all stakeholders to create and promote meaningful opportunities for individuals to fully participate as valued members of their communities. I would also like to thank the staff at DDS for their commitment to the individuals the department supports, and their willingness to collaborate with my office and others to improve people's lives and fulfill the mission of DDS.
- Advocates, Councils, providers, state agencies, and other organizations, particularly the Council on Developmental Disabilities, the Council on Developmental Services, The Arc Connecticut, The CT Family Support Network, The Keep the Promise Coalition, PATH CT, The New England Employees Healthcare Union, District 1199, The CT Supported Decision Making Coalition, The CT State Independent Living Council and Centers for Independent Living, The CT Long Term Care Ombudsperson, The Office of the Childcare Advocate, the DMHAS Client's Rights Grievance Specialist, and the DCF Ombudsperson.
- Lastly, and most importantly, the individuals and families from around the state who entrust me with their problems, and their stories, and who never stop pushing to make things better. You are my constant source of inspiration, and the reason why I am here.

Respectfully submitted,

Shannon Jacovino

She/Her/Hers

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"I wish for a world that views disability not as a hinderance, but as unique attributes that can be seen as powerful assets if given the right opportunities." ~ Oliver Sacks