Office of
Developmental
Disabilities
Ombuds

Annual Report on Activities SFY 2024
Office of Developmental Disabilities Ombuds

The Office of Developmental Disabilities Ombuds advocates for the rights, dignity, and humanity of people with developmental disabilities living in Washington-State.

"The Legislature finds and declares that the prevalence of the abuse and neglect of individuals with developmental disabilities has become an issue that negatively affects the health and well-being of such individuals.” SB 6564 (2016)

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Members of the Legislature October 31, 2024
Governor Jay Inslee
Jilma Meneses, Department of Social and Health Services
Tonik Joseph, Developmental Disabilities Administration

Eight years ago, the legislature created the Office of Developmental Disabilities Ombuds (DD Ombuds) program in response to abusive and neglectful conditions for people with developmental disabilities. In SFY 2024, the DD Ombuds closed out another year of complaint resolution, monitoring, outreach and training, and systemic change policy work.

We assist people with developmental disabilities to resolve their complaints and address abuse and neglect, no matter where they live in Washington State. With 5.5 full-time staff located around the state, DD Ombuds opened 126 new individual complaint investigations. We conducted 101 monitoring visits across the state to review facilities, residences, and programs where people with developmental disabilities receive services. We reached more than 1,805 people across the state to talk about our services, show our videos about DD Ombuds and self-advocacy, and give presentations about rights and responsibilities. We gave out materials, made observations, and listened.

We analyzed trends and used information gathered to bring attention to issues of concern. We brought those issues to state agencies with recommendations for change. We worked very closely with The Developmental Disabilities Administration and Residential Care Services on systemic change to improve services for people with developmental disabilities.

The DD Ombuds continues its focus for systemic change on adults and youth who are stuck in the hospital or sent out of state because no services were available in Washington. Another high priority is the Community Protection Program (CPP). We continue to bring concerns about restrictions of rights of people enrolled in the program and failures of the program to comply with federal rules. Because of these failures, we call for the elimination of the CPP.

We have had great success in reaching people who may not otherwise have access to an advocate and look to find new ways to reach people who have concerns about, or experiences with, abuse and neglect. We will continue to engage in policy work to address the prevention of, and response to, abuse and neglect of people with developmental disabilities.

Thank you for this opportunity to serve and empower people with developmental disabilities.

Betty Sch

Betty Schwieterman, State Developmental Disabilities Ombuds
Office of Developmental Disabilities Ombuds

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Policy Recommendations to the Washington State Legislature, Governor, and State Agencies

The Legislature created an independent Office of Developmental Disabilities Ombuds (DD Ombuds) to monitor and report on services to people with developmental disabilities. The DD Ombuds has the authority to investigate complaints, monitor services, and report on State services utilized by children and adults with developmental disabilities. The DD Ombuds also has the duty to make recommendations for service improvement to State agencies, the Governor, and the Legislature. Policy recommendations from the DD Ombuds are below, followed by a summary of the work of the DD Ombuds for the state fiscal year 2024.

Recommendation 1 - Eliminate the Community Protection Program (CPP).

Problem: CPP is the most restrictive community program administered by the Developmental Disabilities Administration (DDA). The DD Ombuds wrote a report focused on areas of concerns with CPP including: 1. People are referred to the program at a young age before they have access to other supports and services. 2. Individuals must comply with DDA's CPP strict and sometimes inappropriate recommendations or risk losing access to other services. 3. The path to less restrictive services is unclear as the program has a low graduation rate. 4. The DDA documents produced at DD Ombuds' request showed lax adherence to policies that protect the rights of people with disabilities. Based on these findings, the DD Ombuds recommends the CPP be eliminated.

Proposal:
DDA has prepared proposed agency-request legislation to eliminate the Community Protection Program and ensure people have their needs met through the existing waivers. The DD Ombuds agrees with this proposal and recommends that any changes must address the issues identified in the DD Ombuds report "No Way Out – An Introduction to the Community Protection Program" and ensure that services do not isolate people from the community.

a. DDA should collaborate with every person in CPP to create a person-cantered service plan to transition them to other waivers with services to meet their needs.
b. DDA should find and develop resources to meet the needs of young people with developmental disabilities who are identified as having possible "community protection issues," and take other actions to divert them from the restrictive programs like CPP.
c. DDA agency sponsored legislation should ensure individuals are not restricted from other DDA services or hours if they choose not to be in restrictive programs like CPP.
d. DDA should ensure each person has a clear path to graduation from CPP or other restrictions using a person-centered planning process.
e. DDA and their contracted providers must meet all federal, state and policy requirements to guarantee that people are not subjected to unwarranted restrictions of their civil and human rights.

Recommendation 2 - Prevent inappropriate hospitalization of children and adults with developmental disabilities.

Problem: Community hospitals continue to be used as crisis placements for children and adults with developmental disabilities across the state. Since July 2018, DD Ombuds has worked with children and adults with developmental disabilities who were, or are, stuck waiting in a hospital without any medical need because Developmental Disabilities Administration (DDA) cannot provide them with appropriate residential services in the community.

The DD Ombuds released two reports about this issue our Youth report, [“I Want to Go Home”]() in SFY 2023 and our Adult report, [“Stuck in the Hospital”]() in 2018.

DDA now collects data on people with developmental disabilities who are taken to the hospital and tracks demographics, the reason why the person was taken to the hospital, where they were living before hospitalization, and why they are stuck there. Tracking includes people of all ages, and people coming out of residential service settings and private homes.

DDA reported that at least 75 people were stuck in the hospital in SFY 2024 for more than 60 days. The DD Ombuds have worked with several people this year who have been stuck in the hospital for more than a year. While DDA has put new services and processes in place, the problem persists. Hospitals are not the place to provide residential services for people with developmental disabilities.

Proposal:

a. To prevent further or extended hospitalization, ensure that people currently waiting for placement are prioritized to receive services, have assessments and person-centered service plans that comply all state and federal requirements and meet the person’s medical and behavioral support needs.

b. Expand the number and types of specialized providers such as psychologists and behavioral support specialists. DDA should analyze the number and type of specialized providers needed to meet the current demands for service in each Region. Using this data, DDA should employ or contract directly with specialists who can provide the following services throughout the state: Psychological assessments; Consultation on behavior supports for family caregivers, staff, and medical providers; Behavior supports for people with developmental disabilities living in hospitals; and Specialized habilitation services.

c. Direct DDA to identify and remove barriers to utilization of behavioral support, such as in-home consultation, for children and adults who reside with parents.

d. Fund additional community diversion beds, emergency respite or other bed capacity to meet the current need for crisis services so individuals with developmental disabilities have an appropriate placement available.

e. Continued increase in funding for complex transition care-coordinators or teams, mobile diversion rapid response, Intensive Habilitation Services, youth peer mentors, provider development, 24-hour personal care and state operated personal care, smaller caseloads, and enhanced support to providers to prevent unnecessary hospitalization and out of state placement.

f. Continue the Complex Discharge Task Force pilot program under ALTSA and ask for a study on how it can be expanded statewide.
g. Ensure behavioral health service providers are trained and equipped to serve youth with developmental disabilities.

Recommendation 3 - Identify and fix systemic gaps with Washington's abuse investigations and mortality reviews.

Problem: There are numerous systemic gaps with how the Developmental Disabilities Administration (DDA) and Residential Care Services (RCS) investigate suspicious deaths. These gaps lead to abuse and neglect investigations being unfairly biased towards service-providers which could cause a lack of accountability that puts disabled people at risk. In SFY 2024 DDA made significant improvements in their policies concerning reporting and responding to suspicious deaths.

Proposal:
a. Mandate RCS to create a suspicious death investigation and review protocol and track their reports of suspicious deaths to the coroner or medical examiner.
b. DDA must monitor their new Mandatory Reporting requirements for DDA staff to report suspicious deaths to the medical examiner or the coroner's offices.
c. Review how DDA enforces residential quality standards for contracted providers.
d. Create and fund increased quality assurance mechanisms for DDA to use with residential providers.

Recommendation 4 – Ensure the promise of "Nothing About Us Without Us."

Problem: People with developmental disabilities, their services and daily life are affected by decisions that are made by the legislature and workgroups that are created to address disability inequality in our state. In recent years there have been workgroups created that have not included self-advocates and people with lived experience to provide input and feedback.

Proposal: The Nothing About Us, Without Us Act (HB 1541) ensures that people with disabilities are included in any group established by the legislature whose activities are related to people with disabilities. There needs to be funding to ensure agencies can support people and have funds for the "Lived Experience Compensation" for those who qualify. Ensure that the Office of Equity has the resources to support Nothing About Us, Without Us Act.

Recommendation 5 – Legislative investment in quality community supports and services for children and adults with developmental disabilities to reduce use of crisis services.

Problem: The long-term care system in Washington State is ranked as one of the best in the country. Not so for individuals with developmental disabilities: Washington State ranked 41st in the country for fiscal effort for services for individuals with developmental disabilities according to the 2019 State of the State Report. The Staff turnover rate made modest improvement since 2022, but is still unacceptably high at close to 40% in residential supported living services. The DD Ombuds sees a pattern of both children and adults with identified behavioral supports needs who are unable to access services to stay in their own home or at home with a parent. The DD Ombuds also sees a pattern that people currently in crisis don't have service plans that meet the minimum requirements to prevent crisis.

Proposal:

a. Increase direct service workers wages in supported living to reduce turnover and increase retention of well-trained staff.

b. Expand the number of out of home respite services for people living with their families.

c. Expand the number of State-Operated Living Alternatives (SOLAs) across the state.

d. Continue focus on the needs of the 15,000+ clients DDA has identified who asked for services but are waiting (no paid services caseload) by increasing availability of waiver services. Identify children and youth on the no paid services caseload, under the age of 21 and on Medicaid and determine if there are unmet needs and whether those can be met under the state Medicaid plan through EPSDT.

e. Ensure that DDA and contracted support providers have more training in developing individual and person-centered service plans that meet state and federal requirements to prevent crisis and comply with the Federal Integrated Settings and Access Rules.

Recommendation 6 - Improve services for youth with intellectual/developmental disabilities in foster care.

Problem: There are children and youth with developmental disabilities in the Title IV-E foster care system. The DD Ombuds gathered information about how other states serve children with developmental disabilities in foster care in its report "Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care." Children and youth in foster care recently gained access to DDA waiver services. Are they receiving these waiver services? Are they being identified as possible DDA clients and being assessed? Are they able to transition to other DDA services when they leave foster care? Are youth aging out of foster care able to access adult DDA services?

Proposal:

a. Direct the DDA and DCYF to evaluate if children and youth with developmental disabilities in foster care are receiving DDA waiver services as required.

b. Identify gaps in services, including crisis stabilization services, for these children and report back to the legislature with a plan to improve services for children and youth with developmental disabilities.

Recommendation 7 - Identify and close gaps in mental health/behavioral health services for children and youth people with developmental disabilities.

Problem: The integration of Medicaid health care and behavioral health care created gaps in mental health services for children and youth with developmental disabilities. This major overhaul of the health care system did not adequately prepare to address the multifaceted needs of people with developmental disabilities.

Proposal:

Create a behavioral/mental health service system inclusive of children and youth with developmental disabilities.

a. Support Children & Youth Behavioral Health Work Group generated recommendations regarding proposals to identify and examine current gaps in mental health services for children and adults with developmental disabilities.

b. Ensure funding for recommendations from the Children & Youth Behavioral Health Work Group for improvements to community based services for individuals with developmental disabilities. Link for Workgroup https://www.hca.wa.gov/about-hca/programs-and-initiatives/behavioral-health-and-recovery/children-and-youth-behavioral-health-work-group-cybhwg

Priority recommendations are:

- Extend the timeline of HB 1580 (passed in 2023) to ensure the team can fully build a process to support children who remain hospitalized unnecessarily due to barriers to discharge. HB1580 was passed with a timeline that ran only for the 2023-2025 biennium and will expire in June 2025
- Expand the Early Childhood Education and Assistance Program (ECEAP) Complex Needs Funds to support extra staff in the classroom, mental health specialists, training for staff around trauma and behavior support, and necessary curriculum or equipment.
- Expand the RUBI parent provider training program to reach more families with children with Autism and developmental disabilities with co-occurring behavioral health needs.
- Expand access to peer supports in school settings and professional peer pathways for youth.

Office of Developmental Disabilities Ombuds Annual Report SFY 2024

Introduction

In 2016, the Washington State Legislature declared, "The prevalence of the abuse and neglect of individuals with developmental disabilities has become an issue that negatively affects the health and well-being of such individuals." The legislature created an independent Office of Developmental Disabilities Ombuds (DD Ombuds) to investigate complaints and monitor and report on services for people with developmental disabilities.

History

The DD Ombuds began its operations across the state of Washington on May 25, 2017. The Washington State Department of Commerce awarded the nonprofit Disability Rights Washington, through competitive bid, the contract to administer DD Ombuds program. Disability Rights Washington created a separate program to fulfill the contract. The DD Ombuds operates under the authority of RCW 43.382.

Services for People with Developmental Disabilities in Washington State

Developmental Disabilities Administration (DDA) is part of Washington State's Department of Social and Health Services (DSHS). DDA administers programs for children and adults with developmental disabilities and their families to obtain services and supports based on individual assessments, needs, and preferences. According to DDA data, there were 63,696 enrolled clients as of June 2024. Of the enrolled clients, 31,137 were receiving paid services. DSHS and other state agencies also administer services to children and adults with developmental disabilities. DD Ombuds has the duty and authority to investigate complaints and monitor and report on these services in order to resolve complaints and make recommendations to state agencies, the Governor, and the legislature.

Powers and Duties of DD Ombuds

DD Ombuds has the duty to protect the rights and interests of people with developmental disabilities. DD Ombuds has the authority and duty to carry out the following:

- Provide information on the rights and responsibilities of people receiving DDA services or other state services and on the procedures for providing these services;
- Investigate, upon its own initiative or upon receipt of a complaint, an issue related to a person with developmental disabilities. However, DD Ombuds may decline to investigate any complaint;
- Monitor procedures as established, implemented, and practiced by the department to carry out its responsibilities in the delivery of services to people with developmental disabilities;
- Review the facilities and procedures of state institutions, state-licensed facilities, and residences which serve persons with developmental disabilities;

- Recommend changes, at least annually, to procedures for addressing the needs of people with developmental disabilities to service providers, the department, and legislators;
- Establish procedures to preserve the confidentiality of records and sensitive information to ensure the identity of any complainant or person with developmental disabilities is protected;
- Maintain independence and authority within the bounds of DD Ombuds duties; and
- Carry out such other activities as determined by contract.

Budget and Staffing SFY 2024

State appropriation: $768,000
DD Ombuds contract budget: $760,320

Staffing - The Office of DD Ombuds operates with 5.5 full-time equivalent staff statewide.
State DD Ombuds - Betty Schwieterman - 1 FTE
Region 1 DD Ombuds and Legal Counsel - Lisa Robbe - 1 FTE
Region 2 DD Ombuds - Leigh Walters - 1 FTE
Region 3 DD Ombuds - Noah Seidel - 1 FTE
Self-Advocacy Educator - Tim McCue - 1 FTE
Office Assistant – Trang Le - .5 FTE

DD Ombuds Program Approach

The 2016 legislature considered a proactive approach to DD Ombuds services. They recognized some people with developmental disabilities are isolated and do not have the resources or support to reach out for assistance. Therefore, DD Ombuds' approach is to provide services and take complaints in person as much as possible. Even in our very advanced technology dependent society, many people with developmental disabilities do not have access to a phone or the internet, or if they do, other people may control their use.

During 2024, DD Ombuds continued in-person visits although at times, had to cancel because of COVID outbreaks. The DD Ombuds staff wear masks and test for COVID before in-person visits. DD Ombuds continues to take complaints by phone and through a website complaint form.

DD Ombuds resolves complaints at the lowest possible level. DD Ombuds protects choice, autonomy, and ensures people with developmental disabilities have access to advocacy. DD Ombuds promotes the well-being of people with developmental disabilities who receive state services. All DD Ombuds services are resident-directed and person-centered. DD Ombuds operates within strict confidentiality protocols.

DD Ombuds provides information on rights and responsibilities through presentations, trainings, community events, videos, social media, and DD Ombuds website at www.ddombuds.org. DD Ombuds and people with developmental disabilities create these publications, videos, and website content.

DD Ombuds collects information from diverse stakeholders such as self-advocacy groups, parent groups, provider organizations, and others to guide its work. DD Ombuds convenes an advisory committee 5 times a year, with a membership comprised in majority of people with developmental disabilities. The committee meets virtually to review stakeholder input and advise DD Ombuds on priority setting, topics for systemic issue reports, organizational structure to ensure a person-centered, resident-directed program, and program expansion based on the Long-Term Care Ombuds model.

DD Ombuds participates in state-led workgroups and regularly meets with state agencies to exchange information and recommend policy and practice change to improve services for people with developmental disabilities. The DD Ombuds continues to see increased responsiveness by DDA to address concerns raised by the DD Ombuds. DD Ombuds recognizes larger culture change at DDA is necessary to prevent and remedy harm and we support DDA in this effort.

Each year, the DD Ombuds publishes this annual report on the work of the office, including the types of complaints received and resolved, facilities and residences visited, systemic issues addressed, recommendations formulated and achieved, and outreach and trainings presented.

Disability Justice Principles

DD Ombuds examines our work with disability justice principles in mind. People can experience oppression as a direct result of the DDA service system. DD Ombuds brings issues to DDA that highlight that oppression and also amplifies a narrative where people with developmental disabilities are free from abuse and neglect and able to live the life of their choosing. When creating work plans and attending meetings with DDA, disability justice principles inform and guide our work. Here are some examples of those principles:

> Intentional Language - DD Ombuds uses intentional language that centers individuals with disabilities as the ones who know best. There often is coded language used in oppressive systems and DD Ombuds questions this language when used by people working in the service system to bring them back to person-centered practices and the principle of “nothing about us without us.”
>
> Intersectionality - DD Ombuds is mindful of intersectionality framework as we do our work, create our agendas and as discussions occur in meetings. DD Ombuds recognizes that people have multiple identities that make them whole and cannot be separated from the person.
>
> Leadership of the Most Impacted - DD Ombuds centers the leadership of people with intellectual and developmental disabilities (I/DD). In order to do our work, we seek out opinions and listen to individuals with developmental disabilities. People who use services and supports must be involved in creating and evaluating those services.

Priorities

The Washington State Legislature created DD Ombuds because there are high rates of abuse and neglect against people with developmental disabilities. All people have the right to be free from abuse and neglect. DD Ombuds program is a way to have eyes and ears on the ground to collect complaints as well as find and fight abuse against people with developmental disabilities.

DD Ombuds prioritizes issues related to abuse and neglect of individuals with developmental disabilities, including physical and sexual abuse; personal and financial exploitation; physical, mechanical, and chemical restraint; and verbal abuse, neglect, and self-neglect. This includes individuals who are stuck in the hospital, and people in the restrictive Community Protection Program.

The Work of DD Ombuds

Information on Rights and Responsibilities

DD Ombuds has the duty to provide information on the rights and responsibilities of individuals with developmental disabilities, including the right to access DD Ombuds services. Information is provided in a variety of formats and locations across the state.

1. Training, Education and Outreach - DD Ombuds reached 1,805 people with information about DD Ombuds services, trainings on topics such as how to navigate the service systems, voting, self-advocacy and problem solving, and responding to abuse, neglect, and sexual assault through presentations and outreach at 58 events.

Some examples of presentations include:
DD Ombuds collaborated with Open Doors for Multicultural Families to deliver the Self Advocate Leadership Training (SALT) to multicultural youth with disabilities for the 3rd year in a row. SALT youth learned about topics such as personal self-advocacy, voting, and advocating to local leaders on broader issues.

Open Doors for Multicultural Families asked the DD Ombuds to develop a training on voting for them to use in their youth program. The DD Ombuds put the training and materials together and turned it over to ODMF.

DD Ombuds gave presentations each day for a week to the transition students in the Tacoma Public Schools Community Based Transition program, where students learned about self-advocacy and received guided training with their Augmentative and Alternative Communication (AAC) devices.

DD Ombuds delivered a three-hour presentation to the Parent Institute for Engagement program (PIE), for the fourth year in a row. Topics presented include the DD Ombuds office, supporting self-advocacy, legislative advocacy, and games that make learning about self-advocacy fun.

DD Ombuds continued Emerging Leaders presentations during the 2024 Legislative Session over Zoom. Emerging Leaders support self-advocates with developing plans for legislative advocacy, such as providing them with information on the current state of legislation and helping them figure out who their legislators are and how to meet them.

DD Ombuds attended, held a resource table, and presented at the second in-person Community Summit since the pandemic. The DD Ombuds provided feedback on the accessibility problems at the Community Summit.

DD Ombuds also participated in several transition fairs and had a table at the 2024 Spokane Disability Pride fair.

2. Information and Referral - DD Ombuds provided 86 detailed self-advocacy support services to people to assist them in resolving their issue. This type of service is more than just providing referrals. Examples of this type of service include providing explanations about and referrals to services, processes for applying for or requesting services including types of DDA services, the DDA eligibility process, the types of DDA service plans, the process for applying for civil legal aid services, and explanation and referral to the complaint resolution unit for abuse and neglect complaints.

3. Resource Development – DD Ombuds developed resources to inform people with developmental disabilities, their families, service providers, and the community about DD Ombuds and rights and responsibilities. A tri-fold brochure and two videos about DD Ombuds are used in presentations and outreach. One video explains the services of DD Ombuds, and the other covers the importance of self-advocacy. The videos are available on DD Ombuds website in ASL and with subtitles available in English and other languages: Chinese (Simplified and Traditional), Korean, Somali, Spanish, and Vietnamese. The tri-fold brochure is available in 8 languages and Braille. DD Ombuds partnered with People First of Washington to translate and caption 5 videos on client rights in five different languages.

The DD Ombuds developed several new presentations for this year. Supporting Self Advocacy, which is for parents and providers to learn how to support self-advocacy; My Advocacy Journey, which is about a self-advocate's journey, and Half Decade of DD Ombuds, which is a presentation that contains information on the reports and outreach that the DD Ombuds office has accomplished since it opened.

The DD Ombuds office also produced two new materials. One is a button that says, "I Support Self Advocacy" and comes with a paper that says what a person will commit to do to support self-advocacy. The second is a new piece of swag, a pop style fidget toy with the name and logo of the office printed on it.

Complaints

People with developmental disabilities and who receive services from the state are eligible for services from DD Ombuds. Individuals with developmental disabilities, staff or providers, family members, guardians, or other interested individuals may make a complaint. DD Ombuds keeps the identity of those who make a complaint confidential.

Complaints are generated during in-person monitoring visits to places where people with developmental disabilities receive services and from individuals with developmental disabilities, parents or other family members, community members, or service providers. DD Ombuds receives complaints in person, by phone calls, or through DD Ombuds online complaint form.

DD Ombuds reviews, and may investigate, complaints on behalf of people with developmental disabilities who receive state services. Complaints may relate to abuse, neglect, exploitation, the quality of services, or access to services. Complaints regarding abuse or neglect are prioritized for services.

In response to a complaint, DD Ombuds may take steps to resolve the issue by talking with others involved, monitoring a facility or residence, researching DDA policies or practices, reviewing records, and interviewing witnesses, or advocating on behalf of an individual or group to resolve a complaint. Only issues where DD Ombuds took action on and individual complaint are listed below. DD Ombuds addresses other issues by providing information or referral services. DD Ombuds uses information gained during complaint investigations to address larger systems issues and advocate for change to improve services and people’s lives.

Complaints worked on in SFY 2024
The majority of complaints concerned administration issues (includes discharge/transfer from hospitals and from DSHS-funded residential programs); individual care issues (includes access to DDA services); autonomy and exercise of rights (includes dignity/respect, guardianship, personal funds); and complaints about abuse, neglect, and exploitation.

SFY 2023 complaints carried over to SYF 2024
Number of complaints carried over into SFY 2024 – 40

New July 1, 2023 through June 30, 2024
Number of complaints opened – 126

Closed July 1, 2023 through June 30, 2024
Number of complaints closed – 127

Pending as of July 1, 2024
Number of complaints carried over into SFY 2025 - 39

This fiscal year DD Ombuds carried over 40 complaints from SFY 2023, responded to 126 new complaints, resolved/closed 127 complaints, and had 39 pending as of July 1, 2024.

New Complaints (126) in SFY 2024 concerned people with the following issues
Note the number of complaints in each issue category does not necessarily correlate to the seriousness of the issue system-wide. For example, research shows abuse and neglect occurs at a high rate for people with developmental disabilities and it is underreported.

The majority of new complaints opened in SFY 2024 concerned discharge/transfer planning; access to DDA services; autonomy and exercise of rights; and abuse/neglect.

Abuse, Neglect, Exploitation - 16 complaints concerning: Physical abuse (1), Verbal/Psychological abuse (4), Financial Exploitation (1), Neglect (7), Individual-to-individual sexual abuse (1), and Personal Safety Planning (1), and Other (1).

Access to Information - 5 complaints concerning: Access to own records (2), Complaints or grievances (2), and Other (1).

Autonomy and Exercise of Rights - 16 complaints concerning: Dignity/Respect (1); Right to Refuse Care/Treatment (3), Sexual Rights (1), Care Planning (3); Guardianship (6); and Other autonomy/exercise of rights (2).

Individual Care - 37 complaints concerning: Injuries (2); Care plan individual assessment (3); Medications (1); Assistive devices or equipment (3); Access to DDA Services (27); Access to other state services; and Healthcare (1).

Restraints and Seclusion – 1 complaint concerning: Seclusion/isolation (1).

Quality of Life - 2 complaints concerning: Individual conflict (1) and Social engagement (1).

Administration - 44 complaints concerning: Inappropriate or illegal administration (2); and Discharge/transfer planning (42).

Employment – 2 complaints concerning: Employment discrimination (1); and Reasonable accommodations (1).

Housing - 2 complaints concerning: Access/lack of housing (1); and Rental denial/termination (1).

Civil/Legal – 1 complaint concerning: Family Law (1)

Complaint Resolution - Examples of assistance provided in SFY 2024 by DD Ombuds:

1. Summary of complaint: The DD Ombuds received a complaint regarding a young person who was stuck in the hospital after being left there by their supported-living provider. Due to grave disability, the young person was held in the psychiatric ward. Shortly after talking with the person's family, the young person was transferred to a state psychiatric hospital.

Outcome: The DD Ombuds advocated for the person to move to a community-setting that would better meet their needs than a state psychiatric hospital. While at the state psychiatric hospital, the young person found a supported-living provider they felt could meet their needs. The young person was initially accepted to a Residential Habilitation Center (RHC), but with the expectation that they could regularly meet with their new supported-living staff. The DD Ombuds stayed involved and advocated for the young person's rights until they moved to their new supported-living provider. The young person is now doing well living at their new supported-living provider.

2. Summary of complaint: The DD Ombuds received a complaint from someone who wanted to graduate from the Community Protection Program (CPP) but, despite meeting DDA's graduation requirements, was told by DDA they were not eligible to graduate.

Outcome: The DD Ombuds advocated for the person to graduate from CPP because the person had met the requirements to graduate. However, DDA did not agree and wanted to add new graduation requirements. After months of advocating for the person's graduation, DDA let the person graduate from CPP.

3. Summary of complaint: A person called our office upset and afraid of being kicked out of the assisted living facility where they have lived for years. They enjoyed activities with other residents and visits from family who live close by. The facility had recently sold, and although against the rules, the new owners began to restrict residents' activities and visitors. The resident complained to the new owners and called our office for help. However, the new owners said the resident was lying, called them names and threatened them in a meeting as well as in writing. The threats were witnessed by numerous people including an experienced DDA Case Resource Manager (CRM) who reported this abuse to Residential Care Services (RCS).

Outcome: Unfortunately and tragically, RCS investigated and found that there was "no failed provider practice." The person was not believed, and it didn't matter that the provider put the threats in writing. They and their family felt betrayed and reported they will never trust the system again.

We met with the DDA case manager and regional leadership who reported lack of authority to require the provider to comply with rules. We reviewed RCS records and met with RCS leadership about the lack of enforcement of client rights. We began asking RCS staff and investigators about their enforcement of the Home and Community Based Services safeguards and DDA client rights. We continue this focus today.

4. Summary of complaint: The DD Ombuds received a complaint from a person who had been stuck in a hospital for over 2 years. The person was designated as eligible for the Community Protection Program (CPP), but as with many people in that program, they were not informed how difficult it would be to find a place to live because of the stigma with the CPP. During a meeting, DDA regional leadership told the person that because DDA's plans and assessments say that the person had previously "made false allegations" against staff, they must always have two staff available to live in the community. The person said "I never made false allegations. I am not a liar, and I don't need or want two staff at all times." DDA said the staffing requirement is necessary "to protect staff."

Outcome: The person reached out to our office after the meeting, upset that DDA staff would not address the concern. We sent emails to DDA HQ documenting the experience and requesting immediate action. We told DDA HQ that numerous DDA employees witnessed this incident but did nothing. We advocated for DDA to remove the harmful CPP designation and for the assessment to be redone. We advocated for removal of the language in the plans that prevent this person from being believed. DDA leadership did not respond to our concerns about how this person was treated in their meeting. However, after a number of months, DDA did remove the person's CPP designation and they were finally able to find a residential provider. The person is now happily living in the community with minimal support from staff.

5. Summary of complaint: The DD Ombuds received a complaint about a youth who was having trouble getting approval for an IPAD that he used for communication and other tasks. We were told the initial denial was because of the damage to a pervious device and the time between when the requests were made.

Outcome: The DD Ombuds found out why the device was denied and what would be needed to make a new request. The DD Ombuds talked with the family about what type of device would help the youth. The DD Ombuds suggested the family find a new case and IPAD that could be requested that would be harder to damage and fit the person's needs. The equipment was approved, and the youth is using them now.

6. Summary of complaint: The DD Ombuds received a complaint about a person who was approved for DDA services, but was told it would be multiple months before they will receive an assessment for DDA Waiver Services

Outcome: The DD Ombuds met with DDA staff about the concerns we had about the person waiting to receive services and how it would affect them. We met with the regional administration about how they schedule assessments and how that process can be adjusted. They were able to schedule the assessment sooner for the person. The region also changed how they meet and coordinate assessments in order to lessen the wait time from being DDA eligible and being placed on a waiver.

Complaint Data – Summary, Analysis, and Identification of Systemic Issues

DD Ombuds resolves individual complaints and looks for patterns that may indicate a systemic issue. Categories with the highest number of complaints include:

- **Discharge/Transfer.** The number one type of complaint DD Ombuds assisted with were Administration issues, primarily discharge/transfer. DD Ombuds continues to assist people who were in a hospital and unable to discharge into community services this past fiscal year. DD Ombuds identified this as a significant systemic issue in 2018, published a report, "Stuck in the Hospital" and made specific recommendations to address this issue. Toward the end of SFY 2022, DD Ombuds received an increase in the number of referrals of both children and adults stuck in the hospital. DD Ombuds researched the issues with children stuck in the hospital and published a report "I Want To Go Home" in SFY 2023. Although the state has made efforts to address this issue, there continues to be a significant area of advocacy by the DD Ombuds.

- **Individual Care.** The majority of the individual care complaints were about access to DDA services. DD Ombuds has identified access to behavioral supports, access to mental health care, need for increased waiver funding for 15,000 clients waiting for service, the wait times for assessments and the simplification and timeliness of the eligibility process as systemic issues to be addressed.

- **Abuse/neglect.** DD Ombuds assisted people who had complaints about abuse, neglect, or exploitation. The DD Ombuds works with the person to explain their rights and ways to complain. Often people want to complain but do not know how or where to complain. Sometimes people are afraid to complain for fear of retaliation. DD Ombuds identifies gaps or problems in the abuse response system and advocates for systemic improvements.

- **Autonomy and exercise of rights, which includes dignity and respect.** DD Ombuds helped individuals and their families' problem solve with their service providers and their case managers to address these issues. DD Ombuds identified Preference, Rights, and Choice as issues to address systemically. Many of these issues happen to people in the Community Protection Program. DD Ombuds has worked with many people who are in this restrictive program and do not have a copy of their program plan or know what they need to do to graduate. This continues to be a significant area of advocacy.

Monitoring

DD Ombuds made 101 in-person monitoring visits across the state in SFY 2024 to talk with individuals with developmental disabilities and review facilities, residences, and programs. Monitoring visits accomplished several purposes. People who receive services, their families, their staff, and provider administrations receive information about DD Ombuds. DD Ombuds gives out materials such as refrigerator magnets, door hangers, and coasters that have information about DD Ombuds and client rights. DD Ombuds observes living conditions and staff interactions and responsiveness to the residents they support. DD Ombuds also received complaints, initiated complaints, and identified locations for follow-up monitoring.

DD Ombuds made 101 visits in person to the following facilities, residences, and programs:

Certified Residential Services Settings - total visits - 50
Supported Living - 29
Supported Living Community Protection Program (CPP) - 16
State Supported Living - SOLA - 5

Licensed Residential Settings - total visits - 12
Adult Family Homes - 11
Assisted Living Facilities - 1

State Residential Habilitation Centers - total visits to cottages or programs - 20
Fircrest Intermediate Care Facility ICF - 3
Lakeland ICF - 4
Rainier - 8
Yakima NF - 5

Hospitals and Community Psychiatric Facilities - total visits - 11
Adult Community Psychiatric- 3
Eastern State Psychiatric Hospital - 2
Western State Psychiatric Hospital - 2
General Hospital - 4

Own Home (not Supported Living) – total visits - 3

Children's' Residential – total visits - 5
Children's Psychiatric - 3
Out of Home Services Children - 2

Systemic Change Outcomes

DD Ombuds identified numerous systemic issues though monitoring visits and complaints, and recommended system improvements. As a result, the following policies, procedures, or practices were changed.

1. Identify and fix systemic gaps with Washington's abuse investigations and mortality reviews.

Problem: In SFY 2024, The DD Ombuds uncovered numerous systemic gaps with how suspicious deaths are reported and investigated by the Developmental Disabilities Administration (DDA) and Residential Care Services (RCS). These gaps lead to suspicious deaths not being reported and abuse/neglect investigations being unfairly biased towards service-providers. This lack of accountability could put disabled people at-risk for increased abuse and neglect.
Outcome: The DD Ombuds advocated for DDA and RCS to change their policies so that they would not be biased towards service-providers and clarified the definition of suspicious death. In response to the DD Ombuds criticisms, DDA made significant changes to their policies related to suspicious deaths, and abuse and neglect. The DD Ombuds are still in conversation with RCS about what they can do to improve how they respond to suspicious deaths.

2. Expose the harm caused by DDA's Community Protection Program (CPP).

Problem: The Community Protection Program has resulted in segregation, prolonged hospitalization, and denial of community living for some people. DDA has often not followed eligibility criteria which resulted in people getting swept into the program. Although against the federal Home and Community Based Services rules, many people in DDA's Community Protection Program have been isolated for decades with their most basic human rights restricted. Many people in the program complain of having "no way out."

Outcome: The DD Ombuds attended dozens of Community Protection Quarterly Treatment Team Meetings. We provided self-advocacy assistance to people in the CPP and advocated for DDA and their contractors to follow the federal Home and Community Based Services rules that prevent blanket restrictions of human rights.

The DD Ombuds continued to alert DDA HQ and regions about people who have been isolated and restricted as a result of the CPP label. Many are stuck in hospitals or institutions. DDA announced they would conduct CPP eligibility reviews and prioritize reviews for people stuck in institutions. These eligibility reviews resulted in DDA releasing over a dozen people from the confines and stigma of the CPP.

The DD Ombuds has long called for the elimination of the CPP and for DDA to guarantee that the people in it do not lose services as a result. While there may have been some good intentions behind the creation of the CPP, the impact of it has been harmful to many. We are thankful that DDA has committed to asking for the legislature to rescind the Community Protection Program and ensure that people in it don't lose necessary services.

3. Improve services for children and youth with developmental disabilities and behavioral health needs.

Problem: Children and youth with developmental disabilities have difficulty accessing behavioral support services which has led to hospitalization, and youth being sent to out of state facilities.

Outcome: DD Ombuds participated in the Children and Youth Behavioral Health Workgroup. Within the group the DD Ombuds shared concerns about access to services for youth with developmental disabilities and collaborated with other members of the group to work on solutions. New legislation and policy changes were created based of the recommendations of the workgroup.

4. Educate DDA about the harm that stems from DDA's assessment and advocate for reforms.

Problem: The DD Ombuds continues to report that DDA's assessment requires everyone to be assessed using harmful terms and subjective language.

The assessment requires DDA Case Managers to ask people questions about their *attention-seeking*, *over-reactive*, *obsessive,* and *uncooperative* behavior. These terms are subjective. DDA assesses tens of thousands of people who needs DDA services using this judgmental framework.

Using this language to describe people with developmental disabilities is damaging to their credibility. Their staff, and even emergency responders are told not to believe the people who are most at risk for abuse and neglect. This, of course increases the likelihood they will experience abuse and neglect.

When speaking to the DD Ombuds, DDA agrees that the assessment uses harmful and subjective language. However, DDA denies there are any concerns with the assessment in their communications to CMS in the waiver amendments and renewals.

Outcome: To alert DSHS employees of the scope of the name calling and harm, the DD Ombuds created a presentation titled *Sticks and Stones: Names Can Really Hurt Me*. This presentation was delivered multiple times to RCS, DDA HQ, and DSHS regional personnel with the hope of educating them on the harmful language found in DDA's assessments and plans, as well as, the pervasive practice of labeling people who report abuse as "making false allegations." The DD Ombuds discusses how the definition of mental abuse includes name calling and making threats. We recommend instead of name-calling, the first step in preventing abuse and neglect is to believe people when they report it.

We received feedback from DSHS employees on the impact of those presentations. Some DDA employees said they were "shocked" that DDA plans and assessments actually contain this language, reporting that they don't typically read them. Some DDA leaders have said they are going to "root" out this language in DDA plans. We are continuing to monitor this problem.

5. Improve education about Supported Decision Making

Problem: Washington State enacted Supported Decision Making, but it is not widely known about, and was not discussed in the DDA Guardianship report.
Outcome: The DD Ombuds has presented on Supported Decision Making and is working with DDA, the Developmental Disabilities Council and Advocates about how expand the use of Supported Decision Making. The DD Ombuds will continue to advocate for access to this service.

6. Monitor DDA's implementation of Home and Community Based Settings (HCBS) Rule

Problem: In FY23 the DD Ombuds highlighted the failure of DDA to implement the HCBS settings rule and monitored DDA as they rolled out new policies and training for their staff and providers. In FY24 we have continued to monitor DDA's implementation of these critical safeguards. Although the law has been in place for over a decade, DDA staff are only just now learning how to implement it. The DD Ombuds heard concerns from people receiving DDA services about DDA's employees and service providers who are exerting control over people's lives in violation of the HCBS rule. The following are examples of their concerns:

- When I leave my house, staff search through my room.
- I don't get to decide who lives here.
- My staff have an office in my house.
- They make me keep my knives locked up.
- They told me that my boyfriend can't be my boyfriend. Staff have to give us permission first.
- They don't allow me to keep my prescription medication at home. Staff keep it at their office or in their car.

- They keep telling me I can’t do this or can’t do that. I’m sick of it!

We are advocating for DDA leadership to take more action to prevent this type of treatment. DDA has thousands of contracted providers all over Washington who sign contracts agreeing to uphold DDA client rights and follow state and federal law. However, as we’ve reported, some practices violate federal law and DDA client rights. DDA leaders report having “no teeth” to enforce provider contracts.

We continue to highlight the “provider control” in people’s homes where providers prevent people from having visitors, privacy, and choice. One of the more egregious violations is DDA’s practice of allowing supported living providers to rent office space in the same homes where they are providing supported living services. This is an obvious conflict of interest and a clear example of a provider-controlled setting.

Outcome: DD Ombuds alerted CMS to unauthorized restrictions in HCBS settings, particularly in the Community Protection Program in FY23. CMS visited Washington DSHS to review health and welfare concerns in September 2023, and issued a findings letter in March of 2024. CMS agreed with the DD Ombuds reporting that “Some goals to graduate from the program are unfair and unrealistic, for example no sexual thoughts, no cussing and no aggression.” The DD Ombuds will continue to highlight HCBS violations in the CPP and other DDA programs.

The DD Ombuds participates on the Home and Community Based Services Quality Assurance Committee as well as its steering committee, advocating for DDA to share with the public when they seek advice or receive feedback from CMS. Additionally, we are advising the people who control the resources to include more people with developmental disabilities on the committee, and ensure they are compensated for their participation.

Recently DDA HQ indicated they would put more focus on contract compliance and enforcement. The DD Ombuds attends DDA’s quarterly statewide residential provider meetings to monitor DDA’s implementation of the HCBS rule. DDA has used this forum to discuss some of our concerns around provider control and restrictions of human rights. We will continue to monitor.

7. Advocate for improvements to the Positive Behavior Supports Plan Processes.

Problem: The DD Ombuds continues to highlight problems with DDA’s oversight and development of functional behavior assessment and Positive Behavior Support Plans and alert DDA to problematic PBSP’s that contain threats and punishment.

Outcome: We advocated for DDA’s clinical psychologist and DDA’s regional clinical teams to take more responsibility for the problems in PBSP’s with providers and the harmful labels often used in those plans.

We provided recommendations to DDA on their new provider training, and again advocated for the removal of harmful language and restrictive practices from PBSPs. We advocated for the removal of the existing provider training manual on DDA's website for the same reasons. DDA indicated they plan to update that manual.

8. Increase self-advocate involvement in DDA policies and practices through the DDA Self Advocacy Committees

Problem: DDA needs more involvement from Self Advocates to shape policy and give feedback.
Outcome: DD Ombuds staff participate in the DDA HQ Self Advocacy and Eastern WA Self Advocacy Advisory Committee meetings to provide information and support others to have their voices heard.

9. Create lived experience representation in meetings

Problem: People with direct lived experience have been left out or could not participate in government-created workgroups that affect their lives.

Outcome: DD Ombuds helped with the creation of the "Nothing about Us Without Us" Act. The DD Ombuds also provided input on how the Developmental Disabilities Council can compensate its members with lived experience.

10. Protect the DD Ombuds access to information for complaint investigations

Problem: The DD Ombuds conducts investigations during the complaint process. In order for the investigation to proceed, DDA must respond to the requests for information. DDA has been inconsistent responding to our information requests. Often, multiple emails are sent to remind DDA to respond or inform them they sent the wrong documents. These delays waste our limited resources. Access to information in DDA's possession continues to take significant resources and prevents us from completing our duties.

Outcome: DDA agreed to make procedural changes in how they respond to our requests. In February 2024 we proposed a new version of DDA's management bulletin with procedures and timelines for responding to our office but DDA has yet to implement it. Gaining access to the information we need from DDA continues to be an area of difficulty. We will continue to discuss how these barriers at DDA prevent people from getting their concerns resolved and can lead to more abuse and neglect.

11. Critical Case Protocol implementation

Problem: DDA clients were having their residential services terminated and being taken to general hospitals or other less supportive environments while new placements were sought. DDA created a new policy, the Critical Case Protocol, as a way to prevent hospitalizations and have people stay with their current supported living provider.

Outcome: DD Ombuds provided recommendations to DDA on how to create person-centered meetings for people with developmental disabilities to give input on their services, what would help them be successful, and how they can best be served. DD Ombuds continues to monitor how this process is working.

DD Ombuds comments on Washington Administrative Code (WACs) and Waiver Amendments

The DD Ombuds reviews the public rule making notices we receive from DSHS and Department of Health and decides whether to provide comments on those rule changes. DD Ombuds provided comments during SFY 2024 on WACs related to DDA services.

WAC 388-825 Developmental Disabilities Administration Service Rules

In March 2024. The DD Ombuds provided comments to DDA on nearly 50 pages of proposed changes to WAC 388-825. This WAC includes the Individual Family Services Waiver definitions and the language in these rules communicates DDA's intentions for how services are used and paid for. Our recommendations include:

- DDA stop funding any service or service provider to use of *polygraphs*.
- DDA stop labeling people who may need DDA services as *offenders*.
- DDA stop using the term *award* to describe the allotted amount of public funds someone is allowed to receive to meet their needs.
- Additional comments centered on reducing provider-centric language, increasing plain language, and focusing on the humanity of people who need DDA services.

WAIVER Comments

The DD Ombuds submitted comments on DDA's HCBS Waiver Amendments and Renewals in November 23 and March 2024. Our comments centered on DDA's failure to guarantee that people do not have their rights restricted unnecessarily, and the harmful and subjective terms in their assessment.

Legislative recommendations and outcomes (SFY 2024)

One of the DD Ombuds duties is to make recommendations to the Washington State legislature. Each year the DD Ombuds reviews proposed legislation and weighs in on the issues important to people with developmental disabilities.

HB 1541- Establishing the nothing about us without us act.

The DD Ombuds testified in support of the bill. The bill passed. The bill states the membership of each statutory entity, such as a legislatively created workgroup, created on or after January 1, 2025, must include at least three individuals from underrepresented populations who have direct lived experience with the issue that the statutory entity is tasked with examining.

SB 6125- Preserving records and artifacts regarding the historical treatment of people with intellectual and developmental disabilities in Washington state.

The DD Ombuds testified in support of the bill. The bill passed. The bill has the University of Washington Institute on Human Development and Disability, the Department of Social and Health Services (DSHS), and the Department of Archaeology and Historic Preservation, the State Archives working together to create a preservation plan to organize, catalogue, and store historical documents and artifacts identified at Lakeland Village.

HB 2279 - Concerning utilization of developmental disabilities waivers.
The DD Ombuds testified in support of the bill. The bill did not pass. The bill would have required the Developmental Disabilities Administration (DDA) to prioritize certain populations when enrolling clients on home and community-based services waivers and for specific services.

HB 5825 - Concerning guardianship and conservatorship.
The DD Ombuds submitted testimony as "other" on the bill. The bill passed. The bill makes changes to the Uniform Guardianship act and makes changes to the work of the Office of Public Guardianship.

HB 2184 - Authorizing payment for parental caregivers of minor children with developmental disabilities.
The DD Ombuds testified in support of the bill. The bill did not pass. The bill would have DDA apply to have Medicaid waivers to allow parent caregivers of minor children with developmental disabilities to receive state payment.

HB 2080 - Establishing day habilitation services for persons with developmental disabilities.
The DD Ombuds testified in support of the bill. The bill did not pass. The bill would have DDA apply to the Centers for Medicare and Medicaid Services for amendments to relevant waivers to establish day services as a stand-alone waiver service.

E2SHB 1479 Concerning restraint or isolation of students in public schools and educational programs.
The DD Ombuds signed in support of the bill. The bill did not pass. The bill would have: created limits to restraint and isolation of students, including by prohibiting chemical and mechanical restraint; modified requirements for incident notification, incident review, incident reporting, behavioral intervention planning, and policies and procedures; added staff and governing body training requirements; established state compliance monitoring and support, including, subject to appropriation, trainings and coaching services; and required multiple reports from agencies to the Legislature.

HB 1859 - Concerning the rights of residents in long-term care facilities.
The DD Ombuds testified in support of the bill. The bill did not pass. The bill would have applied the rights available to the residents of nursing homes under federal law to the residents of all long-term care facilities under state long-term care resident rights provisions.

HB 2347 - Concerning adult family home information.
The DD Ombuds testified against and other on the bill. The bill passed with some significant changes. The bill changes what the Department is require to post on its website regarding adult family homes concerning inspection and investigation reports. The website must include the following documents and information for the previous three years: deficiency-free inspection letters; statements of deficiency related to inspection visits requiring an attestation of correction; statements of deficiency related to enforcement actions; notices of return to compliance related to statements of deficiency; and enforcement action notices issued by the Department.

Budget Bills - DD Ombuds testified on the state budget advocating for more funding for DD services in the community. DD Ombuds focused on Caseload forecasting, caseload reduction for DDA Case Resource Managers, Community Supports for Children -Families caring for children, and youth with significant behavioral challenges, and Residential Crisis Stabilization Programs.

DD Ombuds Reports on Systemic Issues

The DD Ombuds publishes reports on systemic issues to highlight the need for improvements and make recommendations.

Stuck in the Hospital

The issue of children and adults with developmental disabilities stuck in hospitals and unable to discharge is still prevalent.

DD Ombuds published the "Stuck in the Hospital" report in December 2018. The report responded to the high volume of complaints DD Ombuds received about adults with developmental disabilities stuck in a hospital without any medical need. Most of these individuals were Developmental Disabilities Administration (DDA) clients who had been receiving residential services prior to hospitalization. Some individuals went to the hospital for a medical condition, but when they were ready for discharge, they had no place to go because their residential services provider had terminated their services. Other individuals were dropped off at the hospital by a provider who could no longer manage their care. These individuals with developmental disabilities spent weeks or months in a hospital because DDA could not locate available residential placement with staff to provide care. As a result, these individuals had to live in hospitals while waiting for residential placement.

The report makes recommendations to the State and the Legislature to address this tragic issue. DDA has taken some steps to address this issue and DD Ombuds received fewer complaints from people stuck in the hospital in SFY2020 and saw an increase in SFY2021. The issue of children and adults with developmental disabilities stuck in hospitals and unable to discharge is still prevalent. In SFY 2022, DD Ombuds continued to see an increase of people stuck in the hospital. DD Ombuds began a report about youth with developmental disabilities stuck in the hospital or sent out of state for placement. In SFY 2023, DD Ombuds published the report, "I Want to Go Home – Reevaluating DDA' Children's Services to Prevent Hospitalization and Out of State Placement".

Children and adults with developmental disabilities continue to be boarded in community hospitals without a medical need. They are not receiving the habilitative services they need, sometimes they are restrained and cannot go outside for the duration of their stay. Hospital staff often have not received the training they need to work with individuals with developmental disabilities. Hospitals do not have the capacity to board individuals who have no medical need to be hospitalized.

Community Protection Program

DD Ombuds focused this report, "No Way Out - An Introduction to the Community Protection Program", on the Developmental Disabilities Administration's (DDA) Community Protection Program (CPP). DD Ombuds hears many complaints regarding CPP. This report provides background on CPP and identifies concerns resulting from monitoring and complaint investigation. In the course of developing this report, DD Ombuds identified additional concerns to investigate further and report on in the future.

CPP is far and away the most restrictive community program administered by DDA. DD Ombuds focused on five areas of concern with CPP:

1. People are referred to the program at a young age before they have access to other supports and services.
2. Individuals must comply with DDA's CPP recommendations or risk losing access to other services.
3. The program has a low graduation rate.
4. The documents produced at DD Ombuds' request showed lax adherence to policies that protect the rights of people with disabilities.

To address these concerns, DDA must ensure that person-centered, less restrictive supported living alternatives are offered instead of a referral to CPP. DDA must also ensure that entry into the program is truly voluntary and that other DDA services are not restricted if an individual declines CPP. Each participant must know and understand their path to graduation. Participants must be informed of their rights and the process that must be followed before any restriction of rights is planned. DDA leadership must ensure DDA staff and DDA contracted providers meet federal, state and policy requirements that protect the rights of people with disabilities.

Office of Developmental Disabilities Expansion Plan

DD Ombuds proposed in November 2019, an expansion plan based on DD Ombuds experience providing services, analysis of the LTC Ombudsman Program model and stakeholder input. The DD Ombuds has not yet been funded to expand services. DD Ombuds continues to do this important work with the hope to serve more people across the state with additional resources.

Expansion of DD Ombuds services focus on the key tasks:

- Provide information on the rights and responsibilities of people receiving developmental disabilities administration services or other state services.
- Investigate, upon its own initiative or upon receipt of a complaint, issues related to a person with developmental disabilities.

- Monitor procedures of the department to fulfill its responsibilities in the delivery of services to people with developmental disabilities.
- Review the facilities and procedures of state institutions, state-licensed facilities, and residences which serve people with developmental disabilities.
- Recommend changes, at least annually, to procedures for addressing the needs of people with developmental disabilities to service providers, the department, and legislators.

Key areas of focus for expansion

- Reach people with developmental disabilities in rural areas and isolated settings.
- Reach people with developmental disabilities from diverse communities.
- Increase visits to people with developmental disabilities living in certified and licensed residences.
- Increase number of complaints resolved/closed from people living in the community.
- Increase capacity to respond to incidents which affect groups of people with developmental disabilities, such as a facility closure or provider decertification.
- Increase capacity to provide self-advocacy trainings and support.
- Increase capacity to work with policy makers on improvements to the service system.

DD Ombuds modeled its program after the LTC Ombudsman Program with a State Ombuds and Regional offices but does not yet have the resources to implement a volunteer program. DD Ombuds Program also has a self-advocacy educator to inform people with developmental disabilities about their rights and how to address their concerns about their services. The expansion plan details the model of regional offices, paid DD Ombuds and well-trained DD Ombuds volunteers, an additional self-advocacy educator and a volunteer coordinator.
The plan proposes a graduated increase in paid staff and use of volunteers over three biennia. Phase one would be to stabilize the certainty of the funding for the program by moving DD Ombuds budget into the maintenance budget, which has been completed. In Phase 2, with increased funding, a volunteer coordinator, self-advocacy educator and three DD Ombuds are added. Then staffing is increased by three DD Ombuds and an Office Assistant. The DD Ombuds continues to look for opportunities to expand services.

Annual Report Conclusion

The DD Ombuds staff are dedicated to listening to the concerns and complaints of individuals with developmental disabilities and their families. The DD Ombuds then works with individuals to resolve their complaints and when necessary, takes action at the systemic level to improve systems of supports. As evidenced by the information in this report, much progress has been made in SFY 2024 and the need for the DD Ombuds work continues.

Questions or comments about this report?

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