



Office of
**Developmental
Disabilities
Ombuds**

Annual Report on Activities SFY 2020

Office of Developmental Disabilities Ombuds

Informing the Washington State Legislature's work to ensure safe, quality developmental disabilities services.

"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)





Members of the Legislature
Governor Jay Inslee
Cheryl Strange, Department of Social and Health Services
Evelyn Perez, Developmental Disabilities Administration

October 30, 2020

We are here to assist people with developmental disabilities, no matter where in Washington State they live, to resolve their complaints and address abuse and neglect.

The legislature created the DD Ombuds program in response to abusive and neglectful conditions for people with developmental disabilities. The Office of Developmental Disabilities Ombuds closed out another year of complaint resolution, monitoring, outreach and training, and systemic policy work.

With 5.5 full time staff, located in three offices around the state, the DD Ombuds conducted 129 new individual complaint investigations. We conducted 199 monitoring visits across the state to review facilities, residences, and programs where people with developmental disabilities receive services. We also reached more than 8,000 people across the state to talk about our services, show our videos about the DD Ombuds and self-advocacy, give presentations about rights and responsibilities. We produced and gave out written materials, made observations, and listened.

We published a report, ["Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care"](#) with recommendations for improved systems. We also published a report detailing ways to expand DD Ombuds services.

We worked collaboratively with self-advocates, the state and legislature to pass DDA client rights legislation. Client rights are now in statute! We brought systemic issues to the attention of the state and positive changes were made in the lives of people with developmental disabilities.

We had to find new ways to do our work when the pandemic hit. As we look to the future, we see additional ways to connect with individuals who have concerns about, or experience abuse and neglect. We see opportunities to engage in systemic 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.

A handwritten signature in black ink that reads "Betty Schwieterman". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

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

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Executive Summary

The Legislature created an independent Office of Developmental Disabilities Ombuds (DD Ombuds) to monitor and report on services to persons 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. A summary of the DD Ombuds recommendations to the Governor and Legislature is below, followed by summary of the work of the DD Ombuds for the state fiscal year (SFY 2020).

Summary Policy Recommendations to the Legislature and Governor

Recommendation 1. – Clarify Office of Developmental Disabilities Ombuds Statute

Problem: DDA will only provide the DD Ombuds with contact information for people residing in state-licensed facilities. The DD Ombuds does not have contact information for people receiving residential services in certified settings, or receiving in-home services, or people who are eligible for DDA services but not able to access them. This is not what the legislature intended when they created the DD Ombuds to help prevent abuse and neglect. The DD Ombuds is proposing a statute change to fix this problem and wants to ensure the support of the DD advocacy community.

Currently, the person with developmental disabilities or their legal guardian may not learn about the DD Ombuds unless their DDA Case Resource Manager or their state contracted service provider tells them about DD Ombuds services.

If the DD Ombuds does not have the ability to reach out to people with developmental disabilities receiving state services, people might never learn about the DD Ombuds or how to contact the DD Ombuds if they have a complaint.

Proposal: A statute change is necessary to clarify the legislature intends the DD Ombuds to have access to names and addresses of DDA clients in order to carry out its duties.

Recommendation 2. - Invest 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 ranks 37th in the country for fiscal effort for services for individuals with developmental disabilities according to the 2017 State of the State Report. Staff turnover is close to 50% in residential supported living services, and likely higher since the pandemic. The highest number of complaints the DD Ombuds handles concerned access to DDA services, and discharge/transfer. The DD Ombuds sees a pattern of both children and adults with behavioral supports needs who are unable to access needed services to stay in their own home or at home with a parent. Budget cuts to the service system have been proposed as a result of the pandemic.

Proposals:

- a. Preserve funding for services to children and adults with developmental disabilities.

- b. Mandate caseload forecasting for DDA community supports and services.
- c. Increase direct service workers wages in supported living to reduce turnover and increase retention of well-trained staff.
- d. Address the needs of the 14,000+ 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.

Recommendation 3. - Prevent inappropriate hospitalization of children and adults with developmental disabilities.

Problem: Hospitals are being used as crisis placements for children and adults with developmental disabilities across the state. Since July 2018, the DD Ombuds has worked with over 70 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 an appropriate residential placement in the community.

Proposals:

- a. Require DDA to expand the data collected about all people with developmental disabilities who are taken to the hospital to find out why people are stuck there. This includes people coming out of residential service settings and private homes.
- b. Expand the number and types of specialized providers. 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 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; Therapeutic mental and behavioral health services; and Medication management
- 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 increased diversion bed, emergency respite or other bed capacity so individuals with developmental disabilities have an appropriate placement available if they experience a crisis and need residential services.

Recommendation 4. - 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 who could be better served. There are concerns about how the lack of DDA-paid services might disadvantage youth with developmental disabilities while they are in Title IV-E foster care placements and while they are transitioning from a foster care setting to an adult residential setting. 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.”](#)

Proposal: The legislature can direct the DDA and DCYF to identify gaps in services for these children and report back to the legislature with a plan to improve services for children and youth with developmental disabilities.

Recommendation 5. - Identify and close gaps in mental health services for people with developmental disabilities

Problem: The integration of Medicaid health care and behavioral health care has created gaps in mental health services for individuals 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 mental health service system inclusive of people with developmental disabilities. Support HB 1394 Sec. 10 workgroup generated recommendations regarding proposals to identify and examine current gaps in mental health services for children and adults with developmental disabilities. Examine recommendations from the Children & Youth Behavioral Health Work Group for improvements to services for individuals with developmental disabilities.

Recommendation 6. - Ensure the State Auditor's Office continues performance audits of long-term care training partnership.

Problem: The Washington State Auditor's Office proposed elimination of the mandated performance audits of the long-term care training program on a two year cycle.

Proposal: Maintain performance audits of the work of the training partnership and long-term care worker program on a regular basis.

Executive Summary of DD Ombuds work for SFY 2020

Outreach, Training, Education and Information on Rights and Responsibilities

The DD Ombuds reached 8,012 people with information about the DD Ombuds services, trainings on topics such as how to navigate the service systems, self-advocacy and problem solving, and responding to abuse, neglect, and sexual assault through presentations and outreach at 63 events. One event was live-streamed and had 6,000 participants. The DD Ombuds provided 152 detailed I&R services to people to assist them in resolving their issue. The DD Ombuds developed resources to inform people with developmental disabilities, their families, service providers, and the community about the DD Ombuds and rights and responsibilities. DD Ombuds website (www.ddombuds.org) posted 28 blog posts from around the state. New this year are two self-advocacy story videos, "Advocate for Your Rights" and "Never Give Up and Keep on Trying." ([https://ddombuds.org/videos/.](https://ddombuds.org/videos/))

Complaints

This fiscal year the DD Ombuds carried over 60 complaints from SFY 2019, responded to 129 new complaints, resolved/closed 162 complaints and had 27 pending as of June 30, 2020.

The majority of complaints concerned individual care issues (includes access to DDA services and care plan individualized assessments); administration issues (includes discharge/transfer

from hospitals and from DSHS funded residential programs); autonomy and exercise of rights (includes dignity/respect, preference, choice and rights, privacy); abuse, sexual abuse, neglect; followed by issues of quality of life and housing.

Monitoring

The DD Ombuds made 199 monitoring visits across the state this past fiscal year to meet and 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 the provider administration receive information about the DD Ombuds. The DD Ombuds gives out materials that are easy to keep such as refrigerator magnets, door hangers and coasters that have information about the DD Ombuds and client rights. The DD Ombuds observe living conditions, and staff interactions and responsiveness to the residents they support. The DD Ombuds also received complaints, initiated complaints and identified locations for follow up monitoring. Once the pandemic hit the DD Ombuds stopped in-person visits and developed and tested a telephone visit protocol and began phone visits.

Summary of Systemic Issue Reports

The DD Ombuds continues to utilize its systemic reports to advocate for systemic changes.

Stuck in the Hospital - The DD Ombuds published the [“Stuck in the Hospital”](#) report in December 2018. The report was a response to the high volume of complaints the DD Ombuds received about adults with developmental disabilities stuck in a hospital without any medical need. The report makes specific recommendations to the State and the Legislature to address this tragic, ongoing issue.

Children and Youth with Developmental Disabilities in Foster Care - [“Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care”](#) published in SFY 2020, the report makes specific recommendations for the Developmental Disabilities Administration and the Department of Children, Youth and Families to work together to improve services for children and youth with developmental disabilities in foster care.

Office of Developmental Disabilities Expansion Plan

The DD Ombuds proposed in November 2019, an expansion plan is based on the DD Ombuds experience providing services for the past two and a half years, analysis of the LTC Ombudsman Program model and stakeholder input. The plan proposes a graduated increase in paid staff and use of volunteers over the next three biennium. Phase one would be to stabilize the certainty of the funding for the program by moving the DD Ombuds budget into the maintenance budget. Then in SFY 2022-2023 a volunteer coordinator, self-advocacy educator and three DD Ombuds are added. Staffing is increase by 3 DD Ombuds and an Office Assistant the next two biennium.

Systemic Change Outcomes

Policy, Practice, Procedure: During SFY 2020 the DD Ombuds reports seven major systemic changes related to supported living client rights during provider provisional certification or other enforcement actions; Privacy protections in the supported living referral process; DDA Client Rights created in statute; Emerging Leaders – Access to the legislative process; Preservation of Rights - Guardianship Documentation; Community Protection client participation in treatment team meetings – “Nothing About Us without Us”.

Legislative: The DD Ombuds also made legislative recommendations and had successful outcomes including: House Bill 1651/SB 5843 concerns the rights of clients of the developmental disabilities administration. SB 6205 is an act relating to preventing harassment, abuse, and discrimination experienced by long-term care workers. The DD Ombuds raised concerns about the tone of the bill, the lack of definitions, potential client abandonment, client privacy, and reporting requirements. HB2390 Respectful language. The DD Ombuds supported this bill to revise language in a several statutes to reflect respectful language. This bill passed. 2SHB 2737 The DD Ombuds supported a bill, which passed, to add an organization representing those with developmental disabilities to the children’s mental health workgroup. SB 6040- Concerning the budgeting process for certain state waiver services for individuals with developmental disabilities. SB 6287-Concerning guardianships and conservatorships. The legislation would clarify the uniform guardianship act which would include creating supported decision making for people with Intellectual and Developmental Disabilities. The DD Ombuds testified in support of supported decision making as an alternative to guardianship that some people would choose.

Washington Administrative Code (WAC): As part of its systemic reform work, The DD Ombuds comments on Washington Administrative Code (WACs). The DD Ombuds provided comments on WACs related to DDA services. WAC comments included: Intermediate care facilities for individuals with intellectual disabilities ICF/IDD appeal rights: The DD Ombuds gave WAC comments concerning ICF/IDD appeal rights. Comments identified areas for the need for increased clarity, the need for definitions and timelines. Psychotropic medication: the DD Ombuds gave comments on WACs concerning psychotropic medication. Concerns expressed about the WAC not being person-centered, that references to documenting behaviors were removed, that the provider is not required to report change in a person’s behavior to the prescribing health care provider and concern a person on psychotropic medication will have less access to positive behavior supports. These WACs are still under consideration. Overnight planned respite: The DD Ombuds gave comments on the overnight planned respite WACs. Concerns included clarity, timelines, adherence to person centered principles, and methods for monitoring quality of services provided. Client Rights: The DD Ombuds worked with self-advocates and the legislature to pass a Client Rights statute. DDA began pre-WAC stakeholder work at the end of SFY 2020. The DD Ombuds comments recommended the WACs be written in planning language and that no existing right be diminished.

Waiver Amendments: The DD Ombuds also commented on waiver amendments: Individual and Family Services Waiver - The DD Ombuds gave comments to add clarity in the definition of assistive technology. DD Ombuds comments on Home and Community Based Services (HCBS) Waivers concerned transparency and accessibility of the stakeholder process; Access to institutional level of care; Quality assurance and support for Case resource managers; Communication access for individuals with Limited English Proficiency; Access to state plan services, especially mental health services; Lack of coordination to obtain medical necessary services for individuals under age 21; Informed consent for use of restraints; and Cost limits and caps on CIIBs waiver.

Office of Developmental Disabilities Ombuds Annual Report SFY 2020

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 monitor and report on services to persons with developmental disabilities.

Background

The Washington State Department of Commerce awarded the non-profit, Disability Rights Washington, through competitive bid, the contract to administer the DD Ombuds program. Disability Rights Washington created a separate program to fulfill the contract. The DD Ombuds contract began on May 25, 2017. Since then, the Office of the Developmental Disabilities Ombuds has delivered DD Ombuds services in the state of Washington.

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 55,360 enrolled clients as of June 2020. Of the enrolled clients, 27,784 were receiving services. DSHS and other state agencies also administer services to children and adults with developmental disabilities. The DD Ombuds has the duty and authority to investigate complaints, monitor, and report on these services and make recommendations to State agencies, the Governor and the Legislature.

Powers and duties of the DD Ombuds

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

- Provide information on the rights and responsibilities of people receiving developmental disabilities administration 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, the 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 2020

State appropriation \$643,000

Commerce administrative costs \$32,150

DD Ombuds contract budget is \$610,850

Staffing - The Office of DD Ombuds operates with 5.5 full-time equivalent staff in Olympia, Seattle and Spokane offices.

State DD Ombuds - Betty Schwieterman - 1 FTE (Seattle)

Region 1 DD Ombuds and Legal Counsel - Lisa Robbe - 1 FTE (Spokane)

Region 2 DD Ombuds - Kathleen Chavey-Reynaud - 1 FTE (Seattle)

Region 3 DD Ombuds - Noah Seidel - 1 FTE (Olympia)

Self-Advocacy Educator - Tim McCue - 1 FTE (Olympia)

Office Assistant - Beth Beeman - .5 FTE (Seattle)

DD Ombuds Program Approach

The Legislature considered a proactive approach to DD Ombuds services. They recognized some people with developmental disabilities are isolated and do not have the resources to reach out for assistance. Therefore, the DD Ombuds' approach is to provide services and take complaints in person as much as possible. This had to change in February with the revelation of the COVID 19 pandemic.

Pre-pandemic, the DD Ombuds visited people where they live or where they receive their services to provide information, listen to their concerns, and help resolve complaints. The DD Ombuds created protocol and began monitoring visits by phone in late spring of 2020. However, many people with developmental disabilities do not use the phone or internet and the DD Ombuds will search for new ways to connect. The DD Ombuds continues to take complaints by phone and through a website complaint form.

The DD Ombuds resolves complaints at the lowest possible level. The DD Ombuds protects choice, autonomy, and ensures people with developmental disabilities have access to advocacy. The 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. The DD Ombuds operates within strict confidentiality protocols.

The DD Ombuds provides information on rights and responsibilities through presentations, trainings, community events, videos, social media and the DD Ombuds website, (www@ddombuds.org.) In the winter of 2020, the DD Ombuds moved trainings and events to virtual platforms. The DD Ombuds and people with developmental disabilities create the publications, videos, and website content.

The DD Ombuds collects information from diverse stakeholders such as self-advocacy groups, parent groups, provider organizations, and others to guide its work.

The DD Ombuds convenes quarterly an advisory committee, whose membership is comprised in majority of people with developmental disabilities. The committee meets in person to review stakeholder input and advise the 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.

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

Priorities

The Washington State Legislature created the DD Ombuds because there are still high rates of abuse and neglect against people with developmental disabilities. All people have the right to be free from abuse and neglect. The 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.

The 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, verbal abuse, neglect, and self-neglect. Other issues are addressed as resources are available.

Objectives

The DD Ombuds delivers person-centered, complaint-based services. The DD Ombuds helps people understand their rights and responsibilities and helps people solve their complaints about their services. The DD Ombuds monitors services and reports concerns to the state and the Legislature. The DD Ombuds has the following objectives:

- Provide information on rights and responsibilities;
- Investigate complaints;
- Resolve issues at the lowest level possible through individual complaint resolution;
- Monitor service delivery and review state institutions, state-licensed facilities, and residences;
- Report annually on DD Ombuds services to people with developmental disabilities to stakeholders, the department, the Governor, and the Legislature;
- Publish reports on systemic issues to the Legislature;
- Affect positive change in services for people with developmental disabilities through recommendations for changes in policy and procedures;

- Develop and recommend a plan for growth to expand the DD Ombuds program based on Long-term Care Ombuds model to include regional Ombuds, paid staff, and a significant volunteer force.

The Work of the DD Ombuds

Information on Rights and Responsibilities

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

- 1. Training, Education and Outreach** - The DD Ombuds reached 8,012 people with information about the DD Ombuds services, trainings on topics such as how to navigate the service systems, self-advocacy and problem solving, and responding to abuse, neglect, and sexual assault through presentations and outreach at 63 events. One event was live-streamed and had 6,000 participants.
- 2. Information and Referral** - The DD Ombuds provided 152 detailed I&R services to people to assist them in resolving their issue. Examples of this type of I&R 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.
- 3. Resource Development** - The DD Ombuds developed resources to inform people with developmental disabilities, their families, service providers, and the community about the DD Ombuds and rights and responsibilities. A tri-fold brochure about DD Ombuds and two DD Ombuds videos are used in presentations and outreach. One video explains the services of the DD Ombuds, and the other covers the importance of self-advocacy. The videos are available on the 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 now available in 8 languages and Braille.
- 4. Website and Social Media** - DD Ombuds website (www.ddombuds.org) posted 28 blog posts from around the state. New this year are two self-advocacy story videos, "Advocate for Your Rights" and "Never Give Up and Keep on Trying." (<https://ddombuds.org/videos/>.) The website also includes information, resources, how to file a complaint, an on-line complaint form, and two videos in 7 languages and ASL. The Office of DD Ombuds website has accessibility features including a built-in read aloud screen. The DD Ombuds also has a social media site with almost 2,200 followers. For the period of July 1st 2019 to June 30th 2020 the website has had 4,973 unique visitors. Those users engaged in a total of 6,150 individual sessions, or individual times they went to the website, with a continued average of 2 page views per session. This culminates in a total of 10,769 total page views.

Complaints

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

Complaints are generated during monitoring visits (in-person and phone) 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. The DD Ombuds receives complaints in-person, by phone calls or through the DD Ombuds on-line complaint form. The DD Ombuds was not able to make as many in-person visits because of the COVID-19 pandemic.

The 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, the 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 the DD Ombuds took action are listed below. The DD Ombuds addresses other issues by providing information or referral services.

Complaints worked on in SFY 2020

SFY 2019 complaints carried over to SYF 2020

Number of complaints pending - 60

New July 1, 2019 through June 30, 2020

Number of complaints opened - 129

Closed July 1, 2019 through June 30, 2020

Number of complaints closed - 162

Pending as of July 1, 2020

Number of complaints pending - 27

This fiscal year the DD Ombuds carried over 60 complaints from SFY 2019, responded to 129 new complaints, resolved/closed 162 complaints and had 27 pending as of June 30, 2020.

The majority of complaints concerned individual care issues (includes access to DDA services and care plan individualized assessments); administration issues (includes discharge/transfer from hospitals and from DSHS funded residential programs); autonomy and exercise of rights (includes dignity/respect, preference, choice and rights, privacy); abuse, sexual abuse, neglect; followed by issues of quality of life and housing.

Complaint locations included: own home, family home, Children's Licensed Staffed Residential home, Adult's home with supported living services, Adult's home with state supported living services, Adult Family Homes, Residential Habilitation Centers, General Hospitals, and Psychiatric Hospitals.

New Complaints (129) in SFY 2020 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, the staff shortage complaint number is low, however staff shortage and staff turnover is well-documented as a problem in residential services. DD Ombuds may not see or hear about staff shortages or high turnover on the particular time/date of their monitoring or phone visits. Another example is abuse and neglect which research shows high rates for people with developmental disabilities and is underreported. The majority of new complaints concerned Access to DDA service; Discharge or Transfer; or Preference, Rights, Choice and Abuse.

Abuse, Neglect, Exploitation - 7 complaints concerning: Physical abuse (1), Sexual abuse (1), Verbal/psychological abuse (2), Neglect (1), Personal safety planning (1), and other abuse, neglect (1).

Access to Information - 1 complaint concerning: Access to complaint or grievance process (1).

Autonomy and Exercise of Rights - 23 complaints concerning: Dignity/Respect (1); Preference, Choice and Rights (14); Guardianship (3); Privacy (1); Response to Complaints (2); and Personal property (2).

Individual Care - 52 complaints concerning: Care plan individualized assessment (5); Physician services (1); Mental health services (3); Access to DDA Services (40); and Healthcare (3).

Quality of Life - 6 complaints concerning: Activities (2), Active integrations into community (1), Meaningful day (1), Transportation (1), and Safety and security (1).

Dietary - 1 complaint concerning: Food service (1).

Environment - 2 complaints concerning: Physical accessibility (1), and Infections control (1).

Administration - 30 complaints concerning: Administrator unresponsive (1), Inappropriate administration (1), and Discharge/transfer planning (28).

Staffing - 1 complaints concerning: Shortage of staff (1).

Housing - 4 complaints concerning: Access/Lack of housing (3), and Accommodations/modifications (1).

Civil/Legal - 1 complaint concerning: Family law (1).

Criminal Legal - 1 complaints concerning: Criminal justice issues (1).

Complaint Resolution - Examples of assistance provided by DD Ombuds.

- 1. Summary of complaint** - The DD Ombuds received a complaint from a family member about a person with developmental disabilities who was at a state institution and wanted to move into the community. The individual moved to Washington from another state where they were receiving services. In Washington they were not able to receive proper in home services resulting in a hospitalization. From the community hospital they were transported to the state institution and placed on the DDA Core Waiver.

Outcome - The DD Ombuds assisted in advocacy for the individual. First on the person's treatment and services in the institution, and then on a transition plan to the community. The individual stayed at the institution for over a year while waiting for community placement. The DD Ombuds helped the guardian understand the transition process and how to find information about community providers. The individual discharged to a community residential setting where they are currently living.

- 2. Summary of complaint** - The DD Ombuds received a complaint about a person with developmental disabilities who was in a community hospital ready to discharge home and receive support from their supported living provider. However, the provider did not think they could support the person anymore with the change in the person's support needs. The individual went back and forth between a nursing home and hospitals for almost a year while waiting for community placement. Staff who worked with the individual attributed the nursing setting to have negative effects on their mental and physical health which they believed resulted in increased hospitalizations.

Outcome - The DD Ombuds met with the individual about what supports they needed to help them live in the community, and where they wanted to live. The person wanted to live in their current community in order to keep their guardian whom they liked and trusted. The DD Ombuds advocated for the person to live where they felt safe and happy, although referral packets were sent statewide because a provider in their region could not be found. Through the Pre-Admission Screening and Resident Review (PASRR) Program and Roads to Community Living processes the person was able to receive a higher provider rate that helped them move into an Adult Family Home near where they were living before the hospitalization. The person is happy to be living in the community of their choice!

- 3. Summary of complaint** - A teenaged client of DDA was receiving residential services. The parents received two weeks' notice that services were terminating. The parents did not feel as though that would give them enough time to get therapeutic and safety equipment in place or secure in-home services. The parents contacted the DD Ombuds to help with a discharge plan.

Outcome - The DD Ombuds arranged a meeting with the family, DDA, the client's remote educator, and doctors and staff from the residential program. The team made a list of everything the client and family would need for a safe discharge. DDA approved and

ordered equipment. The family was connected to Wraparound Intensive Services (WISe). The family had everything in place for the client's discharge home.

- 4. Summary of complaint** - During a monitoring phone call visit, a client of DDA reported pain in his leg and foot. He had not spoken with a doctor yet and did not have any upcoming doctor's appointments. The person's staff were unaware of the problem as well.

Outcome - The client and DD Ombuds spoke to staff together about scheduling a doctor's appointment. The DD Ombuds followed up the next day to see if the appointment had been scheduled, and it had. The DD Ombuds reached out to the client after the doctor's appointment for an update. The client's illness was diagnosed and the client received treatment for their pain.

Summary of Complaint Data - Analysis and Identification of Systemic Issues

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

- Individual care issues which include access to DDA services, care plan assessments, and access to mental health service. The majority of the individual care complaints were about access to DDA services. The DD Ombuds worked at the regional level of DDA to address case manager services. The DD Ombuds has identified access to behavioral supports, access to mental health care, need for increased waiver funding for 14,000 clients waiting for service, and the simplification of the eligibility process as systemic issues to be addressed.
- Administration issues, primarily discharge/transfer. The DD Ombuds continues to assist people who were in a hospital and unable to discharge into community services this fiscal year. The DD Ombuds identified this as a significant systemic issue in 2019, published a report and made specific recommendations to address this issue. DDA began to collect some limited data about people who went to the hospital from supported living services and were then unable to go back home with those services. As a result of the pandemic DDA opened a cottage on the grounds of Rainier to transfer clients who were in hospitals, unable to discharge.
- Autonomy and exercise of rights which include Dignity and Respect, Preference, Choice and Rights, and Personal Property and Funds. The DD Ombuds helped individuals and their families to problem solve with their service providers and their case managers to address these issues. The DD Ombuds identified Preference, Rights, Choice as issues to address systemically.
- Abuse, neglect and exploitation which includes physical abuse, sexual abuse, verbal/psychological abuse, physical abuse between housemates, and personal safety planning. The DD Ombuds worked on complaints regarding physical assault by one roommate against another in residential settings. Lack of, and inadequate response by providers and DDA are of great concern. Assaults are often dismissed as minor and victims are not protected from future attacks. The DD Ombuds has identified this as a systemic

issue for continued attention. The DD Ombuds worked on 1 complaint concerning sexual assault of people with developmental disabilities. The DD Ombuds is concerned we are not learning of abuse allegations since the pandemic. Without in-person meetings there is less opportunity to receive complaints concerning abuse.

- Quality of life which includes activities, integration into the community, meaningful day and transportation. Quality of life issues were also of concern as many people are isolated and want more activities and social engagement. The DD Ombuds helped individuals and their families to problem solve with their service providers and their case managers to increase access to activities and day programs. This issue became more prominent when people had to isolate because of the pandemic.
- Staffing, which are all complaints about shortage of staff. Staff turnover in certified residential settings remains a concern.

Monitoring

The DD Ombuds made 199 monitoring visits across the state this past fiscal year to meet and 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 the provider administration receive information about the DD Ombuds. The DD Ombuds gives out materials that are easy to keep such as refrigerator magnets, door hangers and coasters that have information about the DD Ombuds and client rights. The DD Ombuds observe living conditions, and staff interactions and responsiveness to the residents they support. The DD Ombuds also received complaints, initiated complaints and identified locations for follow up monitoring. Once the pandemic hit the DD Ombuds stopped in-person visits and developed and tested a telephone visit protocol and began phone visits. Phone visits have been successful with people who typically use the phone. During one phone visit the DD ombuds introduced themselves and the person, a DDA client, said “Ombuds! You are with the Ombuds? OMG your magnets are on the fridge and the “Respect the No” door hanger is on my door!”

The DD Ombuds made 199 visits (in person or by phone) to the following types of facilities, residences and programs:

Certified Residential Services Settings - total visits - 141

Group Training Home - 0

Supported Living - 78

Supported Living Client Protection Program (CPP) - 33

State Supported Living - State Operated Living Alternatives (SOLA) - 29

State Supported Living - State Operated Living Alternatives (SOLA) Community Protection - 1

Licensed Residential Settings - total visits - 19

DD Group Homes Adult Family Homes (AFH) - 0

DD Group Homes Assisted Living Facilities (ALF) - 3

Adult Family Homes - 14

Assisted Living Facilities - 0

Nursing Homes - 2

State Residential Habilitation Centers - total visits to cottages or programs - 36

Fircrest Intermediate Care Facility (ICF) - 4

Fircrest Nursing Facility (NF) - 2

Lakeland ICF - 10

Lakeland NF - 6

Rainier - 11

Yakima NF - 3

Licensed Children’s Residential Facilities - total visits - 1

Voluntary Placement Services - 1

Other Private Residence - 1

Own home – 1

Hospitals - total visits - 1

Eastern State Psychiatric Hospital - 0

Western State Psychiatric Hospital - 0

General Hospitals - 1

Total monitoring visits – 199

Systemic Change Outcomes

The DD Ombuds identified several systemic issues through monitoring visits and complaints, and recommended system improvements. As a result the following policy or procedures were changed.

1. Supported Living Clients Rights during Provider Provisional Certification or other Enforcement actions.

Problem: In October 2018, a contracted provider of residential supports was decertified and could no longer provide services for 214 DDA clients. The provider had received two consecutive 90 day provisional certifications before decertification. The clients had not received any notification even though this provider had received numerous health and safety citations. No notice was given and clients were not informed of their rights or their options for a new provider. In addition, DDA agreed to a plan for clients to be transferred to another agency run by the same parent company of the agency that had been decertified. Since then, other providers have received provisional certifications or other enforcement actions.

Outcome: As a result of the DD Ombuds advocacy, DDA sends information about the provisional certifications or other enforcement actions to clients and their legal representatives. The DD Ombuds recommended this notice be required by statute. The legislature passed HB 1651 in 2020 which requires this notice.

2. Supported Living Referral Packet - Privacy Concerns

Problem: The DD Ombuds worked with several people who were concerned about the supported living referral process. Specifically, both clients and parents were concerned the referral process sent a significant amount of private information to prospective providers. The DD Ombuds raised the concerns heard from clients to DDA. Clients did not want all their private medical and service records to go out to providers that will never provide supports to them. The DD Ombuds asked if there was another way for providers to get enough information about the person to know if they could possibly serve the person and then, if the provider was interested in serving the person, they could request additional information.

Outcome: As a result of the DD Ombuds advocacy DDA created a new system to send a cover sheet and then only send additional information if the provider was considering serving the person. This new practice increases privacy protections. The DD Ombuds monitored this practice in SFY 2020. The clients the DD Ombuds were in contact with were pleased with this change.

3. Client rights

Problem: There was no one section of Washington law that spelled out the rights of those who utilize DDA services. Further, people who use DDA services may have different rights depending on where they live and receive services. This was confusing, difficult to navigate, and created barriers to problem solving.

Outcome: The DD Ombuds worked to help create a statute spelling out the rights of people who use DDA services so everyone can easily find them. DDA client rights are now in statute. HB 1651 passed the legislature in the 2020 session. The bill gathered rights which were scattered throughout the Revised Code of Washington (RCW) and Washington Administrative Code (WAC) into one place in the RCWs. It established certain rights for clients of the Department of Social and Health Services Developmental Disability Administration. It specifies the right to participate in service planning, access service and healthcare information, file grievances, privacy, confidentiality, access to advocates, and rights upon termination of services.

4. Emerging Leaders – Access to the legislative process

Problem: Individuals with developmental disabilities did not have a place to discuss issues and topics relating to legislative advocacy in depth. Individuals said they needed a place they could ask questions and take time to fully understand proposed legislation. Individuals new to the legislative process did not have a place to learn about legislative advocacy from their peers and strategize for more effective advocacy at the capitol.

Outcome: Individuals receive the tools and information they need to communicate their position successfully at the legislature, both in meetings and when testifying at hearings.

5. Preservation of Rights - Guardianship Documentation

Problem: The DD Ombuds identified a systemic issue where DDA was not routinely gathering guardianship orders, only the guardianship letters. The guardianship order spells out the scope of guardians' authority. Without the guardianship order DDA would not be

able to determine which decisions the guardian has authority to make on behalf of the person they provide guardianship support.

Outcome: The DD Ombuds worked on several complaints where DDA has acknowledged they need to collect the guardianship orders to determine the scope of the guardians' authority. The DD Ombuds will continue to work on this issue to assure that people under guardianship have their rights upheld and guardians are not making decisions that are the person's to make.

6. Community Protection – “Nothing About Us without Us”

Problem: The DD Ombuds worked on several complaints where the person receiving supports through the community protection program was excluded from their treatment team meetings. The DD Ombuds identified this as a systemic issue. People receiving services are guaranteed the right to participate in their treatment team meeting.

Outcome: DDA acknowledge that some treatment team meetings were happening without the DDA client in attendance and that should not be happening. The DD Ombuds continues to monitor this practice to ensure people are able to attend and participate in their treatment team meetings.

7. Legislative recommendations and outcomes -

- a. House Bill 1651/SB 5843 concerns the rights of clients of the Developmental Disabilities Administration of the Department of Social and Health Services. The DD Ombuds provided suggested bill language, worked with stakeholders and gave testimony. The bill passed this last session. To read the session law visit <https://app.leg.wa.gov/billsummary?BillNumber=1651&Year=2019&Initiative=false> 2SHB 1651 spells out the rights of people who use Developmental Disability Administration services in statute, gathers rights into one place in the RCWs, establishes certain rights for clients, and specifies the right to: participate in service planning, access service and healthcare information, file complaints and grievances, privacy and confidentiality, access to advocates, and rights when services end. The DD Ombuds will be working with DDA and advocates across the state to inform and educate people about their rights and how to advocate for their rights!
- b. SB 6205 is an act relating to preventing harassment, abuse, and discrimination experienced by long-term care workers. The DD Ombuds raised concerns about the tone of the bill, the lack of definitions, potential client abandonment, client privacy, and reporting requirements. The DD Ombuds recommended that DSHS convene the work group rather than L&I, and it should include advocates and self-advocates receiving DDA services. The DD Ombuds worked with stakeholders to improve this bill which did pass. The session law requires home care agencies and the consumer directed employers to establish certain protocols related to employee discrimination and abuse and requires the Department of Social and Health Services to convene a stakeholder work group to recommend best practices for training employers, workers, and service recipients to keep home care settings free from discrimination and abusive conduct.
- c. HB2390 Respectful language. The DD Ombuds supported this bill to revise language in a several statutes to reflect respectful language. This bill passed.

- d. 2SHB 2737 The DD Ombuds supported a bill, which passed, to add an organization representing those with developmental disabilities to the children’s mental health workgroup.
 - e. SB 6040-Concerning the budgeting process for certain state waiver services for individuals with developmental disabilities. The caseload forecast council shall present the number of individuals who are assessed as eligible for and have requested a service through the individual and family services waiver and the basic plus waiver administered by the developmental disabilities administration as a courtesy. The DD Ombuds testified in support of caseload forecasting for certain state waivers in order to understand and fund DDA waivers.
 - f. SB 6287-Concerning guardianships and conservatorships. The legislation would clarify the uniform guardianship act which would include creating supported decision making for people with intellectual and developmental disabilities. The DD Ombuds testified in support of supported decision making as an alternative to guardianship that some people would choose.
- 8. The DD Ombuds comments on Washington Administrative Code (WACs) and Waiver Amendments** - The DD Ombuds provided comments on WACs related to DDA services.
- a. WACs - Intermediate care facilities for individuals with intellectual disabilities ICF/IDD appeal rights: The DD Ombuds gave WAC comments concerning ICF/IDD appeal rights. Comments identified areas for the need for increased clarity, the need for definitions and timelines.
 - b. WACs - Psychotropic medication: the DD Ombuds gave comments on WACs concerning psychotropic medication. Concerns expressed about the WAC not being person-centered, that references to documenting behaviors were removed, that the provider is not required to report change in a person’s behavior to the prescribing health care provider and concern a person on psychotropic medication will have less access to positive behavior supports. These WACs are still under consideration.
 - c. WACs - Overnight planned respite: The DD Ombuds gave comments on the overnight planned respite WACs. Concerns included clarity, timelines, adherence to person centered principles, and methods for monitoring quality of services provided.
 - d. WACS - Client Rights: The DD Ombuds worked with self-advocates and the legislature to pass a Client Rights statute. DDA began pre-WAC stakeholder work at the end of SFY 2020. The DD Ombuds comments recommended the WACs be written in planning language and that no existing right be diminished.
 - e. Waiver Amendments – Individual and Family Services Waiver - The DD Ombuds gave comments to add clarity in the definition of assistive technology.
 - f. Waiver Amendments – Home and Community Based Services (HCBS) Waivers – In March 2020 the DD Ombuds submitted comments regarding the HCBS waiver amendments. Comments concerned transparency and accessibility of the stakeholder process; Access to institutional level of care; Quality assurance and support for case resource managers; Communication access for individuals with limited English proficiency; Access to state plan services, especially mental health services; Lack of coordination to obtain medical necessary services for individuals under age 21; Informed consent for use of restraints; and Cost limits and caps on CIIBs waiver.

Reports on Systemic Issues

Stuck in the Hospital - The DD Ombuds published the [“Stuck in the Hospital”](#) report in December 2018. The report responded to the high volume of complaints the 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 the DD Ombuds received fewer complaints from people stuck in the hospital in SFY2020. However, there still are people stuck in hospitals unable to discharge.

Children and Youth with Developmental Disabilities in Foster Care – The DD Ombuds published [“Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care”](#) in September 2019. During the 2019 legislative session, the Washington State House of Representatives’ Human Services and Early Learning Committee held a work session on youth with developmental disabilities served by the child welfare system. During this work session, a group of advocates articulated serious concerns about how youth with developmental disabilities are being served by the Title IV-E foster care system. The advocates brought concerns about how the lack of DDA-paid services might disadvantage youth with developmental disabilities while they are in Title IV-E foster care placements and while they are transitioning from a foster care setting to an adult residential setting. The advocates brought these concerns to the State Legislature and the public to raise awareness and to ask for a legislative response. The action by the advocacy community prompted the DD Ombuds to look more closely at how children and youth with developmental disabilities are served in the Title IV-E foster care system. The report makes recommendations for the Developmental Disabilities Administration and the Department of Children, Youth and Families to work together to improve services for children and youth with developmental disabilities in foster care. Advocates continue to work on this very important issue.

Office of Developmental Disabilities Expansion Plan

The DD Ombuds proposed in November 2019, an expansion plan is based on the DD Ombuds experience providing services for the past two and a half years, analysis of the LTC Ombudsman Program model and stakeholder input.

Expansion of the 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 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.

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.

The 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. The 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 the next three biennium. Phase one would be to stabilize the certainty of the funding for the program by moving the DD Ombuds budget into the maintenance budget. Then in SFY 2022-2023 a volunteer coordinator, self-advocacy educator and three DD Ombuds are added. Staffing is increase by 3 DD Ombuds and an Office Assistant the next two biennium.

Detailed Recommendations to the Legislature

Recommendations to the Legislature are based on analysis of complaints, monitoring, Developmental Disabilities Ombuds (DD Ombuds) systemic issue identification and reports.

Recommendation 1- Clarify Office of Developmental Disabilities Ombuds Statute

Problem: DDA will only provide the DD Ombuds with contact information for people residing in state-licensed facilities. The DD Ombuds does not have contact information for people receiving residential services in certified settings, or receiving in-home services, or people who are eligible for DDA services but not able to access them. This is not what the legislature intended when they created the DD Ombuds to help prevent abuse and neglect. The DD Ombuds is proposing a statute change to fix this problem and wants to ensure the support of the DD advocacy community.

Currently, the person with developmental disabilities or their legal guardian may not learn about the DD Ombuds unless their DDA Case Resource Manager or their state contracted service provider tells them about DD Ombuds services.

If the DD Ombuds does not have the ability to reach out to people with developmental disabilities receiving state services, people might never learn about the DD Ombuds or how to contact the DD Ombuds if they have a complaint.

Proposal: A statute change is necessary to clarify the legislature intends the DD Ombuds to have access to names and addresses of DDA clients in order to carry out its duties.

Recommendation 2 - Invest 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 ranks 37th in the country for fiscal effort for services for individuals with developmental disabilities according to the 2017 State of the State Report. Staff turnover is close to 50% in residential supported living services, and likely higher since the pandemic. The highest number of complaints the DD Ombuds handles concerned access to DDA services, and discharge/transfer. The DD Ombuds sees a pattern of both children and adults with behavioral supports needs who are unable to access needed services to stay in their own home or at home with a parent. Budget cuts to the service system have been proposed as a result of the pandemic.

Proposals:

- a. Preserve funding for services to children and adults with developmental disabilities.
- b. Mandate caseload forecasting for DDA community supports and services.
- c. Increase direct service workers wages in supported living to reduce turnover and increase retention of well-trained staff.
- d. Address the needs of the 14,000+ 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.

Recommendation 3 - Prevent inappropriate hospitalization of children and adults with developmental disabilities.

Problem: Hospitals are being used as crisis placements for children and adults with developmental disabilities across the state. Since July 2018, the DD Ombuds has worked with over 70 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 an appropriate residential placement in the community. Some individuals with developmental disabilities were taken 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 or by a family-member who could no longer provide the specialized services the person needed. These individuals with developmental disabilities spend weeks or months in a hospital, which is often traumatizing to both the individual and the hospital staff, because DDA cannot locate available residential supports or placement with staff to provide care.

Solution: Make changes to the service system to ensure individuals with developmental disabilities have access to services that prevent inappropriate hospitalization: 1. DDA provide residential services to all eligible clients so people can discharge from hospitals as soon as they are declared ready by medical personnel. 2. DDA provide enhanced crisis and behavior supports in the community to address changing needs and prevent hospitalizations.

Proposals:

- a. Require DDA to expand the data collected about all people with developmental disabilities who are taken to the hospital to find out why people are stuck there. This includes people coming out of residential service settings and private homes.
- b. Expand the number and types of specialized providers. 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 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; Therapeutic mental and behavioral health services; and Medication management
- 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 increased diversion bed, emergency respite or other bed capacity so individuals with developmental disabilities have an appropriate placement available if they experience a crisis and need residential services.

Recommendation 4 - 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 who could be served better. There are concerns about how the lack of DDA-paid services might disadvantage youth with developmental disabilities while they are in Title IV-E foster care placements and while they are transitioning from a foster care setting to an adult residential setting. 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.”](#) The information from other states can be a resource for identifying improvements in Washington’s system for supporting and coordinating services for youth with developmental disabilities in Title IV-E foster care; for creating a smooth and productive transition between Title IV-E foster care and DDA services; and for supporting foster care families who serve children and youth with developmental disabilities.

Solution: Create policy and legislative solutions to any gaps in services experienced by children with developmental disabilities served by Title IV-E foster care in Washington State.

Proposal: The legislature can direct the DDA and DCYF to take the following actions and report back to the legislature with a plan to improve services for children and youth with developmental disabilities.

- a. Medicaid waivers** - Investigate if and how DDA waiver services may improve access to specialized services for youth with developmental disabilities in Title IV-E foster care and/or consistency of services as children and youth move between service settings.
- b. Service Coordination between State Agencies** - Investigate options for better service coordination between DDA and DCYF at both the individual and systemic levels; Create opportunities for cross training between DCYF and DDA case managers.
- c. Screening and Eligibility** - Research and develop protocols for automatic screening for developmental disabilities when a child or youth enters the Title IV-E foster care system; Create a system where identification of developmental disability by DCYF is referred to DDA for application and eligibility determination.
- d. Transition out of Foster Care Services** -
 - i. Solicit policy recommendations from the current workgroup comprised of developmental disabilities and foster care advocates looking at the issues posed by transition from foster care to adult services;
 - ii. Investigate how many months before transition the planning process needs to begin;
 - iii. Ensure all DDA eligible youth are screened for developmental disability and DDA eligibility upon entering the foster care system;
 - iv. Produce caseload forecast of the number of children and youth who will transition out of Title IV-E foster care to DDA services based on data from DDA eligibility assessments;
 - v. Investigate if and how DDA waiver services improves access to specialized services for youth with developmental disabilities in Title IV-E foster care and/or consistency of services as children and youth move between service settings.
- e. New License to Extend Age for Foster Care Homes** - Research possible licensure options for continued placement of youth with developmental disabilities in foster care homes after the

age of 21; Recruit and retain foster care families to provide continued services for youth with developmental disabilities past age 21.

- f. Developmental Disability Certification for Foster Care Homes** - DCYF and DDA develop foster care family training/certification for serving children and youth with developmental disabilities; DCYF recruit, train and retain foster care families to care for children and youth with developmental disabilities.

Recommendation 5 - Identify and close gaps in mental health services for people with developmental disabilities

Problem: The integration of Medicaid health care and behavioral health care has created gaps in mental health services for individuals 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. Both children and adults have been turned away from mental health services because of their developmental disability diagnosis. Adults with developmental disabilities have experienced barriers to access medication management because of provider rules about participation in therapy. DDA clients in crisis often bounce in and out of crisis mental health services, jails and hospital emergency departments. Transitions into DDA services can take months, are disjointed, or do not happen. DDA and the Health Care Authority (HCA) have not identified ways to systematically detect the gaps in mental health services for children and adults with developmental disabilities.

Solution: Create a mental health service system inclusive of people with developmental disabilities. Children and adults with developmental disabilities and co-occurring mental illness are able to access mental health services in all regions of the state and at all levels of care.

Proposal: Support HB 1394 Sec. 10 workgroup generated recommendations regarding proposals to identify and examine current gaps in mental health services for children and adults with developmental disabilities. Examine recommendations from the Children & Youth Behavioral Health Work Group for improvements to services for individuals with developmental disabilities.

Recommendation 6 - Ensure the State Auditor's Office continues performance audits of long-term care training partnership.

Problem: The Washington State Auditor's Office proposed elimination of the mandated performance audits of the long-term care training program on a two year cycle.

Solution: Performance audits are the way the training partnership work is examined on a regular basis.

Proposal: Maintain performance audits of the work of the training partnership and long-term care worker program on a regular basis.

Questions or comments about this report?

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To learn more about the DD Ombuds visit: www.ddombuds.org