Annual Report on Activities SFY 2019
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)

Office of Developmental Disabilities Ombuds

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

November 1, 2019

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 six full time staff, located in three offices, the DD Ombuds responded to 256 new individual complaints and 16 new group complaints. 828 people benefitted from individual and group complaint investigations. We conducted 270 monitoring visits across the state to review facilities, residences, and programs where people with developmental disabilities receive services. We also talked with people across the state about our services, showed our videos about the DD Ombuds and self-advocacy, gave presentations about rights and responsibilities, produced and gave out written materials, made observations, and listened.

We published a report, "Stuck in the Hospital," about people with developmental disabilities who were receiving services, were taken to the hospital, and remain there without a medical need for long periods of time unable to discharge. The report calls for data collection to determine the scope of the problem and makes recommendations for system improvements.

We worked collaboratively with the state to create system change and made recommendations to the Legislature focused on ways to improve the lives of people with developmental disabilities. 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.

We are here to assist people with developmental disabilities, no matter where they live, to resolve their complaints and address abuse and neglect. Thank you for this opportunity to serve and empower people with developmental disabilities.

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 2019).

Policy Recommendations to the Legislature and Governor

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

Recommendation 1. - Secure rights of people who use DDA services

Problem: Currently, there is no one section of Washington law that spells 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 is confusing, difficult to navigate, and creates barriers to problem solving.

Proposal: Spell out the rights of people who use DDA services in statute as proposed in HB 1651 and SB 5843. They establish certain rights for clients of the Department of Social and Health Services Developmental Disability Administration. They specify the right to participate in service planning, access service and healthcare information, file complaints and grievances, privacy, confidentiality, access to advocates, and rights upon termination of services.

Recommendation 2. - 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. Individuals with developmental disabilities spend weeks or months in a hospital, which is often traumatizing to both the individual and hospital staff, because DDA cannot locate available residential supports with staff to provide care.

Proposal: Make changes to the service system to ensure individuals with developmental disabilities have access to services that prevent inappropriate hospitalization:

- **a.** 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.
- **b.** Require DDA to expand the data collected about all people with developmental disabilities who are taken to the hospital.
- **c.** Expand the number and types of specialized providers.
- **d.** Direct DDA to identify and remove barriers to utilization of behavioral support.

Recommendation 3. - 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 that 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."

Proposal: 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.

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.
b. **Service Coordination between State Agencies** - Investigate options for better service coordination between DDA and DCYF at both the individual and systemic levels.
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** -
    - Investigate how many months before transition out of foster care the planning process needs to begin;
    - Ensure all DDA eligible youth are screened for developmental disability and DDA eligibility upon entering the foster care system;
    - Produce caseload forecast of the number of children and youth who will transition out of Title IV-E foster care to DDA services;
    - Investigate if and how DDA waiver services 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.
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 4. - 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.

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. The workgroup is in progress to address children mental health services, adult mental health services, transitions between children and adult mental health services, and linkages between mental health services and DDA services.

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

Problem: The long-term service 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.

Proposals:

1. Mandate caseload forecasting for DDA community supports and services.

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

3. Modify RCW 74.34 to clarify definitions, give authority to APS to share information with law enforcement and some state agencies, and clarify APS authority to share information with DD Ombuds. (DSHS request legislation)
4. Address the needs of the 13,000 clients DDA has identified who asked for services but are waiting by increasing availability of waiver services.

Executive Summary of DD Ombuds work for SFY 2019

Outreach, Training, Education and 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. DD Ombuds staff reached 3,093 people at 108 training and outreach events and provided detailed information and referrals to 172 people. The DD Ombuds produced two videos in 7 languages, and American Sign Language (ASL), a trifold brochure, a door hanger, and developed other educational materials. The DD Ombuds website and social media sites posted 28 blog posts from around the state.

Complaints
This fiscal year the DD Ombuds carried over 16 complaints from SFY 2018, responded to 272 new complaints, resolved/closed 228 complaints and had 60 pending as of June 30, 2019. Sixteen of the new complaints were group complaints. 615 people with developmental disabilities benefitted from group complaint investigations. The majority of complaints concerned individual care issues (includes access to DDA services, care plan assessments, access to mental health service); administration issues (discharge/transfer); autonomy and exercise of

rights; abuse, sexual abuse, neglect; followed by issues of quality of life and shortage of staff. Total number of people benefitting from individual and group complaints: 828.

Monitoring

The DD Ombuds made 270 monitoring visits across the state to meet individuals with developmental disabilities and review facilities, residences, and programs. The DD Ombuds made 204 monitoring visits to certified residential service settings, 17 monitoring visits to licensed residential settings, 40 visits to cottages or programs at Residential Habilitation Centers, 1 visit to licensed children's residential setting, 2 monitoring visits to parent or own home, and 6 visits to psychiatric of general hospitals. The DD Ombuds observed living conditions, staff interactions and responsiveness to the residents they support. The DD Ombuds also received complaints, initiated complaints, and identified locations for follow-up monitoring.

Summary of Systemic Issue Reports

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. 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 specific recommendations to the State and the Legislature to address this tragic issue.

Children and Youth with Developmental Disabilities in Foster Care **-** Work on "Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care" began in 2019. During the 2019 legislative session, 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 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 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 Ombuds Annual Report SFY 2019

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 48,422 enrolled clients as of June 2019. Of the enrolled clients, 34,935 were receiving services. It is estimated by DDA almost 13,500 clients are waiting for 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 2019

State appropriation $643,000
Commerce administrative costs $32,150
DD Ombuds contract budget is $610,850
Other revenue - DRW contribution $54,297
Total SFY 2019 DD Ombuds revenue $665,147

Staffing - The Office of DD Ombuds operates with 6 full-time equivalent staff in Olympia, Seattle and Spokane offices.
State DD Ombuds, Betty Schwieterman - 1 FTE
Region 1 DD Ombuds - Lisa Robbe - 1 FTE
Region 2 DD Ombuds - Andrea Kadlec - .5 FTE
Region 2 DD Ombuds and Legal Counsel - Beth Leonard - 1 FTE
Region 3 DD Ombuds - Noah Seidel - 1 FTE
Self-Advocacy Educator - Tim McCue - 1 FTE
Office Assistant - Kathleen Chavey-Reynaud - .5 FTE

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.

The DD Ombuds visits people where they live or where they receive their services to provide information, listen to their concerns, and help resolve complaints. The DD Ombuds also takes complaints by phone and through a website complaint form, but recognizes many people with developmental disabilities do not have access to the phone or internet. The DD Ombuds operates within strict confidentiality protocols.

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 provides information on rights and responsibilities through presentations, trainings, community events, videos, social media and the DD Ombuds website,

(www@ddombuds.org.) 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.

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 3,093 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 108 events.

2. **Information and Referral** - The DD Ombuds provided 172 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.

4. **Website and Social Media** - DD Ombuds website (www.ddombuds.org) posted 28 blog posts from around the state. The website also includes information, resources, how to file a complaint, an on-line complaint form, and two videos in 7 languages and ASL (https://ddombuds.org/videos/). 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 over 2,100 followers. The DD Ombuds website had 4,029 unique visitors viewing and average of 2.5 pages per visit.

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 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. Complaints are made in-person, by phone calls or the DD Ombuds on-line complaint form.

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 2019
SFY 2018 complaints carried over to SYF 2019
Number of complaints pending - 16
- 12 complaints for individuals
- 4 complaints for groups

New July 1, 2018 through June 30, 2019
Number of complaints opened - 272
- 256 complaints for individuals
- 16 complaints for groups (group complaints affecting 495 people).

Closed July 1, 2018 through June 30, 2019
Number of complaints closed - 228
- 213 complaints for individuals
- 15 complaints for groups (group complaints affected 615 people).

Pending as of July 1, 2019
Number of complaints pending - 60
- 55 complaints for individuals
- 5 complaints for groups (group complaints affecting 109 people)

This fiscal year the DD Ombuds carried over 16 complaints from SFY 2018, responded to 272 new complaints, resolved/closed 228 complaints and had 60 pending as of June 30, 2019.

Sixteen of the new complaints were group complaints. 615 people with developmental disabilities benefitted from group complaint investigations. The majority of complaints concerned individual care issues (includes access to DDA services, care plan assessments, access to mental health service); administration issues (discharge/transfer); autonomy and exercise of rights; abuse, sexual abuse, neglect; followed by issues of quality of life and shortage of staff.

Total number of people benefitting from individual and group complaints closed/resolved in SFY 2019: **828**.

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

New Complaints 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 staff shortage complaint number is lower, 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 visits.

Abuse, Neglect, Exploitation - 29 complaints concerning: Physical abuse (3), Sexual abuse (4), Verbal/psychological abuse (1), Neglect (8), Individual-to-Individual physical abuse (4), Personal safety planning (3), Lack of response by authorities (1) and other abuse, neglect (5).

Access to Information - 5 complaints concerning: Access to own records (2), Access to Ombuds (1), Access to complaint or grievance process (1), and other access to information (1).

Autonomy and Exercise of Rights - 41 complaints concerning: Dignity/Respect (8); Preference, Choice and Rights (11); Care planning (1); Guardianship (2); Privacy (3); Retaliation (1); Personal funds (8); Personal property (3); Representative Payee (1); other autonomy and rights (2).

Individual Care - 76 complaints concerning: Care plan individualized assessment (6); Active treatment (2); Medications (3); Physician services (1); Dental services (1); Access to communication (3); Mental health services (5); Access to DDA Services (38); Access to other state services (7); Healthcare (4), Other individual care (6).

Restraints and Seclusion - 1 complaint concerning: Other restraint, seclusion, confinement (1).

Quality of Life - 11 complaints concerning: Activities (3), Active integration into community (3), Meaningful day (2), Transportation (2), and Individual conflict (1).

Dietary - 1 complaint concerning: Therapeutic diet (1).

Environment - 6 complaints concerning: Cleanliness/Housekeeping (3), Equipment/Buildings (2), and Furnishings/Storage (1).

Administration - 67 complaints concerning: Administrator unresponsive (1), Inappropriate administration (1), Discharge/transfer planning (63), and Healthcare administration (2).

Staffing - 7 complaints concerning: Shortage of staff (7).

Education - 2 complaints concerning: Special education (2).

Employment - 5 complaints concerning: Division of Vocational Rehabilitation (1), Employment discrimination (1), Reasonable accommodation (2), other employment (1).

Housing - 9 complaints concerning: Access/Lack of housing (6), Accommodations/modifications (1), and Landlord/tenant (2).

Civil/Legal - 8 complaint concerning: DDA eligibility/denial of services (6); Family law (2).

Criminal Legal - 4 complaints concerning: Criminal justice issues (4).

The majority of complaints concerned individual care issues (includes access to DDA services, care plan assessments, access to mental health service); administration issues (discharge/transfer); autonomy and exercise of rights; abuse, sexual abuse, neglect; followed by issues of quality of life and shortage of staff.

Complaint Resolution - Examples of assistance provided by DD Ombuds.

1. **Summary of complaint -** A supported living agency stopped providing residential support services to 65 people after being put on provisional certification and cited for their pattern of non-compliance with applicable laws and regulations. These violations concerned serious health and safety issues such as inadequate staffing and supervision of clients; failure to protect clients from verbal and mental abuse; restricting clients' access to food; failure to take clients to the medical appointments; failed medication management; and failure to call emergency medical services.

   People who received services needed to transition to new providers for their care. Many of these same people had been served by an agency that was decertified. Both agencies were part of the same parent company. The DD Ombuds was again concerned people did not have information about the health and safety citations to protect themselves or have information they needed to make an informed decision about their services.

   Outcome - The DD Ombuds wrote to DDA to ask that: All affected clients and their legal representatives receive information on provisional certification and process; All affected clients have the information necessary to make an informed choice about their supported living provider, including timeline and process for changing providers; DDA ensure new supported living providers are available for affected clients in the homes they currently occupy with attention to keeping current housemates and current staff if desired; DDA create a new Quality Assurance approach that can adequately assess the quality and safety of services to DDA clients.

The DD Ombuds visited the affected clients in their homes to gather information about how or if they were informed of the citations and process for choosing a new provider. The DD Ombuds answered questions, explained DD Ombuds services and took complaints from residents, staff, and guardians. The DD Ombuds took concerns to DDA and advocated for DDA to fully inform everyone involved about the provider status and client rights. DDA increased their efforts to provide information and notify clients and their guardians about their rights and service options. DDA also worked with the provider community to increase the number of providers available to step in and provide services. The DD Ombuds continues to follow up with people affected by this event.

2. **Summary of complaint -** A mother contacted the DD Ombuds after believing there was incorrect information about her daughter's extensive medical and support needs in her daughter's care plan. The daughter lives at home with the mother and receives her care support from the mother and an individual provider. The mother was having a difficult time connecting with the assigned DDA Case Resource Manager (CRM) to correct the information and discuss what other services could be available.

   Outcome - The DD Ombuds met with the mother and daughter to learn about what was incorrect in the care plan and what they would like to change moving forward. The DD Ombuds worked with the mother and the DDA supervisor to have the daughter moved to a case manager with a smaller caseload who can meet with the family more often. Once that was set up, the DD Ombuds coordinated a meeting with the CRM and the family to update the language in the care assessment and answer questions about DDA services. The information in the care assessment was updated and the CRM was able to provide information about other services the daughter can use.

3. **Summary of complaint -** The DD Ombuds met a young woman while on a monitoring visit to supported living. The young woman talked with the DD Ombuds about her extreme dissatisfaction with her provider and her desire to live in a single occupancy household instead of a group household. She was having difficulty communicating her desires to her provider and DDA case manager and was feeling overwhelmed with the process of moving households, transferring her housing voucher, and looking for a new provider.

   Outcome - The DD Ombuds assisted the young woman in making a list of tasks that needed to be accomplished to reach her goal of moving to a single occupancy apartment and changing providers. The DD Ombuds helped her communicate these tasks to her provider and to her DDA case manager and helped the young woman confirm her provider and case manager would assist with the tasks. The young woman is currently living in a single occupancy apartment with a new provider.

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 13,000 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 has assisted over 50 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, published a report and made specific recommendations to address this issue.

- 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.

- 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 several 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 4 complaints concerning sexual assault of people with developmental disabilities. The DD Ombuds is reviewing DDA policies and training on response to sexual assault and will make recommendations.

- 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. The DD Ombuds will monitor this issue.

- Staffing, which are all complaints about shortage of staff. The DD Ombuds helped each individual with their complaints, and identified if these could stem from staff training issues or staff turnover. The DD Ombuds worked with DDA to improve direct service worker training. Staff turnover in certified residential settings remains a concern.

Monitoring

The DD Ombuds made 270 monitoring visits across the state this past fiscal year to meet 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 received information about the DD Ombuds. The DD Ombuds observed 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.

During the last quarter of the fiscal year 2018, a large supported living contractor was decertified. The DD Ombuds focused monitoring visits to meet with people who had received service from the decertified provider. The DD Ombuds continued this work into SFY 2019. The DD Ombuds checked to see if people had information about the reasons for the decertification, had received a choice of new provider, and if people had any complaints about their services. The DD Ombuds continues to check with people affected by the decertification about their satisfaction with current services or desire to change providers. Another provider serving 65 people gave up its contract after being notified of provisional certification. The DD Ombuds visited people affected to provide information and to take any complaints. The DD Ombuds visited 170 residences were supported living services were delivered. The DD Ombuds also focused monitoring visits at Fircrest and Rainier as both facilities failed the certification process.

The DD Ombuds made 270 visits to the following types of facilities, residences and programs:

Certified Residential Services Settings - total visits - 204
Group Training Home - 0
Supported Living - 170
Supported Living Client Protection Program (CPP) - 28
State Supported Living - State Operated Living Alternatives (SOLA) - 5
State Supported Living - State Operated Living Alternatives (SOLA) Community Protection - 1

Licensed Residential Settings - total visits - 17
DD Group Homes Adult Family Homes (AFH) - 3
DD Group Homes Assisted Living Facilities (ALF) - 1
Adult Family Homes - 9
Assisted Living Facilities - 1
Nursing Homes - 3

State Residential Habilitation Centers - total visits to cottages or programs - 40
Fircrest Intermediate Care Facility (ICF) - 8
Fircrest Nursing Facility (NF) - 5
Lakeland ICF - 2
Lakeland NF - 1
Rainier - 22
Yakima NF - 2

Licensed Children's Residential Facilities - total visits - 1
Enhanced Respite Children & Youth
Other Private Residence - 2

Hospitals - total visits - 6
Eastern State Psychiatric Hospital - 1
Western State Psychiatric Hospital - 3
General Hospitals - 2

Total monitoring visits - 270

Systemic Change Outcomes

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

1. **Residential Service Provider Training**
   Problem: In SFY 2018, as the DD Ombuds staff visited people who receive residential services, we observed many instances where the staff went into bedrooms without knocking, spoke over or for the person they support, talked about the person in front of them as if they were not present, and other instances of disrespect and consideration of privacy. The DD Ombuds wondered how the provider training addressed these issues, reviewed the core training curriculum, created a list of concerns, and approached DDA with those concerns.

   Outcome: Developmental Disabilities Administration was very responsive to the DD Ombuds concerns. DDA agreed to revamp the residential provider training. The DD Ombuds participates in the workgroup DDA formed to review and update the entire curriculum.

2. **Supported Living Clients Rights During Provider Decertification**
   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. In addition another program run by the same company was on the verge of decertification and gave up its contract to serve 65 people.

   Outcome: The DD Ombuds visited the majority of the clients in their homes and talked with staff, guardians, and DDA case managers to gather information, concerns and complaints. The DD Ombuds sent recommendations to DDA to ensure all affected clients and their legal representatives received clear information about the reasons for the decertification, meaningful opportunity to choose a new provider, and staff training to avoid any continued health and safety concerns. DDA sent additional information about the decertification including the decertification letter to clients and guardians, put in place a quality assurance system to work with the provider to address health and safety issues, and agreed to notify clients and their legal representative when a provider received a provisional certification. DDA now sends notice when there is a provisional certification. The DD Ombuds recommends this notice be required by statute.

3. **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: 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.

4. **Rainier Resident Moves**
   Problem: DDA planned to move 40-60 people out of Rainier Residential Habilitation Center in a short period of time.

   Outcome: The DD Ombuds met with DDA, DD advocates and the Long Term Care Ombuds to hear DDA's plan for the moves. The DD Ombuds worked with the Long Term Care Ombuds to co-create a plan for Ombuds services for the residents moving to nursing homes. The DD Ombuds and Long Term Care Ombuds provided resources to DDA about successful transitions and mitigation of transfer trauma. The DD Ombuds met with clients and family members to provide information about rights and referrals to legal services.

5. **Legislative recommendations and outcomes**

a. Safe egress in Adult Family Homes. The DD Ombuds provided suggested language to state agency representatives who were drafting language for an agency request legislation. Comments included to use clear and understandable language and to avoid words which may be disrespectful. Some suggestions were incorporated into the bill.

b. Senate Bill 5483 An Act improving services for individuals with developmental disabilities. The DD Ombuds provided information to the sponsors of this bill which is based on the DD Ombuds report "Stuck in the Hospital." A small section of this bill was included in HB 1394.

c. House Bill 1394 concerned the community facilities needed to ensure a continuum of care for behavioral health patients. DD Ombuds provided language for a section of this bill that established a workgroup to make recommendations about ways to address the mental health needs of children and adults with developmental disabilities. This bill passed.

d. 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 did not pass this last session because of a fiscal note. The DD Ombuds and DDA continue to work together on the bill language.

e. Senate Bill 5359 concerns funding investigations to protect individuals with disabilities in the supported living program. The DD Ombuds gave testimony supporting this bill which passed. DSHS will collect certification fees which must be used by DSHS to conduct complaint investigations in certified residential services and supports programs.

6. **The DD Ombuds comments on Washington Administrative Code (WACs) -** The DD Ombuds provides comments on WACs related to DDA services.

a. Core and Community Protection Waiver Comments: The DD Ombuds recommended: That the waivers be amended so the tiered rate system can easily be adjusted when a participant's needs change without causing them to lose their home or provider; and that a

rate be developed that includes placement protections for waiver participants. For example, if a client is set at a rate that includes placement protections, providers must accept them when they are referred for services and cannot terminate services to the participant unless certain conditions are met. Placement protections would create stability for the waiver participants and encourage the service system to be responsive to each participant's individual and changing needs without requiring a change in their home or service provider.

b. Changes to Group Training Home WACs: The DD Ombuds gave extensive written and verbal comments to propose WACS changing the way group training homes are regulated. Comments included concerns about resident rights, tenant rights, and reasonable accommodations.

c. Intermediate care facilities for individuals with intellectual disabilities ICF/IDD appeal rights: The DD Ombuds gave pre-WAC comments concerning ICF/IDD appeal rights. Comments identified areas for the need for increased clarity, the need for definitions and timelines.

Reports on Systemic Issues

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. Most of these individuals were Developmental Disabilities Administration (DDA) clients who had been receiving residential services prior to their 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.

Children and Youth with Developmental Disabilities in Foster Care **-** Work on "Improving Services for Youth with Intellectual/Developmental Disabilities in Foster Care" began in 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.

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. - Secure rights of people who use DDA services

Problem: The highest number of complaints handled by the DD Ombuds (32) concerned autonomy and exercise of rights. Current law sets out rights for people with developmental disabilities. However, many people with developmental disabilities, service providers, and family members do not know all of these rights or where to find them in the law. Currently, there is no one section of Washington law that spells 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 is confusing, difficult to navigate, and creates barriers to problem solving. Also, people do not currently receive information about enforcement actions taken against their providers.

Solution: Create a statute that spells out the rights of people who use DDA services so everyone can easily find them. Equalize rights between residential settings so everyone that uses DDA services has the same rights and protections no matter where they live.

Proposal: Spell out the rights of people who use DDA services in statute as proposed in HB 1651 and SB 5843. These bills gather rights which are currently scattered throughout the Revised Code of Washington (RCW) and Washington Administrative Code (WAC) into one place in the RCWs. They establish certain rights for clients of the Department of Social and Health Services Developmental Disability Administration. They specify the right to personal power and choice, participate in service planning, access service and healthcare information, file complaints and grievances, privacy, confidentiality, access to advocates, and rights upon termination of services.

Recommendation 2. - 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 50 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 3. - 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** -
    - 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;
    - Investigate how many months before transition the planning process needs to begin;
    - Ensure all DDA eligible youth are screened for developmental disability and DDA eligibility upon entering the foster care system;
    - 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;
    - 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 4. - 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. The workgroup is in progress to address children mental health services, adult mental health services, transitions between children and adult mental health services, and linkages between mental health services and DDA services. DDA, HCA and Department of Children Youth and Families, based on gaps identified through current data and stakeholder input, develop an implementation plan with measurable action steps and timeline to assure access to mental health services by children and adults with developmental disabilities.

Recommendation 5. - 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 close to 50% in residential supported living services. The highest number of complaints the DD Ombuds handles concerned access to DDA services, and discharge/transfer. A supported living provider who supported 214 individuals was decertified for health and safety reasons in 2018 and another that served 65 people went out of business after being cited for health and safety violations. The DD Ombuds sees a pattern of both children and adults with behavioral supports needs unable to access needed services to stay in their own home or at home with a parent.

Solution: Complete Washington State's investment in the long term community support system by addressing the needs of people with developmental disabilities.

Proposals:

a. Mandate caseload forecasting for DDA community supports and services.
b. Increase direct service workers wages in supported living to reduce turnover and increase retention of well-trained staff.
c. Modify RCW 74.34 to clarify definitions, give authority to APS to share information with law enforcement and some state agencies, clarify APS authority to share information with DD Ombuds, and clarify definitions. (DSHS request legislation)
d. Address the needs of the 13,000 clients DDA has identified who asked for services but are waiting by increasing availability of waiver services.

Questions or comments about this report?

Contact: Betty Schwieterman, State Developmental Disabilities Ombuds
Office of Developmental Disabilities Ombuds
betty@ddombuds.org 833.727.8900 ext. 209
To learn more about the DD Ombuds visit: www.ddombuds.org