



Office of
**Developmental
Disabilities
Ombuds**

Annual Report on Activities SFY 2018

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

November 1, 2018

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

With six full time staff, located in three offices, the DD Ombuds responded to 130 individual complaints and 17 group complaints. 345 people benefitted from individual and group complaint investigations. We conducted 348 monitoring visits across the state to review facilities, residences and programs where people with developmental disabilities receive services. We talked with people about our services, showed our DD Ombuds videos, gave presentations, produced and gave out written materials, made observations, and listened.

We published a report about people with developmental disabilities who lose their housing because crisis prevention and response services are not available, or easily accessed, and made recommendations for system improvements.

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.

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

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 work of the DD Ombuds for state fiscal year (SFY 2018) is below, followed by a summary of the DD Ombuds recommendations to the Governor and Legislature.

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 2,129 people at 106 training and outreach events, and provided detailed information and referrals to 43 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 21 blog posts from around the state.

Complaints

This fiscal year the DD Ombuds responded to 130 new complaints for 82 people, resolved/closed 114 complaints and had 16 pending as of June 30, 2018. Seventeen (17) of the new complaints were group complaints. 263 people with developmental disabilities benefitted from group complaint investigations. The majority of complaints concerned autonomy and exercise of rights, followed by issues with individual care, abuse, neglect, and then quality of life. Total number of people benefitting from individual and group complaints: 345.

Monitoring

The DD Ombuds made 348 monitoring visits across the state to meet individuals with developmental disabilities and review facilities, residences, and programs. The DD Ombuds made 180 monitoring visits to certified residential services, 117 monitoring visits to licensed residential settings, 48 visits to cottages or programs at Residential Habilitation Centers, and 2 monitoring visits to children's voluntary placement. 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

The DD Ombuds in May, 2018 published a report [“Diverting Crisis - Maintaining housing and supports for people with developmental disabilities”](#). This report identified gaps in the developmental disabilities service system and recommended changes to benefit people with developmental disabilities. Specifically, this report identified situations where adults with developmental disabilities lost housing because there were no, or not enough, support services available to keep them in their home after physical, behavioral or mental health crisis.

Summary of Outcomes for Systemic Change

The DD Ombuds identified several systemic issues through monitoring visits and complaints, and recommended system improvements. As a result, policy or procedures were changed. DDA revised its core training for direct service workers, removed outdated and demeaning videos from the training and created a workgroup of DDA clients and providers to further review and revise training. Also, DDA changed its practices to better inform clients and their legal representatives of rights and choices when a provider receives a provisional certification.

Summary of systemic issues identified for continued work include:

- Staff shortages and staff turnover in certified residential settings;
- Access to behavioral supports, access to mental health care and simplification of the eligibility process;
- Access to activities and social engagement;
- Abuse and neglect, especially procedures for handling 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. Also, investigate procedures for handling sexual assault.)

Recommendations to the Legislature

Recommendation 1. – 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 legislatively-mandated workgroup with specific duties and accountability to identify and examine current gaps in mental health services for children and adults with developmental disabilities. The workgroup must 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 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.

Proposals: Continue investment in the long-term care system by addressing the needs of people with developmental disabilities.

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

2. 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 modify abuse registry structure. (Department of Social and Health Services ((DSHS)) request legislation)
3. Fund investigations to protect individuals with disabilities in the supported living program. (DSHS request legislation)
4. Direct DDA to identify and remove barriers to utilization of behavioral support, such as in-home technical assistance and consultation, for children and adults who reside with parents.

Recommendation 3. – Secure rights of people who use DDA services

Problem: 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, nor where to find them in the law. Further, people who use DDA services may have different rights depending on where they live and receive services.

Proposal: Spell out the rights of people who use DDA services in statute. Gather rights which are currently scattered throughout the Revised Code of Washington (RCW) and Washington Administrative Code (WAC) into one place in the RCWs. Equalize the timeline for notice of termination of residential services. Provide written notice to clients when a provider receives provisional certification or is decertified.

Include the following rights:

Right to Personal Power and Choice. Right to be free from any kind of abuse or punishment; the right to be free from unnecessary medication, restraints and restrictions; and the right to make choices about your life.

Right to Participate in Service Planning Processes. Right to be present, understand and give input on service plans written by DDA and providers and the right to have your visions for a meaningful life and your goals included in the planning process.

Right to Access Information about Services and Healthcare. Right to possess a full copy of all your current service plans and the right to receive prompt notice of any enforcement action by the state against your provider or place that you live.

Right to Make Complaints, Grievances, and Appeals. Right to appeal any decision by DDA; the right to submit grievances to your provider about your services or other concerns.

Right to Privacy and Confidentiality. Right to personal privacy and confidentiality of your personal and other records; the right to privacy in your communications.

Rights during Discharge, Transfer, and Termination of Services. Right to not be discharged, transferred, or have your services terminated except under specific circumstances; the right to adequate notice of discharge, transfer or termination of services.

Right to Advocates. Right to receive information from agencies acting as client advocates, and the opportunity to contact these agencies.

Office of Developmental Disabilities Ombuds Annual Report SFY 2018

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 provides services and programs to people with developmental disabilities who live in Washington State. According to DDA data, there were 50,283 enrolled clients as of June 2018. Of the enrolled clients, 27,399 were receiving services. DDA administers programs to assist children and adults with developmental disabilities and their families to obtain services and supports based on individual assessments, needs, and preferences. DSHS and other state agencies also administer services to children and adults with developmental disabilities. The DD Ombuds has the 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 2018

State appropriation \$643,000

Commerce administrative costs \$32,150
 DD Ombuds contract budget is \$610,850
 Other revenue - DRW contribution \$43,198
 Total SFY 2018 DD Ombuds revenue \$654,048

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 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. A 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 2,129 people with information about the DD Ombuds services, how to navigate the service systems, and problem solving through presentations and outreach at 106 events.
- 2. Information and Referral** – The DD Ombuds provided detailed I&R services to 43 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 new 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 were completed. 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 (<https://ddombuds.org/videos/>) 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 21 blog posts from around the state. The website also includes information, resources, an on-line complaint form, and 2 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 over 2,100 followers. Google returns roughly 2,370 results for “Developmental Disabilities Ombuds” and 462 “DD Ombuds” results. Major outlets have reported on or mentioned the Ombuds: Informing Families, Resource Talk, Trillium, Arc of Washington, Resource House, Northwest Autism Center, Walla Walla Valley Disability Network, and PC2.

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 through 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.

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 practice, 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.

Complaint data

This fiscal year, the DD Ombuds responded to 130 new complaints for 82 people, resolved/closed 114 complaints, and had 16 pending as of June 30, 2018. Seventeen (17) of the new complaints were group complaints, meaning they concerned an issue affecting a group of 2 to 10 people with developmental disabilities who lived in a facility or residence. However, one group complaint concerned 214 people who were receiving services from a Supported Living provider who lost their certification. Total number of people with developmental disabilities benefiting from group complaint investigations: 263. Total number of people benefitting from individual and group complaints: 345.

Complaint locations included family home, own home, Supported Living, State Supported Living, Adult Family Homes, Residential Habilitation Centers, General Hospitals, and Psychiatric Hospitals.

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 low, however staff shortage and 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.

Complaints concerned people with the following issues:

Abuse, Neglect, Exploitation - 14 complaints concerning: Physical abuse, Sexual abuse, Verbal/psychological abuse, Neglect, Individual-to-Individual physical abuse, and Lack of response by authorities.

Access to Information - 9 complaints concerning: Access to own records, Access to visitors, Access to Ombuds, Access to medical information, and Access to complaint or grievance process.

Autonomy and Exercise of Rights – 32 complaints concerning: Dignity, Respect, Preference, Choice and rights, Sexual rights, Care planning, Guardianship, Privacy, Personal funds, and Personal property.

Individual Care – 22 complaints concerning: Injuries, Care plan individualized assessment, Active treatment, Medications, Personal hygiene, Assistive devices or equipment, Access to communication, Mental health services, Access to DDA Services, Healthcare, Other.

Restraints and Seclusion - 3 complaints concerning: Seclusion/isolation, Other restraints, seclusion or confinement.

Quality of Life – 14 complaints concerning: Activities, Active integration into community, Meaningful day, Transportation, Social engagement, Safety and security.

Dietary – 7 complaints concerning: Food service, Snacks and meal times, Other dietary.

Environment – 9 complaints concerning: Cleanliness, Housekeeping, Equipment/Buildings, Laundry, Odors, Space for activities, dining, Other environment.

Administration – 9 complaints concerning: Administrator unresponsive, Inappropriate administration, and Discharge/transfer planning.

Staffing – 3 complaints concerning: Shortage of staff

Education – 1 complaint concerning: Early childhood education

Employment – 2 complaints concerning: Employment discrimination, Other employment

Housing – 4 complaints concerning: Access/Lack of housing, Rental denial/termination, Other housing.

Civil/Legal – 1 complaint concerning: DDA eligibility/denial of services

Criminal Legal – 0 complaints

Complaint Resolution – Examples of assistance provided by DD Ombuds.

- 1. Summary of complaint** - A supported living agency was decertified for serious health and safety violations and could no longer provide residential support services to 214 people in King, Spokane, and Yakima counties. People who received services, families, guardians, and staff were not informed about the health and safety violations which lead to decertification. DDA allowed another agency, managed by the same parent company as the decertified provider, to begin serving people from the decertified agency. Many of the same staff and management staff remained in place. The people being served, their families and staff were told there was a “name change”. The DD Ombuds was concerned people did not have information about the health and safety citations to take action to protect themselves or information they needed to make an informed decision about their services.

Outcome - The DD Ombuds visited the majority of the 214 people affected in their homes to gather information about how or if they were informed of the decertification. The DD Ombuds gave people copies of decertification documents, explained the decertification, and explained DD Ombuds services to 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. The DD Ombuds also provided information and referral, took complaints from residents, staff, and guardians, and linked people who wanted to move, change providers, or find resources related to the disruptions and traumatic events to information and advocacy. Once people understood their options, many chose to change providers. The DD Ombuds continues to follow up with people affected by the provider decertification.

- 2. Summary of complaint** - A mother contacted the DD Ombuds after her adult son’s nursing hours were cut drastically. Her son lives with her and receives in-home nursing services and other services. The mother was extremely concerned her son would be left without the support he needs to live in the community. While continuing to care for her son, including providing night-time coverage, the mother navigated the systems to try to informally resolve the problem. She had taken many steps to avoid an administrative hearing. When she called the DD Ombuds she was looking for legal resources for her son’s case.

Outcome - The DD Ombuds gave her information about legal representation, the administrative hearing process, and how to prepare for working with an attorney. After she received all the information she expressed how overwhelmed she was by the systems to get what her son needed. The DD Ombuds walked her through the application step by step and she was able to find legal representation for her son in time for the hearing deadline.

3. Summary of complaint – The family of a young child with autism contacted the DD Ombuds office for assistance with accessing needed services in the home and pending expiration of DDA eligibility. Their child had been in and out of the hospital for the past year, and they did not realize they did not have all of the required testing done to complete the application process. The family was frustrated by receiving inaccurate information from their DDA case manager about available supports and was recently denied placement on the Children’s Intensive In-home Behavioral Supports (CIIBS) Waiver. They were terrified that if they couldn’t access additional in-home services, their child was at risk of out of home placement. The family had no doubt their child would continue to meet criteria for DDA services. This was one of many barriers to receive services for their child in their home.

Outcome - The DD Ombuds attended meetings with the family and advocated for more information to be provided to the family from the case manager and case manager supervisor. The DD Ombuds asked for a list of psychologists who could complete the IQ testing be provided and provided education around the denial of the CIIBS waiver. The DD Ombuds questioned the validity of a hospital discharge safety plan that relies upon calling the police to intervene. The DD Ombuds raised concerns about this case with the DDA Outstation Manager, the DDA Field Services Administrator, and the Regional Administrator, highlighting the dangerous behaviors and risk of injury to all involved. When DDA indicated they were hesitant to look at additional services because the child’s eligibility is in question, the DD Ombuds reminded DDA personnel he remained DDA eligible for 90 days. The child was approved for a 30 day stay in an enhanced respite facility to allow the family time to make environmental modifications to the home and arrange for IQ testing.

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. The highest number of complaints concerned autonomy and exercise of rights including dignity, respect, privacy, preference, choice, sexual rights, care planning, personal property and funds. The DD Ombuds helped each individual with their complaints, and identified 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.

Individual Care had the next highest number of complaints. The DD Ombuds has identified access to behavioral supports, access to mental health care and the simplification of the eligibility process as systemic issues to be addressed.

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 worked at the regional level of DDA to address case manager services. The DD Ombuds will monitor this issue.

Complaints about abuse, neglect, and exploitation had the same number of complaints as quality of life. 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 to be addressed.

Monitoring

The DD Ombuds made 348 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, 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 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.

The DD Ombuds made 348 visits to the following types of facilities, residences and programs:

Certified Residential Services Settings – total visits - 180

Group Training Home - 2

Supported Living – 146

Supported Living Client Protection Program (CPP) - 3

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

Licensed Residential Settings – total visits - 117

DD Group Homes Adult Family Homes (AFH) - 12

DD Group Homes Assisted Living Facilities (ALF) - 22

Adult Family Homes – 74

Assisted Living Facilities - 0

Nursing Homes – 8

Provider out of business - 1

State Residential Habilitation Centers – total visits to cottages or programs - 48

Fircrest Intermediate Care Facility (ICF) – 16

Fircrest Nursing Facility (NF) - 8

Lakeland ICF - 12

Lakeland NF - 3

Rainier - 9

Yakima NF - 2

Licensed Children’s Residential Facilities – total visits - 2

Voluntary placement - 2

Other Private Residence - 1

Total monitoring visits - 348

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. Residential Service Provider Training

Problem Identified: 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. Concerns included:

- The actors portraying people with developmental disabilities did not have disabilities. The actors are playing characters of how they think people with developmental disabilities act.
- The actors portray characters with developmental disabilities in a negative light in some of the videos; they are rude, mean, and sloppy. It establishes a negative view of people with developmental disabilities.
- Several of the videos exaggerate both how providers and people with developmental disabilities behave. New providers might not take the videos seriously.
- It appears the videos are an attempt at humor, but they come off as unrealistic. Also, the wigs and the shooting style are distracting.
- The history of DD in Washington video leaves out the history of bad/abusive past (and present) practices that have taken place in Washington. It leads the viewer to believe abuses did not and do not happen in the Washington service system. It also may lead the viewer to believe segregated employment is a thing of the past.
- Some videos lack a clear message. The videos used in conjunction with the training curriculum should put forth very clear take-away messages.
- It doesn’t seem the people with DD were involved in the development or making of any points of the videos.
- Overall these videos may not teach or reinforce the tenets of person-centered services.

Outcome: Developmental Disabilities Administration was very responsive to the DD Ombuds concerns. DDA agreed to revamp the residential provider training as announced in April 2018. “Based on recent feedback, DDA is undertaking a new project! We are organizing a workgroup to update the training videos included in our Residential 40-hour CORE curriculum. We will work together to reflect our Guiding Values and a person-centered approach. For now, a few videos needed immediate replacement. These videos will be removed from the YouTube website on April 15, 2018 and replaced by simple discussions and activities.” DDA removed from the training curriculum 13 videos identified by the DD Ombuds as disrespectful, confusing, or not person-centered. The DD Ombuds participates in the workgroup DDA formed to review and update the entire curriculum.

2. Supported Living Clients Rights During Provider Decertification – Group Complaint

Problem Identified: 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 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. Clients and guardians were told the action was only a “name change”.

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. The DD Ombuds recommends this notice be required by statute.

Report on Systemic Issues

DD Ombuds in May, 2018 published a report [“Diverting Crisis - Maintaining housing and supports for people with developmental disabilities”](#). This report identifies gaps in the Developmental Disabilities Administration (DDA) service system and recommends changes that will benefit people with developmental disabilities. Specifically, this report identifies situations where adults with developmental disabilities lose their housing because there are no, or not enough, support services available to keep them in their home during or after physical, behavioral or mental health crisis.

People with developmental disabilities deserve access to the DDA support services they need, the providers they choose, and housing in their communities. A change or decline in health

should not destabilize housing or act as a barrier to continued access to DDA services. The DD Ombuds' investigation highlighted gaps in the DDA service structure that affect people with developmental disabilities when they experience a health crisis. These service gaps can be filled by adjusting DDA services and policies to prevent relocation, prevent termination of services, develop community housing, and evaluate crisis stabilization services.

The DD Ombuds will publish a follow-up report in November 2018. The report focuses on the lack of preventative crisis services, lack of readily available crisis response services and the use of hospital emergency departments and general hospital "social" admissions to provide adults with developmental disabilities crisis services.

The DD Ombuds is currently working on complaints related to the use of hospital emergency departments for crisis services by children.

Recommendations to the Legislature

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

Recommendation 1. – 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. The Developmental Disabilities Administration and the Health Care Authority have not identified ways to systematically detect the gaps in mental health services for children and adults with developmental disabilities.

Solution: Support children and adults with developmental disabilities and their families by creating a seamless service system which includes services and supports from DDA and medical and mental health services from Health Care Authority.

Proposal: Create a legislatively-mandated workgroup with specific duties and accountability to identify and examine current gaps in mental health services for children and adults with developmental disabilities. The workgroup must 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. Work group stakeholders must include clients of DDA and their families, service providers, hospital discharge staff, designated crisis responders, Office of Developmental Disabilities Ombuds and Developmental Disability advocacy groups. The Developmental Disabilities Administration, Department of Children Youth and Families, and the Health Care Authority shall, 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 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 over 40% in residential supported living services. The highest number of complaints the DD Ombuds handles concerned autonomy and exercise of rights (32), individual care (22), quality of life (14), and abuse, neglect and exploitation (14). A supported living provider who supported 214 individuals was decertified for health and safety reasons. The DD Ombuds began to see 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 care system by addressing the needs of people with developmental disabilities.

Proposals:

1. Increase direct service workers wages in supported living to reduce turnover and increase retention of well trained staff.
2. 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 modify abuse registry structure. (DSHS request legislation)
3. Fund investigations to protect individuals with disabilities in the supported living program. (DSHS request legislation)
4. Direct DDA to identify and remove barriers to utilization of behavioral support, such as in-home technical assistance and consultation, for children and adults who reside with parents.

Recommendation 3. – Secure rights of people who use DDA services

Problem: 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. The highest number of complaints handled by the DD Ombuds (32) concerned autonomy and exercise of rights.

Solution: Create a statute that spells out the rights of people who use DDA services so that 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. Gather rights which are currently scattered throughout RCW and WAC into one place in the RCWs. Equalize the timeline for notice of termination of residential services and provide for written notice to clients when a provider receives provisional certification or is decertified. Include the following:

Right to Personal Power and Choice. Right to be free from any kind of abuse or punishment; the right to be free from unnecessary medication, restraints and restrictions; and the right to make choices about your life.

Right to Participate in Service Planning Processes. Right to be present, understand and give input on service plans written by DDA and providers; the right to have meaningful opportunities to lead planning processes; and the right to have your visions for a meaningful life and your goals for education, employment, housing, relationships, and recreation included in the planning process.

Right to Access to Information about Services and Healthcare. Right to possess a full copy of all your current service plans; the right to review copies of the policies and procedures for any service you receive at any time, including policies and procedures about how to make complaints to service providers and the Department, the right to receive prompt notice of any enforcement action by the state against your provider or place that you live.

Right to Make Complaints, Grievances, and Appeals. Right to appeal any decision by DDA that denies, reduces, or terminates your eligibility, your services or your choice of provider; the right to submit grievances to your provider about your services or other concerns.

Right to Privacy and Confidentiality. Right to personal privacy and confidentiality of your personal and other records; the right to privacy in your communications.

Rights during Discharge, Transfer, and Termination of Services. Right to not be discharged, transferred, or have your services terminated except under specific circumstances; the right to adequate notice of discharge, transfer or termination of services.

Right to Advocates. Right to receive information from agencies acting as client advocates, and have the opportunity to contact these agencies.

Enforcement of Rights. The Department of Social and Health Services shall promulgate regulations to ensure sufficient oversight and enforcement of the DDA client rights.

Questions or comments about this report?

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