Office of Developmental Disabilities Ombuds

Diverting Crisis

Maintaining housing and supports for people with developmental disabilities

May 2018

Executive Summary

The Office of Developmental Disabilities Ombuds (DD Ombuds) is a private, independent office focused on improving the lives of persons with developmental disabilities in Washington State. The legislature gave the DD Ombuds the duty to monitor procedures and services provided to people with developmental disabilities; review facilities and residences where services are provided; resolve complaints about services; and issue reports on the services provided.[1]

The purpose of this report is to identify gaps in the Developmental Disabilities Administration (DDA) service system and to make recommendations for changes that will benefit people with developmental disabilities. Specifically, this report identifies situations where adults[2] with developmental disabilities lose their housing because there are no, or not enough, support services available to keep them in their home when there is a health crisis.

The information in this report was gathered between June 2017 and April 2018. It contains conclusions drawn from complaints made by individuals with developmental disabilities and care providers, as well as examples of these complaints. This report also includes additional information from DDA policies, state laws and regulations, data produced by DDA, and conversations with DDA staff.

Issues

- Individuals are living in undesired or inappropriate housing
- Individuals are unable to access crisis support services when they are in crisis
- Individuals have to move far away from their family, community, and jobs in order to receive services
- Services providers do not accommodate the changing needs of the individuals they serve

Recommendations

If the right DDA services are available, people are able to stabilize their housing and health situations. With access to necessary services, individuals can remain in their homes or move to new housing that is capable of meeting their level of support need. The DD Ombuds investigation shows that the limited availability of housing placements, the limited availability of additional in-home supports, the limited availability of crisis stabilization services, and the ability of service providers to terminate services to individuals with changing needs create barriers to stability for many adults with developmental disabilities in crisis. To address these barriers, the DD Ombuds makes the following recommendations:

1. Prevent Relocation

a. Additional in-home supports

DDA should structure services so that additional or replacement in-home supports can be located and put in place quickly. Further, when there is a request for additional or replacement assistance, DDA could conduct a significant change assessment to get a clear and updated understanding of the individual's support needs.

b. Crisis stabilization services in every community

Diversion bed services should be expanded so that there are more diversion beds available throughout the state. Increasing the amount of diversion beds would make these services more available to DDA clients when they have a behavioral health crisis. Further, DDA could strategically place the beds throughout the state so that they are available in more local communities.

2. Prevent Termination of Services

DDA should take steps to change policy and practice to slow or prevent the termination of services to individuals. DDA should make additional services readily available to DDA clients so their current

providers can support changing needs as they arise, including on an emergency basis. DDA should develop policies that require providers to give 60 days' notice before terminating services. Further, until replacement services are secured and in place, the current provider should be required to continue to support the individual.

3. Develop Community Housing

DDA should make non-institutional housing options available that must accept individuals for continuing services. For example, State Operated Living Alternatives (SOLAs) could be expanded so that they have greater capacity and polices could be developed that guarantee SOLA services to all eligible DDA clients. Further, DDA should develop policies that would prevent SOLAs from being able to terminate services to SOLA residents. SOLAs should be staffed to accommodate changing needs and should not be permitted to terminate services to the DDA clients they support. SOLA expansion could create permanence for DDA clients and reduce the risk of institutionalization and hospitalization.

4. Evaluate Crisis Stabilization Services

DDA should develop a method of collecting data on the following for each type of crisis stabilization services:

- How far people have to travel to receive crisis stabilization services
- How long people utilize crisis stabilization services
- Where people live immediately after receiving crisis stabilization services
- Where people live in the years after receiving crisis stabilization services

DDA could evaluate which types of crisis stabilization services successfully prevent hospitalization and institutionalization in the short

and long term. DDA could also evaluate how to broaden access to crisis stabilization services so that more people could receive these services in their community.

Conclusion

People with developmental disabilities should have 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 be 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 implement the above recommendations to prevent relocation, prevent termination of services, develop community housing, and evaluate crisis stabilization services

The DD Ombuds will continue to provide information, advocacy, and support to DDA clients experiencing service and housing instability as a result of a health crisis. The DD Ombuds looks forward to working with self-advocates, family members, DDA, and other stakeholders to make needed changes to the service system so that DDA services are accessible and effective for all DDA clients.

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Introduction

In Washington, over 45,000 individuals with developmental disabilities are enrolled in the Developmental Disabilities Administration (DDA).[3] DDA offers case management and other necessary services and programs to people with developmental disabilities from infancy through end of life.[4] Generally speaking, over the course of any person's lifetime, it is expected that individuals will experience some changes in their health.

Since June 2017, the Office of the Developmental Disabilities Ombuds (DD Ombuds) has spoken to hundreds of adults with developmental disabilities and care providers for adults with developmental disabilities across the state of Washington. Individuals and care providers contacted the DD Ombuds for assistance with or questions about their DDA services. From these conversations, a pattern emerged – many of the contacts were related to a sudden change in health. It became clear that a change in health can easily have a significant and lasting impact on an individual's access to their DDA services and, possibly, to their housing stability.[5]

Background

Office of the Developmental Disabilities Ombuds

The DD Ombuds is a private, independent office focused on improving the lives of persons with developmental disabilities in Washington State.[6] The DD Ombuds was created by the legislature in 2016 as a response to the high prevalence of abuse and neglect against people with developmental disabilities.[7] The legislature gave the DD Ombuds the duty to monitor procedures and services provided to people with developmental disabilities; review facilities and residences where services are provided; resolve complaints about services; and issue reports on the services provided.[8]

Purpose and Scope of Report

The purpose of this report is to identify gaps in the DDA service system and to make recommendations for changes that will benefit people with developmental disabilities. Specifically, this report identifies situations where adults[9] with developmental disabilities lose their housing because there are no, or not enough, support services available to keep them in their home when there is a health crisis.

To maintain stability and independence, people with developmental disabilities often use support services.[10] Support services include, but are not limited to, personal care services, skill-building services, behavior support services, supported employment services, and community inclusion services.[11] DDA funds support services for people with developmental disabilities, which can be provided by staff or a family caregiver in the individual's housing.[12]

The DD Ombuds learned of issues with housing and service instability through complaints that were made by individuals with developmental disabilities, family members, and service providers. These complaints highlighted how vulnerable people with developmental disabilities are to losing their housing. If an individual with a developmental disability or a caregiver experiences a physical or behavioral health crisis, the support services may no longer be available or sufficient to meet the individual's support needs. When needs cannot be met in current housing, the individual with a developmental disability will have to move to alternative housing where their needs can be met. This report focuses on these situations where individuals with disabilities are unable to receive adequate services at their current home and are forced to move into new housing in order to access services that meet their needs.

Methodology

The information in this report was gathered between June 2017 and April 2018. The examples and individual stories contained in this report are from complaints

made to the DD Ombuds during this timeframe. Individual stories are being used with the complainant's permission – however, the names and other identifying information have been changed to protect the privacy of complainants and individuals with developmental disabilities. The report includes additional information from DDA policies, state laws and regulations, data produced by DDA, and conversations with DDA staff.

Where do People with Developmental Disabilities Live?

Adults with developmental disabilities live in many different types of housing with varying levels of supports.[13] Some individuals live in their parents' or a relative's home and receive support services there.[14] For example, about 11,000 adults with a developmental disability live with their parents and may have a parent or family member that provides support services.[15] Approximately 50% of family caregivers that provide support to a person with a developmental disability are over the age of 51.[16] About 9,000 individuals live in their own apartments or homes where they may receive personal care or other support services from an agency or individual provider.[17] There are also about 3,000 individuals that live in state institutions or state-licensed facilities, like assisted living or adult family homes, where they can receive support services.[18] In each of these situations, the individual needs the housing and the support services to maintain stability.

DDA Services and Supports

DDA is part of Washington State's Department of Social and Health Services.[19] DDA provides services and programs to people with developmental disabilities that live in Washington State.[20] In 2017, there were 45,032 total clients enrolled in DDA.[21] Of those, 24,499 were adults.[22] DDA conducts assessments for each individual to determine their needs and the services for which they qualify.[23] After the assessment, DDA works with the individual to connect them with service providers that can meet their support needs.[24]

DDA has established a system that makes services available to individuals in coordination with the type of housing they live in.[25] For instance, DDA may refer someone to a housing placement, like an Adult Family Home, where they can live and receive additional services funded by DDA.[26] DDA clients can also receive services in a private or family home.[27] For example, a person with a developmental disability may receive personal care services from their parent or another caregiver in a private home.[28] The individual with the developmental disability needs housing and the associated support services to maintain stability.

Housing and Service Placement

DDA clients that are approved to receive support services work with DDA staff to obtain services.[29] DDA assists clients in obtaining in-home supports or, depending on the individual's support needs, with finding housing placements where supports can be provided to the individual.[30] For individual's that need a housing placement, Case Resource Managers (CRMs) work to match their wants and needs with housing placements that can provide appropriate services.[31] When CRMs are assisting a client with finding housing placements in the community, they consider the following factors:

- Personal preference of the Individual
- Identified advocate or legal representative requests
- Personal preferences of potential housemates
- Provider's ability to meet the client's health, safety, and program needs
- Needs of all persons in the residence, including safety and protection
- Capacity in existing homes
- Provider's area of specialty
- Provider's interest and ability to expand services; and
- Enforcement action regarding placements[32]

These factors are evaluated along with the individual's needs for support and a referral packet is compiled for the individual.[33] The CRM sends the referral packet out to service providers in housing placements in the community that are the best fit for the individual.[34]

CRMs must provide options for housing placements in the community before the individual is placed in an institution for people with developmental disabilities.[35] If no community placement is available, if the individual does not want a community placement, or if a community placement will not meet the individual's needs, DDA staff review the individual for admission at one of the State's four institutions for people with developmental disabilities, called Residential Habilitation Centers (RHCs).[36] RHCs were established to provide continuous treatment for people with developmental disabilities that need a high level of care.[37] The goal of treatment at an RHC is to help people develop skills to become as independent as possible so they can move to a less restrictive housing option.[38] There are four RHCs that have been permanently established in Washington State to serve people with developmental disabilities.[39] The RHCs are located in Buckley, Shoreline, Selah, and Medical Lake, Washington.[40]

Emergency Residential Placement

A physical or behavioral health crisis can destabilize an individual's housing. A health crisis may cause a temporary or permanent change in an individual's care needs that cannot be met by the staff or caregiver in their current housing. Or, a caregiver's health crisis may prevent or limit their ability to continue providing care to a person with developmental disabilities. In either situation, the individual will need to replace or add supports in their current housing or change housing in order to obtain the services they need.[41]

If there is a health crisis and alternative housing is needed, there may not be time for the DDA CRM to locate new housing that meets all of an individual's needs.[42] In some instances, an individual may temporarily need escalated support

services to stabilize their health crisis before they move to new housing.[43] For these situations, DDA has established facilities and procedures to provide housing and services to individuals experiencing a crisis.[44] The following temporary placements are equipped to provide extra supports and services to help stabilize the individual in crisis so the individual can move into permanent housing.[45]

Emergency Short Term Stay at RHCs

In addition to providing long term placement, the State's four RHCs can provide housing to adults with developmental disabilities in need of crisis stabilization or in need of short-term housing.[46] If an individual is at risk of losing their home within 10 days and they meet the eligibility requirements for admission at an RHC, they may be temporarily housed at an RHC on a short-term basis.[47] These short-term stays are time limited and meant to be utilized until the individual locates housing in the community or until a crisis is resolved.[48]

There are eight crisis stabilization beds at Yakima Valley School (RHC).[49] The other RHCs can take individuals in crisis for short-term stays if they have capacity.[50] In 2017, 163 individuals were placed at one of the RHCs for crisis stabilization or for an emergency short-term stay.[51]

Behavioral Health Stabilization Services in the Community

DDA has established behavioral health stabilization services for adults with developmental disabilities experiencing a behavioral health crisis.[52] These services provide extra supports to individuals who are at risk of psychiatric hospitalization or institutionalization at one of the four RHCs.[53] DDA provides the following behavioral health stabilization services: (1) behavior support and consultation; (2) specialized psychiatric services; and (3) crisis diversion bed services.[54] Services can be provided in-home or at a crisis diversion bed, which also serves as short-term housing.[55]

Behavioral health stabilization services are limited and are provided based on an individual's needs as assessed by DDA or behavioral health professionals.[56] Currently, there are eleven diversion beds available for DDA clients located throughout the State.[57] DDA also provides in-home behavioral health stabilization services and ten intensive mental health case managers for DDA clients.[58]

Issues

In response to complaints received, the DD Ombuds conducted an investigation of DDA services available to people with developmental disabilities during and after they experience a crisis that affects their housing stability. During the investigation, the DD Ombuds spoke with DDA clients, family members, caregivers, service professionals, DDA management staff, and DDA CRMs across the state. Further, the DD Ombuds reviewed relevant law and policy as well as DDA data concerning crisis services. Through this investigation, the DD Ombuds identified the following issues and concerns about the services available to people with developmental disabilities who have lost, or are at high risk of losing, their housing due to a physical or behavioral health crisis.

Individuals Are Living in Undesired or Inappropriate Housing

A physical or behavioral health crisis can disrupt or change an individual's support services and cause them to need new housing. DDA has established procedures for locating new housing placements for individuals, but it takes time to locate housing that will meet an individual's needs, including medical, behavioral, geographic, and social needs.[59] The DD Ombuds investigation shows that the process of locating new housing placements can take months or years. While an individual is waiting for new housing that meets their needs, they remain living in housing that they do not like, that does not meet their needs, or that is not in their community.

Parent Suddenly Unable to Provide Care: Youth Placed with Seniors

Jonathan, a DDA client, was living with his mother in their family home. He went to school, had friends and had a close connection to his family. Mary, his mother, was the primary caregiver and provided personal care, including physical transfers.

In 2016, when Jonathan was 19, Mary had a physical health crisis and was hospitalized. Mary was suddenly no longer physically able to provide care for her son. Mary's doctor advised her she would not ever be able to return to her caregiver duties. Mary requested alternative services as she was desperate to get Jonathan the daily physical assistance he needed.

Jonathan had to quickly be moved to new housing that could support his care needs. Jonathan was moved to an Adult Family Home where all the other residents were seniors. As the only teenager living with seniors, Jonathan felt out of place and his mental health began to decline. "They cannot take care of him there" Mary said about the Adult Family Home. "I want to live with people my own age" Jonathan stated. Despite repeated requests from Jonathan and Mary to move to housing with peers close to Jonathan's age, DDA did not start looking for alternative housing for Jonathan until almost two years later, in 2018. As of the date of this report Jonathan is still waiting for a new housing placement.

Sometimes, when appropriate alternative housing placements cannot be located, individuals are placed at an RHC for an emergency short-term stay.[60] Short-term stays at an institution are meant to be temporary while DDA helps an individual locate appropriate housing in the community.[61] At maximum, short-term stays are supposed to last 180 days.[62]

A December 2017 census of Fircrest School and October 2017 census of Lakeland Village (two of the RHCs) showed that multiple people remained on short-term stays for well over the 180 day maximum.[63] Census data showed that

twelve people had been on short-term stay for six months to two years; four people had been on short-term stay for two to three years; six people had been on short-term stay for three to five years; and two people had been on short-term stay for over five years.[64]

In total, 24 people are at these two RHCs for short-term stays past the 180 day maximum.[65] These individuals could request to be admitted to the RHC, but they have not.[66] Instead, the individuals are choosing to remain on short-term stay and wait for DDA to locate a housing placement in the community.[67] Unfortunately, community placements that can meet their support needs have not been located for these individuals.[68] It costs about $22,000 per month to house an individual in an RHC,[69] and these individuals have been at the RHCs for years waiting for housing placements in the community.[70]

Individuals Unable to Access Crisis Support Services when in Crisis

DDA has established crisis stabilization services for individuals experiencing a behavioral health crisis.[71] These services are designed to prevent psychiatric hospitalization or institutionalization at an RHC.[72] However, crisis stabilization services are limited and it can be difficult or impossible to access these services and prevent institutionalization.

Denial of Behavior Support Services: Risk of Institutionalization

Gloria received supported living services from the same provider for many years. In 2017, she started to have a decline in behavioral health. Her provider was concerned that they could not meet her escalating needs and reached out to DDA for extra support. “[The provider] was begging for more help,” reported the DDA CRM. But no extra supports were available to keep Gloria in her home. As a result, Gloria was hospitalized, then transferred to an RHC where she stayed for months before new housing and residential supports were located.

Once in her new housing, her provider and DDA reached out to the local Behavioral Health Organization (BHO) so that Gloria could receive additional behavioral health supports in her new home. The BHO declined to serve Gloria because of her developmental disability. Without behavioral health support, Gloria remains at risk of losing her new housing and being hospitalized or institutionalized.

Some individuals who are unable to obtain additional supports during a behavioral health crisis request placement at an institution to avoid a more severe consequence, such as arrest and incarceration. However, DDA retains the right to deny admission to an RHC.[73] Further, in December 2017, the Intermediate Care Facilities (ICF) at two RHCs were decertified by the Center for Medicaid Services which prevents those institutions from accepting any new admissions or emergency short-term stays in the ICFs.[74] The result is that individuals are left with no additional supports and no alternative placements – they are at extreme risk of losing their housing or suffering more extreme consequences.

Last Resort Placement at RHC Denied, No Additional Services

Jackson, a client of DDA, has lived at home with his parents for years. His parents are his legal guardians and his caregivers. In 2017, Jackson began to have an unprecedented behavioral and physical health decline. His parents reached out to DDA for respite and additional support services, but DDA was unable to accommodate their request for help.

Jackson was hospitalized in a psychiatric unit for weeks. “We were waiting for an alternative placement while he was hospitalized, but DDA could not find an available placement. We did not want him to be involuntarily committed to a hospital, so we brought him home” said his father. They thought their only hope for help was getting him into an RHC where his staffing and support needs could be met. In late 2017, DDA denied their

request to place Jackson at an RHC citing lack of capacity. Since the denial, Jackson remains at home still in need of additional support services. Jackson's parents are fearful for his and their well-being. They recently had to resort to calling the police for assistance with their son.

To Receive Services, Individuals Move Far from Family, Community, and Jobs

DDA has crisis service housing in every region of the state. (See map below.) However, crisis service housing is limited and not available in every community. The DD Ombuds' investigation shows that individuals who need to utilize a diversion bed or RHC emergency short-term stay may be forced to move hours from their family, community, and job in order to receive services. This puts individuals in the position of having to give up their jobs and natural community supports in order to receive crisis services.

Hours from Work

Zac lived at home with his parents and went to work in the neighboring community. In 2017, Zac had a sudden decline in behavioral health and his parents requested additional services from DDA. DDA was unable to provide services to Zac in his home, but offered him placement at a diversion bed. The diversion bed was located approximately one to two hours from Zac's home and worksite. Zac moved to the diversion bed, but wanted to keep his job to maintain some stability and continuity in his life. "He has had his job for years and it is a very important source of structure and social interaction, he could not lose his job" his parents said. In order to receive diversion services and maintain his employment, Zac's parents drove up to two hours each way to pick up Zac, take him to work, and take him back to the diversion bed.

No Local Service: Sent Eight Hours from Home

Guillermo is very close to his family. He likes to talk to his mom every day and visit when possible. Guillermo lived in supported living close enough to his Mom's house that they could have regular visits. In 2017, Guillermo experienced a decline in his behavioral health. DDA was unable to provide Guillermo with additional services in his supported living housing. He was placed at a RHC for an emergency short-term stay. However, the RHC was almost an eight hour drive from his Mom's house. His mom could not afford the time off work or money it would cost to visit her son. The lack of visitation was very difficult for both Guillermo and his Mom. Guillermo and his Mom both wished he could access services closer to home so that he could maintain his connection to his family and community.

Service Providers Do Not Accommodate Changing Needs: Discharge Instead

Service providers can discharge individuals or terminate services if they cannot meet the individual's needs.[75] In some housing settings, the provider can terminate services to the individual on ten days' notice, or on 72 hours' notice in an emergency.[76] Often, ten days or 72 hours is not enough time to find replacement services and/or housing. Without support services, the individual is not stable in their housing or cannot return to their housing.

Left at the Hospital

Jim lived in the same home with the same provider for more than 15 years. In 2018, Jim began to experience some new physical health issues. Jim's provider did not feel capable of providing the extra medical support that Jim now requires. Additional medical services were not put in place at Jim's home to maintain his stability and meet his new needs. Instead, Jim's provider took him to the hospital for treatment and refused to pick him up when the hospital was ready to discharge him. Jim is unable to return home because the provider does not feel capable of serving him. Jim has stayed in the hospital for over six weeks, without any medical need to be there, because he cannot return home.

Recommendations

Home and Stable in a SOLA

Ted was placed at an RHC for an emergency short-term stay in 2017. He lost his former housing due to escalating need and alternative services could not be found quickly enough to prevent institutionalization. "It was not fun [at the RHC], the staff tell you what to do" reported Ted. DDA worked with Ted to refer him to a State Operated Living Alternative (SOLA) where he could live and receive the services he needs in the community, instead of an institution.

Ted has had some struggles adjusting to his new home in the SOLA, but the SOLA has the capacity and ability to be accommodating. “The SOLA staff are better trained and can meet his needs” said Ted’s family. The SOLA staff have been able to adjust to his new behaviors and work with him to adjust to his new home. “SOLA is the best place I’ve lived,” says Ted. The SOLA staff are providing Ted with the supports he needs so he can live in the community and enjoy all the benefits of living outside an institution.

If the right DDA services are available, people are able to stabilize their housing and health situations. With access to necessary services, individuals can remain in their homes or move to new housing that is capable of meeting their level of support need. The DD Ombuds investigation shows that the limited availability of housing placements, the limited availability of additional in-home supports, the limited availability of crisis stabilization services, and the ability of service providers to terminate services to individuals with changing needs create barriers to stability for many adults with developmental disabilities in crisis.

To address these barriers, the DD Ombuds makes the following recommendations:

1. Prevent Relocation

a. Additional In-Home supports

When there is a health crisis that requires a change or addition of support services, it would be least disruptive if the additional services were provided in the individual’s current home. For example, if a parent-caregiver has to undergo emergency surgery, they may not have much notice of their absence and may not be able to provide caregiving services for weeks or months during their recovery. It would provide more stability for the individual with disabilities if a temporary replacement caregiver was readily available to deliver services in their home until their parent fully recovered. Or, if an individual has a decline in their

behavioral health that requires additional behavioral health supports, it would be beneficial if those supports could be easily provided to them without requiring a change in housing.

A decline in health or change in support needs should not require a person to relocate, be hospitalized, or institutionalized in order to access adequate services. The DD Ombuds investigation shows that relocation often causes individuals to lose access to their family, friends, jobs, and other community resources. Additionally, the stress of relocation can have a negative impact on the health and wellness of individuals.

DDA should structure services so that additional or replacement in-home supports can be located and put in place quickly. Further, when there is a request for additional or replacement assistance, DDA could conduct a significant change assessment to get a clear and updated understanding of the individual's support needs. A current understanding of the support needs may help ensure that the new supports are effective. Easy access to appropriate replacement or additional in-home supports could assist individuals with getting their needs met without having to relocate to new housing.

b. Crisis Stabilization Services in Every Community

In situations where additional in-home supports are not sufficient, temporary out of home care should be readily available in the individual's current community. For example, if an individual needs to utilize diversion bed services, the bed should be located near the person's home. Currently, an individual may have to travel hours from home to receive care in a diversion bed. This distance can cause a major disruption to the individual's life and disconnect them from family, friends, and other community supports.

Diversion bed services should be expanded so that there are more diversion beds available throughout the state. Increasing the amount of diversion beds would make these services more available to DDA clients when they have a

behavioral health crisis. Further, DDA could strategically place the beds throughout the state so that they are available in more local communities. Increasing access to diversion bed services would enable individuals to maintain their home and community based support system, like friends, family, neighborhood, and work, while they are receiving the services.

2. Prevent Termination of Services

This investigation highlighted multiple situations where a service provider terminated services to a DDA client causing them to lose their housing and spend time in hospitals or institutions. This causes major disruptions for the individual in multiple areas of life. The individual loses their provider, spends time in a hospital or institution, and ultimately must relocate on short notice. Additionally, sudden termination of services can result in the individual spending time in a hospital or institution even though they do not need the high level of service or restrictions provided in those settings. For these reasons, DDA should take steps to change policy and practice to slow or prevent the termination of services to individuals.

Providers need to be better equipped to support people with changing medical and behavioral needs. DDA should make additional services readily available to DDA clients so their current providers can support changing needs as they arise, including on an emergency basis. The availability of additional services may prevent a service provider from terminating services.

Further, DDA clients should be protected from housing and service instability caused by gaps in services. Currently, some providers can discontinue services with ten days' notice. DDA should develop policies that require providers to give 60 days' notice before terminating services. This would give the individual and DDA more time to adjust to the pending change and to locate replacement services. Further, until replacement services are secured and in place, the current provider should be required to continue to support the individual. This

would prevent a gap in services that destabilizes the individual and their housing. Expanding the notice period to 60 days and requiring alternative services to be in place before termination would create a continuity of services for individuals during changes in providers.

3. Develop Community Housing

People with developmental disabilities should have access to stable housing placements in the community that can meet their changing needs. Currently, community providers can decline to provide services to individuals and can terminate services to individuals. DDA should make non-institutional housing options available that must accept individuals for continuing services. For example, State Operated Living Alternatives (SOLAs) could be expanded so that they have greater capacity and polices could be developed that guarantee SOLA services to all eligible DDA clients. With this expanded capacity, SOLAs could be a community housing resource that is always available to individuals.

Further, DDA should develop policies that would prevent SOLAs from being able to terminate services to SOLA residents. SOLAs should be staffed to accommodate changing needs and should not be permitted to terminate services to the DDA clients they support. This policy development for SOLAs would create a system in which people with developmental disabilities had a guaranteed and stable community placement. SOLA expansion could create permanence for DDA clients and reduce the risk of institutionalization and hospitalization.

4. Evaluate Crisis Stabilization Services

During the course of this investigation, the DD Ombuds discovered that DDA does not currently have a method of evaluating the success of the various crisis stabilization services. It is important to understand if and how the crisis stabilization services available to DDA clients are preventing hospitalization and

institutionalization in the short and long term. DDA should develop a method of collecting data on the following for each type of crisis stabilization services:

- How far people have to travel to receive crisis stabilization services
- How long people utilize crisis stabilization services
- Where people live immediately after receiving crisis stabilization services
- Where people live in the years after receiving crisis stabilization services

With this data, DDA could evaluate which types of crisis stabilization services successfully prevent hospitalization and institutionalization in the short and long term. DDA could also evaluate how to broaden access to crisis stabilization services so that more people could receive these services in their community.

Conclusion

People with developmental disabilities should have 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 be 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 implement the above recommendations to prevent relocation, prevent termination of services, develop community housing, and evaluate crisis stabilization services. The DD Ombuds will continue to provide information, advocacy, and support to DDA clients experiencing service and housing instability as a result of a health crisis. The DD Ombuds looks forward to working with self-advocates, family members, DDA, and other stakeholders to make needed changes to the service system so that DDA services are accessible and effective for all DDA clients.

Authors

Beth Leonard

Region 2 Developmental Disabilities Ombuds and Legal Counsel

Beth Leonard joined the DD Ombuds in 2017. She is a passionate advocate for justice who focused her legal career working on behalf of low-income and marginalized communities. Prior to joining the DD Ombuds, she worked as a staff attorney at Legal Action Center providing eviction defense services to low-income tenants in King County. Beth also served as Washington State's first Pro Bono Council Manager where she provided coordinated support and advocacy to Washington's 17 Volunteer Lawyer Programs. Beth is an adjunct professor at Seattle University and a graduate of Washington's JustLead Leadership Academy. Beth graduated cum laude from Seattle University School of Law where she was chosen by faculty as the Law Faculty Trust Scholar for the class of 2013. In her free time, she enjoys being outdoors, cooking, and visiting with her family and friends. Beth can be reached at beth@ddombuds.org

Betty Schwieterman

State Developmental Disabilities Ombuds

In 2017, Betty began her new position as the head of the Office of Developmental Disabilities Ombuds, a program of Disability Rights Washington. She works to change systems to be responsive to people with disabilities. She leads the statewide DD Ombuds program to promote the well-being of people with developmental disabilities through rights education, monitoring services and facilities, identifying concerns and complaints, complaint resolution at the lowest level possible and making recommendations for improvements to the service system and legislature. Previously with Disability Rights Washington, Betty worked to improve the abuse response system and victim rights of people with disabilities; election accessibility; self-directed personal assistance services; and address gaps in the services systems for people with traumatic brain injury. Betty's passion is to support people with disabilities who are new to advocacy, build advocacy coalitions and provide support and technical assistance to advocates. Betty can be reached at betty@ddombuds.org

Endnotes

[1] *See* Revised Code of Washington (RCW) 43.382.005(4).
[2] For the purposes of this report, the DD Ombuds defines an "adult" as anyone over the age of 18.
[3] *See* Developmental Disabilities Administration (DDA), "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).
[4] *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[5] The information in this paragraph is consistent with complaints received by the DD Ombuds office in 2017.
[6] Developmental Disabilities Ombuds (DD Ombuds), "Office of the Developmental Disabilities Ombuds," http://ddombuds.org/ (last visited April 2018).
[7] LAWS OF 2016, ch 172 § 5 (included in the finding for RCW 43.382.005).
[8] *See* Revised Code of Washington (RCW) 43.382.005(4).
[9] For the purposes of this report, the DD Ombuds defines an "adult" as anyone over the age of 18.
[10] *See* DDA, "DDA EMIS Report," (January 2018). The EMIS report is a document that details the DDA client enrollment and total costs for services. The EMIS report shows that 27,693 individuals with developmental disabilities were receiving services from DDA in January 2018.
[11] *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services, (last visited April 2018); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[12] *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services, (last visited April 2018); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[13] *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services (last visited April 2018).
[14] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[15] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).
[16] Lynda Lahti Anderson, Amy Hewitt, and Amie Lulinski, "Research Brief: 60% of family caregivers provide more than 40 hours of support per week," pg 2 (2018).
[17] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018); DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[18] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).
[19] *See* DDA, "Developmental Disabilities Administration," https://www.dshs.wa.gov/dda (last visited April 2018).

[20] *See* DDA, "Developmental Disabilities Administration Services & Programs," https://www.dshs.wa.gov/dda/developmental-disabilities-administration-services-programs (last visited April 2018).
[21] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).
[22] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).
[23] *See* Washington Administrative Code (WAC) 388-828-1040.
[24] *See* DDA Policies 3.04, 4.02, 4.08, and 15.02; *See* RCW 71A.16.010; *See* DDA, "DDA Assessment," https://www.dshs.wa.gov/dda/consumers-and-families/dda-assessment (last visited April 2018).
[25] *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services, (last visited April 2018).
[26] *See* DDA Policy 4.08; *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services, (last visited April 2018).
[27] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[28] *See* DDA, "2017 DDA Caseload and Cost Report," pg 24, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).
[29] *See* DDA Policies 3.04, 4.02, 4.08, and 15.02; *See* RCW 71A.16.010; *See* DDA, "Developmental Disabilities Administration Services & Programs," https://www.dshs.wa.gov/dda/developmental-disabilities-administration-services-programs (last visited April 2018).
[30] *See* DDA Policies 3.04, 4.02, 4.08, and 15.02; *See* RCW 71A.16.010; *See* DDA, "Developmental Disabilities Administration Services & Programs," https://www.dshs.wa.gov/dda/developmental-disabilities-administration-services-programs (last visited April 2018).
[31] *See* DDA Policies 3.04, 4.02, 4.08, and 15.02; *See* RCW 71A.16.010.
[32] *See* DDA Policies 4.02 and 4.08.
[33] *See* DDA Policies 4.02 and 4.08.
[34] *See* DDA Policies 4.02 and 4.08.
[35] *See* DDA Policy 3.04; See RCW 71A.16.010.
[36] *See* DDA Policy 3.04.
[37] *See* RCW 71A.20.010; *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services (last visited April 2018).
[38] *See* RCW 71A.20.010; *See* DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services (last visited April 2018).
[39] RCW 71A.20.020; DDA, "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services (last visited April 2018).
[40] RCW 71A.20.020; "Residential Services," https://www.dshs.wa.gov/dda/consumers-and-families/residential-services (last visited April 2018).
[41] The information in this paragraph is consistent with complaints received by the DD Ombuds office in 2017.
[42] This information is consistent with complaints received by the DD Ombuds office in 2017.

[43] This information is consistent with complaints received by the DD Ombuds office in 2017.

[44] *See* DDA Policies 4.01 and 4.02; RCW 71A.20.180(c); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[45] *See* DDA Policies 4.01 and 4.02; *See* RCW 71A.20.180(c); *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[46] *See* RCW 71A.20.180(c); *See* DDA Policy 4.01.

[47] *See* DDA Policy 4.01.

[48] *See* DDA Policy 4.01.

[49] RCW 71A.20.180(c); DDA, "Yakima Valley School," https://www.dshs.wa.gov/dda/consumers-and-families/yakima-valley-school (last visited April 2018).

[50] *See* DDA policy 4.01.

[51] DDA compiled and provided this data to the DD Ombuds on March 15, 2018 in response to a DD Ombuds' request.

[52] *See* WAC 388-845-1150; *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[53] *See* WAC 388-845-1150; *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[54] *See* WAC 388-845-1150; *See* WAC 388-845-1110; *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[55] *See* WAC 388-845-1150; *See* WAC 388-845-1110.

[56] *See* WAC 388-845-1160.

[57] DDA compiled and provided this data to the DD Ombuds on February 15, 2018 in response to a DD Ombuds' request.

[58] DDA compiled and provided this data to the DD Ombuds on February 23, 2018 in response to a DD Ombuds' request.

[59] *See* DDA Policies 3.04, 4.02, 4.08, and 15.02.

[60] *See* DDA policy 4.01.

[61] *See* DDA policy 4.01.

[62] *See* DDA policy 4.01.

[63] Lakeland Village Respites (October 2017) and Fircrest School Client Roster (December 2017). DDA compiled and provided this information to the DD Ombuds in October and December 2017 at the DD Ombuds request. This report only reflects short term stay data for Fircrest School and Lakeland Village. However, there are people at Rainier School in emergency respite cottages and people at Yakima Valley School in crisis stabilization beds.

[64] Lakeland Village Respites (October 2017) and Fircrest School Client Roster (December 2017). DDA compiled and provided this information to the DD Ombuds in October and December 2017 at the DD Ombuds request.

[65] Lakeland Village Respites (October 2017) and Fircrest School Client Roster (December 2017). DDA compiled and provided this information to the DD Ombuds in October and December 2017 at the DD Ombuds request.

[66] *See* DDA Policy 3.04; The information in this statement was communicated to the DD Ombuds by Fircrest School administrative staff on January 19, 2018. The DD Ombuds and Fircrest School staff had an informal conversation about short term stays at Fircrest School. Fircrest School administrative staff indicated that many individuals on short term stay could be admitted to the RHC permanently if the individuals requested admission.

[67] The information in this statement was communicated to the DD Ombuds by Fircrest School administrative staff on January 19, 2018. The DD Ombuds and Fircrest School staff had an informal conversation about short term stays at Fircrest School. Fircrest School administrative staff indicated that many individuals on short term stay could be admitted to the RHC permanently if the individuals requested admission. However, administrative staff indicated that some individuals choose not to request admission to the RHC because they want a community placement.

[68] The information in this statement was communicated to the DD Ombuds by Fircrest School administrative staff on January 19, 2018. The DD Ombuds and Fircrest School staff had an informal conversation about short term stays at Fircrest School. Fircrest School administrative staff indicated that many individuals on short term stay could be admitted to the RHC permanently if the individuals requested admission. However, administrative staff indicated that some individuals choose not to request admission to the RHC because they want a community placement. The result is that these individuals remain on short term stay for months or years while they wait for community placement.

[69] *See* DDA, "2017 DDA Caseload and Cost Report," pg 19, https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/FINAL-2017-DDA-Caseload-and-Cost-Report.pdf (last visited April 2018).

[70] Lakeland Village Respites (October 2017) and Fircrest School Client Roster (December 2017). DDA compiled and provided this information to the DD Ombuds in October and December 2017 at the DD Ombuds request.

[71] *See* WAC 388-845-1150; *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[72] *See* WAC 388-845-1150; *See* DDA, "Services and Programs (non-residential)," https://www.dshs.wa.gov/dda/consumers-and-families/services-and-programs-non-residential (last visited April 2018).

[73] *See* RCW 71A.20.090; *See* DDA Policy 3.04.

[74] Centers for Medicare & Medicaid Services, "Fircrest Provider Agreement Cancellation PAT A," (Dec. 19, 2017); Centers for Medicare & Medicaid Services, "Rainier Provider Agreement Cancellation PAT E," (Dec. 19, 2017).

[75] *See* RCW 70.129.110; *See* WAC 388-101D-0200; *See* DDA, "Client Service Contract: Community Residential services," pgs 13-14 (June 15, 2017).

[76] *See* DDA, "Client Service Contract: Community Residential services," pgs 13-14 (June 15, 2017).