Washington State Department of Social and Health Services

Transforming Lives

REPORT TO THE LEGISLATURE

Community respite and stabilization progress report

ESSB 5092 Sec. 203 1(y)(b)
Chapter 334, 2021 Laws PV
ESSB 5268 Sec. 4
Chapter 219, 2022 Laws
ESSB 5693 Sec. 203 1(z)(b)
Chapter 297, 2022 Laws PV

October 1, 2023

Developmental Disabilities Administration
Office of the Assistant Secretary
PO Box 45310
Olympia, WA 98504-5310
(360) 407-1500
www.dshs.wa.gov/dda

Washington State Department of Social & Health Services
Transforming lives

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Overview

Through Engrossed Substitute Senate Bills 5092, 5268 and 5693, the Department of Social and Health Services' Developmental Disabilities Administration was asked to examine the need for community respite beds for eligible adults and stabilization, assessment and intervention beds to provide crisis stabilization services for people with complex behavioral needs.

ESSB 5092 and 5693 require a final report to be submitted no later than Oct. 1, 2023, to the governor and the appropriate committees. However, ESSB 5268 required the final report to be submitted by Oct. 1, 2024. We exercised the option to submit the final report by Oct. 1, 2024, to inform the Legislature with additional stakeholder input and data.

This progress report details the work completed to better understand the respite and stabilization needs of adults with intellectual and developmental disabilities and barriers to accessing these services. We updated data from our initial 2022 report which has helped us evaluate our progress of improving services. We collected feedback from DDA clients, family members, caregivers, providers, DSHS staff and other stakeholders. We also engaged in initial listening sessions with self-advocates and tribal partners to hear their stories and get feedback on how we can reduce barriers to respite and stabilization services.

We will conduct additional data reviews and listening sessions to develop final recommendations for the 2024 report.

"As caregivers we and our families sacrifice a LOT and deserve breaks. The respite stays help me to care for myself and my family so in turn, I can be a better caregiver and advocate for my client."
— Caregiver

Background

In 2019, the DDA collaborated with the William D. Ruckelshaus Center to submit the Rethinking Intellectual and Developmental Disability Policy to Empower Clients, Develop Providers, and Improve Services legislative report. Recommendations in this report included:

- Increased funding for community-based overnight planned respite.
- Expanded access to crisis services for clients currently supported in the community.

In Oct. 2022, we submitted the first of three community respite and stabilization reports. This first report highlighted existing respite and stabilization services and our plan to gather additional information from stakeholders and subject matter experts to better understand the statewide need for these services including initial recommendations to expand contracted diversion beds and mobile diversion services.

This second report reflects progress and shares additional recommendations for two categories, **respite** and **stabilization**.

Respite Services include the following:

Overnight Planned Respite Services

OPRS is a community-based service for adults living with their primary caregivers. The service offers a break in caregiving and provides individualized activities and supports to the client during the respite stay. Services are provided in a community setting, such as a home or apartment and are staffed by contracted, certified providers. Each OPRS respite setting serves one person at a time and clients may use the service up to 14 days in a calendar year.

Residential Habilitation Center Planned Respite

Adults living with their primary caregivers may receive planned respite at state-operated Residential Habilitation Centers certified as nursing facilities. This includes Fircrest, Lakeland Village and Yakima Valley School. Planned respite offers a scheduled break for caregivers and provides personalized activities and supports to the client during their respite stay. RHC planned respite is limited to 30 days in a calendar year and cannot exceed 30 consecutive days across two calendar years.

Stabilization Services include the following:

Diversion Services

Diversion Services are designed to provide temporary services and supports for DDA eligible individuals who are experiencing a crisis that may result in harm to self or others, property destruction or which otherwise indicates a serious deterioration in functioning. The service is intended to provide an alternative to hospitalization or institutionalization. This service may be offered as a 24-hour bed-based service or may be provided as a mobile service that is delivered in the person's home or other community setting as appropriate.

Crisis Stabilization at an RHC

In 2011, RCW 71A.20.180 established up to eight state-staffed crisis stabilization beds at Yakima Valley School. Individuals may access these services when there is a risk of hospitalization without medical need or when they remain hospitalized without medical need. Crisis stabilization provided at YVS differs from the services provided at an RHC certified as an Intermediate Care Facility. The primary purpose of our ICFs is to provide continuous aggressive, active treatment to support an individual to acquire the skills necessary for the client to function with as much self-determination and independence as possible and to return to their home in the community. Fircrest, Lakeland Village and Rainier RHCs are certified as Intermediate Care Facilities.

State-Operated Stabilization, Assessment and Intervention Facility

DDA's State-Operated Stabilization, Assessment and Intervention Facility, also known as SAIF, is certified to provide up to 90 days of short-term stabilization services under Chapter 388-847 WAC. This program provides 24-hour support, for up to six eligible people who have behavioral health needs. They are supported with a team of professionals, such as a behavior specialist, Advanced Registered Nurse Practitioner and a level of staffing to meet the client's needs. Upon discharge to the community, SAIF provides 30-days of post discharge technical support to the long-term care provider.

Stabilization "gives the agency time to regroup and figure out how to best support the individual in crisis once they return to their residence."
— Provider

Enhancements to existing services funded in the 2023-2025 biennial budget

Diversion Services

The legislative appropriation in the 2023-2025 biennial budget will allow us to expand bed-based and mobile diversion services statewide. When implemented, this will help us to better evaluate future needs for diversion beds in various geographical locations.

With this funding, we will offer services in 18 diversion beds across the state with six beds contracted per region. Additionally, funding was allocated to expand the mobile diversion service model to serve individuals in Region 2 in FY2024 and to Region 1 in FY2025.

Diversion Services Planned Expansion for 2023-2025 Biennial Budget

	Current capacity	FY2024 Budget Allocation	FY2025 Budget Allocation	Total
Region 1	3 beds	2 beds	1 bed and mobile diversion	6 beds and mobile diversion
Region 2	2 beds	2 beds and mobile diversion	2 beds	6 beds and mobile diversion
Region 3	3 beds and mobile diversion	1 bed	2 beds	6 beds and mobile diversion

Data source: 2023-2025 DDA Biennial Budget

We are exploring various options to expand mobile and bed-based diversion services using the additional funding allocated.

About the new funding, field staff said, "I'm grateful we will have the ability to begin developing additional options throughout the state."

Emergency Transitional Support Services

We received legislative appropriation to continue emergency transitional services at Rainier School in the 2023-2025 operating budget. This state-funded service was created in direct response to the 2020 COVID-19 state of emergency declared by the governor to ensure critical hospital capacity was available for individuals who needed medical care. This model supports successful transitions from acute care settings to more appropriate long-term services and reduces or prevents rehospitalization under WAC 388-829Z. With the declared state of emergency over, permanent rules were finalized on July 17, 2023 to inform clients about the service they are receiving and the future of that service. We will provide additional data on emergency transitional support services in our final report.

Sharing progress from Fiscal Year 2022 to Fiscal Year 2023

In preparation for this report, we reviewed data for individuals accessing these services and compared them to the 2022 report. As mandated in ESSB 5268, this report documents:

- Our progress towards understanding the number and location where additional respite and stabilization beds are needed.
- The differences between services at our RHCs certified as an intermediate care facility versus a nursing facility.

We have also listened to stakeholders and tribal partners' feedback on these services. Their input on how respite and stabilization services could better meet their needs is reflected in our next steps and recommendations. It is also detailed in the appendix.

Fiscal Year 2023 respite data review

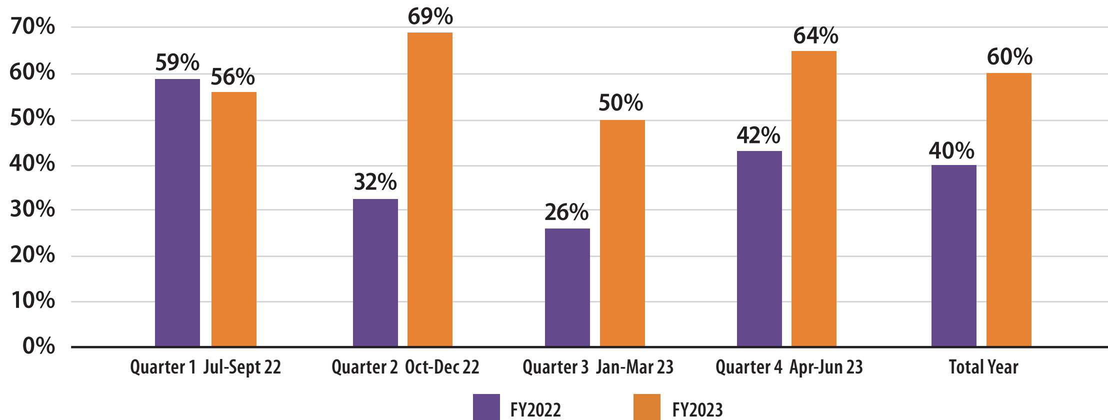
Overnight Planned Respite Services

In FY2023, 276 adults received overnight planned respite services. The OPRS data shows a nearly 14% increase compared to FY2022, which served 243 clients. Both counts include duplicated clients who accessed OPRS multiple times during the 12-month periods.

In FY2023, there were 57 clients denied OPRS services due to their needs exceeding the providers ability to deliver respite services. The overall 21% denial rate is based on client needs. The denial count includes duplicated clients who requested OPRS multiple times during the 12-month period.

In FY2023, we maintained on average a 60% bed occupancy rate. This represents a 50% increase over the 40% bed occupancy rate in FY2022.

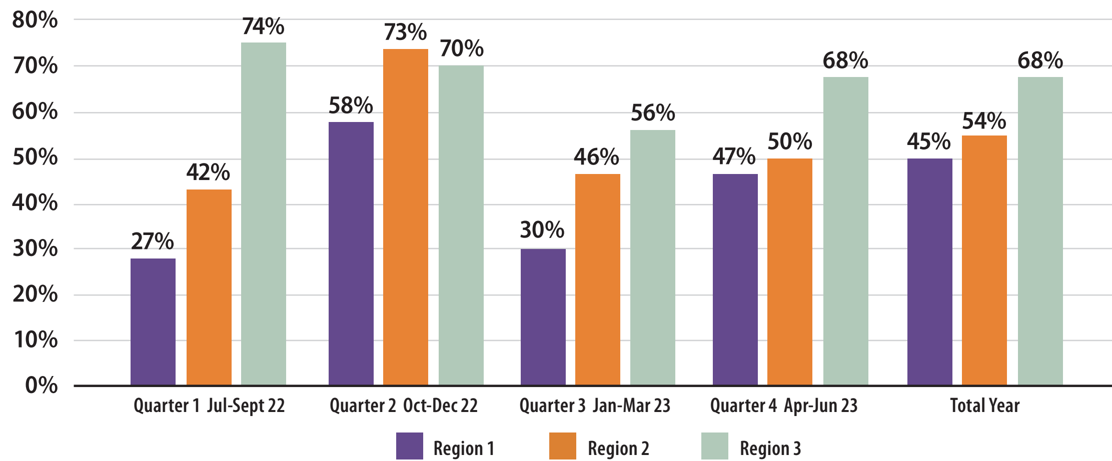
OPRS FY2022 and FY2023 Bed Occupancy Rates Statewide



Data source: Respite and Short-term Services Unit, Date: July 2023

Region 1 had one bed available for most of FY2023 resulting in the lowest bed occupancy in FY2023. Region 3 consistently shows the highest levels of occupancy in the state during each quarter and overall.

OPRS FY2023 Bed Occupancy Rates by Region



Data source: Respite and Short-term Services Unit, Date: July 2023

At the beginning of FY2023, there were 10 contracted beds with four different agencies. One contract was terminated by a provider and two additional locations were offline due to the inability to hire and retain sufficient staff. With the public health emergency unwinding, one of these OPRS locations was able to reopen in May 2023. FY2023 is ending with eight open OPRS locations serving adults and nine contracts across four agencies. One more OPRS location is scheduled to reopen during the first quarter of FY2024.

In FY2023, Olympia, Vancouver and Lynnwood showed the highest rates of bed occupancy, while Bellingham showed the lowest. The OPRS contract in Shoreline was terminated in July of FY2023 and was otherwise offline for most of FY2022. Lynnwood B was offline for Q2-Q4 due to staff hiring and retention issues and will reopen FY2024 in Q1. Spokane B was offline Q1-Q3 due to staff hiring and retention issue but reopened during Q4 of FY2023.

Each OPRS location has different accessibility options and staffing resources, which can impact bed occupancy. Further, an individual or caregiver's preference during higher travel months, and weekend use versus weekday use, all impact monthly bed occupancy rates and date range availability.

OPRS FY2023 Bed Occupancy Rates by Location

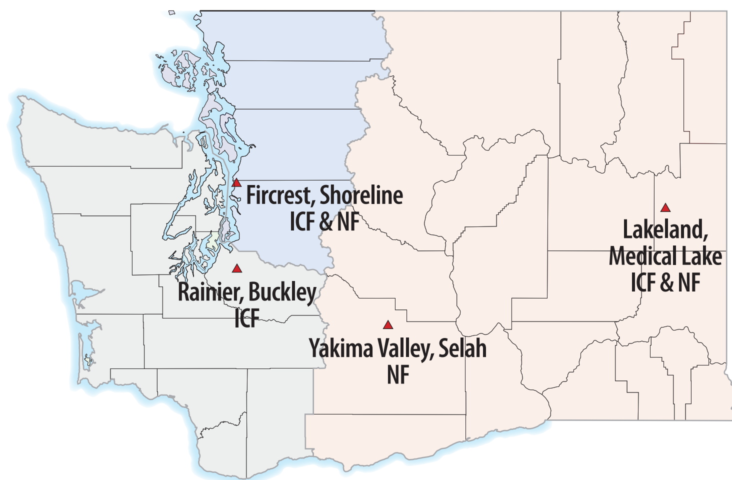
Location	Quarter 1 Jul-Sept 22	Quarter 2 Oct-Dec 22	Quarter 3 Jan-Mar 23	Quarter 4 Apr-Jun 23	Total Year
Lynnwood A	66%	76%	78%	79%	75%
Lynnwood B	42%	Offline	Offline	Offline	42%
Tacoma	50%	53%	29%	59%	48%
Bellingham	18%	71%	15%	30%	34%
Spokane B	Offline	Offline	Offline	50%	50%
Spokane L	27%	58%	30%	59%	44%
Vancouver	80%	73%	76%	73%	76%
Olympia A	84%	84%	55%	80%	76%
Olympia B	80%	70%	65%	73%	72%
Shoreline	Contract Terminated	N/A	N/A	N/A	N/A

Data source: Respite and Short-term Services Unit, Date: July 2023

Residential Habilitation Center Planned Respite Services

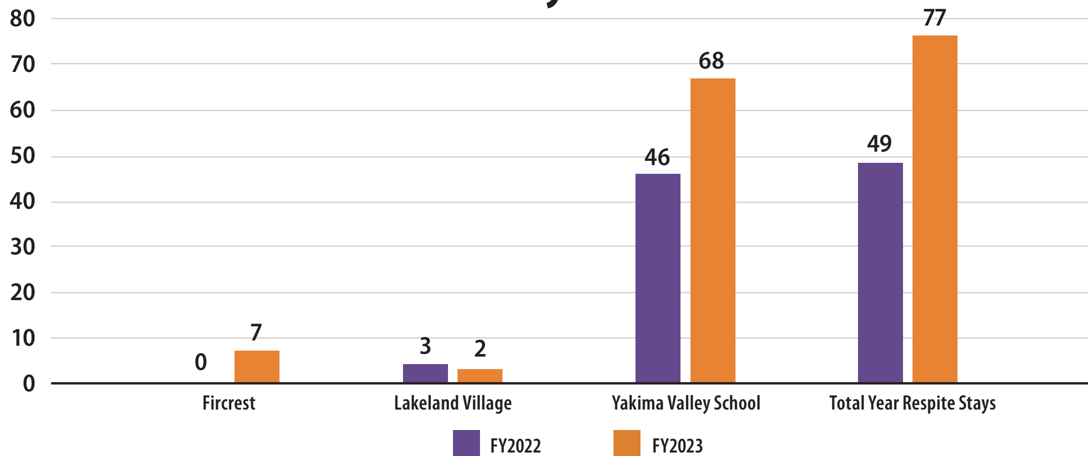
Planned respite is provided at the following RHCs which are certified as nursing facilities:

- Lakeland Village- Region 1
- Yakima Valley School- Region 1
- Fircrest- Region 2



What I like best about planned respite at RHCs is that "you can have peace of mind knowing that your loved one is being cared for—they are safe, healthy, staff know what to do in case of a health event."
— Caregiver

The RHCs provided limited planned respite starting in the second quarter of FY2022 due to the COVID-19 pandemic. Only 49 clients accessed planned respite in FY2022. Despite the break in service, there remains a demand for planned respite services at the RHCs. In Q2 of FY2023, the RHCs resumed accepting requests for planned respite. Since then, 77 individuals accessed the service in FY2023, showing a significant 55 percent increase of those served. Some of these individuals are duplicated in the data as they may have used respite on more than one occasion.



Data source: Respite and Short-term Services Unit, Date: July 2023
**Planned Respite only available at RHCs certified as nursing facilities.*

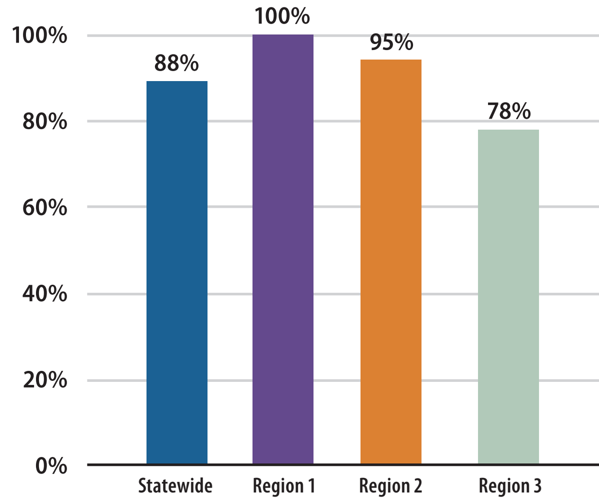
In FY2023, 51 people were denied RHC planned respite due to client needs that exceeded RHC staffing availability. Some people may have been denied more than once in the data based on how many respite requests they made. Of these denials, 14 were determined from Fircrest, 19 from Lakeland Village and 18 from Yakima Valley School.

Fiscal Year 2023 stabilization data review

Crisis Diversion Services

In FY2023, there were six diversion beds available which supported 11 people statewide. These services were integral in preventing inpatient treatment in hospitals or other facility-based settings for the individuals.

- Region 1 had one diversion bed in Benton County.
- Region 2 had two diversion beds in King County.
- Region 3 had three diversion beds, two in Pierce County and one in Thurston County.



The statewide average occupancy rate for diversion beds remains above our established minimum expectation of 80%. The average for FY2023 was 88%, an increase from 85% in FY2022. The remaining 12% vacancy rate reflects time for diversion providers to support transition activities for exiting individuals and training of staff to support new people entering diversion bed services.

Mobile diversion services

Presently this service, which delivers diversion services in a person's home or other community setting, is only available in Region 3. Mobile diversion services are designed to:

- Evaluate the challenges an individual is experiencing.
- Identify strategies that will help to stabilize them.
- Prevent further disruption including loss of caregivers or residence.
- Provide training to the primary caregivers to foster a successful home environment for all involved.

Mobile diversion services supported 26 individuals to successfully remain in their homes and in their communities during FY2023.

State-Operated Stabilization, Assessment and Intervention Facility update

The SAIF program provides stabilization services that support individuals to return to their homes in the community. SAIF provides services to clients in a temporary facility, which opened Sept. 2022 in Tacoma, WA. This facility has the capacity to serve up to three adults. The planned permanent site is located in Gig Harbor, WA. Once renovations are complete and the facility is open, it will have the capacity to serve up to six adults.

SAIF program supporting a client with community integration.

Requests for SAIF services exceed our ability to serve clients in the temporary location. By the end of FY2023, we had served five clients at the temporary location. Referrals for stabilization services provided by the SAIF program came from all areas of the state with the majority coming from the greater Seattle and Tacoma areas. Clients who accessed the SAIF program in FY2023 were between the ages of 18 and 45 and came from either an acute care hospital or their family home. The SAIF program successfully transitioned all clients back into their homes in the community within the 90-day service timeline.

Barriers to expanding access to SAIF services

The SAIF program experienced barriers in finding a facility large enough to accommodate a six-bed program. First was locating a site with enough space to support six clients in crisis needing stabilization services. Second was gaining the appropriate county approvals to create a Level 1 Residential Care Facility.

We are working with Pierce County to obtain the permits needed to modify the Gig Harbor permanent facility. In our final Oct. 2024 report, we will update the Legislature on our progress and provide recommendations on how barriers might be removed for future SAIF locations.

General population hospitalization and escalation updates for FY2023

Acute care hospital admissions and discharge updates

This data reflects the number of individuals admitted to an acute care hospital who remained as a patient after being medically cleared for discharge due to a lack of appropriate services and supports in the community.

- In FY2022, 39 clients were admitted to an acute care hospital. The average length of stay before discharge was 142 days.
- In FY2023, 40 clients were admitted to an acute care hospital. The average length of stay before discharge was 121 days.

> *"Our DDA case worker tells us that the existing facilities are full and have no availability."*
> *— Parent caregiver*

Western State Hospital and Eastern State Hospital admission and discharge updates

Both WSH in Lakewood and ESH near Spokane maintain waitlists for admission to the Habilitative Mental Health wards, which provide support specifically for individuals with IDD. When discharges occur, the resulting vacancy is immediately filled from the respective waitlist. Additional community stabilization options for individuals with IDD may be used to help individuals discharge promptly.

	Admitted to WSH	Admitted to ESH	Total Discharged
FY2022	33	9	14
FY2023	31	10	23

Data source: State Hospital Transition, 6/30/23

State hospital discharges increased 64% from FY2022 to FY2023. As of June 30, 2023:

- There are four individuals who have mutual acceptance for residential habilitation services and are awaiting discharge.
- An additional 14 individuals are engaged in discharge planning activities.

Barriers to accessing state plan adult behavioral health services

We have a process to escalate concerns to the Health Care Authority when there are barriers to accessing state plan services. The process allows DDA and HCA to collaborate directly with the managed care organizations and find solution-based remedies to access needed supports. All escalations are followed through to resolution.

- In FY2022, there were 48 escalation requests sent to Health Care Authority regarding DDA clients.
- In FY2023, there were 60 escalation requests sent to Health Care Authority regarding DDA clients.

Documenting the need for additional respite days

We were asked to recommend whether an increase in respite days was needed. To understand if this was enough, we surveyed clients, family members, guardians, caregivers and paid providers. Over 1,100 respondents shared their input on whether additional respite days are needed.

OPRS — Currently individuals are allowed up to 14 calendar days of community-based overnight planned respite each year. Nearly half of respondents didn't know if additional days were needed. Those who felt 14 days was not enough suggested on average adding at least an additional 20 OPRS days.

	Percent responding if additional OPRS days are needed.			If yes, the average additional OPRS days requested.
Respondents	I don't know	No	Yes	
Clients	42%	15%	42%	24
Families, guardians, caregivers and paid providers	48%	9%	42%	20

RHC Planned Respite — Currently individuals may access planned respite at the RHCs for up to 30 days in a calendar year. Although over half of respondents didn't know if additional RHC respite was needed, those who felt 30 days was not enough suggested adding at least 33 additional RHC respite days.

	Percent responding if additional RHC respite days are needed.			If yes, the average additional respite at RHC days requested.
Respondents	I don't know	No	Yes	
Clients	50%	19%	31%	41
Families, guardians, caregivers and paid providers	61%	19%	19%	33

Next Steps

Our plan to continue reviewing respite and stabilization services over the next year is outlined below. We will include the data and information gathered in our final report due by Oct. 2024.

In the next year we will:

- Partner with providers to identify enhanced trainings and certification opportunities available to OPRS staff to support individuals with more complex behavioral, mental health and/or medical needs.
- Explore respite and stabilization provider development and the expansion of services that is inclusive of underserved communities.
- Continue to investigate additional best practices in respite and stabilization services by reaching out to national partners.
- Explore opportunities to learn more from tribes about their respite and stabilization needs and to contract with tribes or tribal members to provide culturally relevant services.
- Conduct additional listening sessions and surveys to better understand the needs of our clients and assess our progress.

The final report due Oct. 1, 2024, will:

- Provide estimates of future needs around respite and stabilization services.
- Identify gaps in service location for these beds.
- Provide options for contracting with community providers for SAIF beds.
- Make recommendations for whether an increase to respite days is needed.

Initial Recommendations

Our final report in Oct. 2024 will share final data and stakeholder input on our progress toward improving respite and stabilization access and services to adults with IDD. In addition, we will provide our final recommendations at that time.

In this progress report, we are sharing our initial recommendations developed from the data we gathered from surveys and listening sessions with partners and stakeholders over the past year. For example, clients, family members, tribal partners, self-advocates and DDA staff all recommend increasing the number and location of respite beds statewide. Over the coming year, we will further investigate and develop this and other recommendations, such as:

- Consider requesting an increase in funding to support a 24-hour full-time staffing model for each OPRS location.
- Consider requesting an increase in funding for diversion and respite services at the same frequency and amounts as supported living increases. Supported living, respite and diversion providers compete for the same pool of staff. Currently stabilization and respite services are falling behind supported living because they are not included in the legislatively provided rate increases.

"Investing in rates and support for more community providers in more locations around the state is really important; most families won't send a loved one so far."
— Caregiver

Summary

This report summarizes current data and outreach efforts that were completed in FY2023 and our progress in improving access to respite and stabilization services. In the final report we will evaluate efforts that are currently being implemented as we continue to reach out to our key stakeholders and tribal partners for feedback on changes implemented. We will incorporate this to inform final recommendations for further service expansion of respite and stabilization services.

Appendix

This appendix summarizes what stakeholders and tribal partners shared with us about the need for respite and stabilization beds. While overall we saw improvements in our ability to deliver respite and stabilization services in FY2023 compared to FY2022, some needs go unmet and barriers to accessing services remain. Over the past year, we collaborated with partners and stakeholders to gain more information about the barriers they encounter, their needs and how best to meet them.

What we learned from our Provider Survey

We surveyed providers statewide about supporting individuals who receive respite and stabilization services. Below is a synopsis and key takeaways from the provider survey.

Providers' Key Themes on Respite

Increase communication:

Providers highlighted a critical need for more accurate, transparent, timely and comprehensive information in respite referrals. Increasing the amount and level of communication allows providers to determine if they can safely support an individual. Providers also indicated that inconsistent communication with caregivers hampers their ability to support the individual during their stay. Providers must also connect with a caregiver or family member prior to a respite stay and review medication logs, inventory of personal items and the respite agreement. When there are delayed responses, it leads to longer processing times. Providers also reported that pick-ups at the end of a stay, that occur outside of the scheduled time, result in unexpected and extended working hours for staff.

Staff shortages:

Providers reported in the survey that finding, training and retaining qualified staff remains a challenge. The providers indicated that increased funding would help to address this issue. Providers shared they face increased costs of living, overhead and staff salaries that surpass the rate set by the Legislature. Some providers are unable to support a 24/7 staffing model due to a lack in funding which results in denials of respite referrals for individuals who require 1:1 or 2:1 staff to adult ratios. To address these issues, OPRS providers seek a higher daily rate that would allow them to employ staff consistently, rather than solely when a client is present. This would allow providers to accept more referrals, increase staff retention and provide a more stable work schedule.

More widely available respite resources:

Providers would like to see respite become more widely available for adults with behavioral and mental health support needs. Providers are currently limited by staffing ratios and the need for enhanced training to accept individuals with more complex needs.

Providers also suggest respite services should be provided to adults who live with a variety of caregiver types, such as adult family homes or supported living, and who are otherwise ineligible for respite based on their living situation. As of July 2023, DDA updated WAC 388-829C-230 to allow companion home providers to access OPRS and RHC planned respite services.

Providers like:

OPRS providers enjoy meeting new clients and providing relief to caregivers and families. They enjoy taking adults out into the community, creating outlets for them to meet new friends, have new experiences, and support individuals to gain a sense of independence away from home.

Providers' Key Themes on Stabilization

Barriers to accessing services:

An analysis of responses from providers regarding barriers to accessing stabilization services indicate that they feel they often receive outdated, incomplete or even inaccurate information in client referrals. They report challenges in assisting individuals to access mental health and crisis services through community partners. In addition, they feel there is a lack of alternate providers and housing options for individuals transitioning from stabilization services to more traditional community support settings.

Need more alternatives:

Providers noted that some people remain for extended periods of time in settings intended to provide short-term supports up to 90 days. This is due to the lack of community residential capacity related to ongoing staff shortages and limited housing availability. One diversion service provider said, "For the bed-based crisis diversion services we have problems getting people discharged after stabilization because they have nowhere to go." As previously noted, when individuals remain in diversion beds beyond the need for the service, it prevents others from accessing the service. Providers also believe that a more responsive and timely approach by community first responders to intervene when individuals are experiencing a crisis is critical to their ability to offer supports to this population.

What we learned from the DDA staff survey

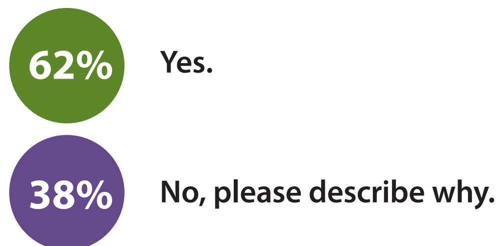
We surveyed DDA staff regarding their experience helping individuals to access respite and stabilization services. We received responses from 107 staff who shared their experience, concerns and feedback for service delivery and improvements. Of respondents, 82% described themselves as either case managers or case manager supervisors.

Staff Key Themes on Respite

Access to services:

An analysis of the survey data, shows most staff respondents who referred clients to respite services were successful in receiving those services for adults on their caseload, with an overall success rate of 62%.

Was OPRS or planned respite at an RHC successfully accessed?



Data source: DDA Staff Respite and Stabilization Survey, May 2023

Lack of provider availability was cited by 70% of survey respondents as being the largest barrier to accessing respite services. Scheduling can be another barrier. Although respite beds are reserved based on a family's choice of dates, beds are not always available for the dates requested.

Respite providers have differing limitations for the programs they operate depending on the location. For example, certain locations are only able to offer shared nighttime staffing. Shared staffing does not allow for the 24-hour staffing model required for 1:1 or 2:1 supervision of adults with medical, behavioral or mental health acuity that require enhanced support. OPRS locations that do provide 24-hour staffing tend to book quickly and are not available in all regions. OPRS providers can only serve one person at a time at each location whereas RHCs can serve more clients in their location. However, RHC staff are shared among individuals residing at the facility, limiting employees' ability to provide 1:1 or 2:1 supervision as well.

Additionally, 56% of staff reported that the distance to the provider posed a significant barrier. The distance to providers creates a challenge for adults who have needs preventing or limiting their ability to travel. The individual may need to travel several hours to find a location that's suitable for what they need, which could prevent them from accessing respite altogether.

Behavioral health:

Client behavior needs remain a primary challenge reported when attempting to access respite services. Sixty-four percent of staff surveyed reported that client behaviors were a significant barrier to receiving services, followed by client's medical needs at 44% and client's mental health needs at 42%.

DDA staff identified barriers to respite services

Data source: DDA Staff Respite and Stabilization Survey, May 2023

Staff Key Themes on Stabilization

DDA staff were asked about their experiences assisting individuals to access the various stabilization services offered by the administration. We sought to validate our preliminary assessment of identified barriers to accessing these services and gather input regarding additional barriers not previously identified. Staff were also offered an opportunity to provide additional information or suggestions regarding efforts to secure stabilization services for those they support.

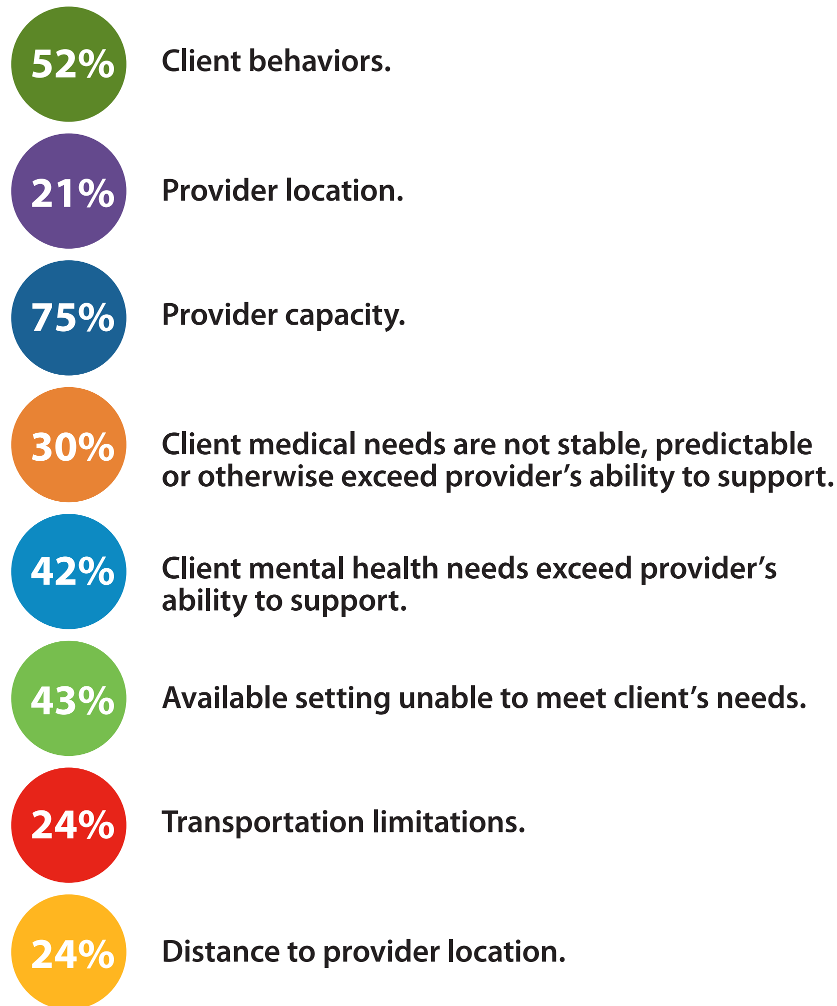
Barriers to accessing stabilization:

Preliminary data from DDA staff surveyed in May 2023 regarding their experiences in assisting clients to access services such as stabilization and diversion indicates that the previously identified barriers continue to limit opportunities for individuals to access these services. Of the DDA staff who responded, over 70% cited limited provider capacity as the single greatest barrier to individuals accessing a diversion bed for stabilization. Limited capacity can be attributed to two primary factors:

> *Case managers shared there aren't enough providers trained and compensated to a level that they feel capable and comfortable supporting people with high behavioral needs.*

- Not enough beds contracted to provide the service.
- Challenges in securing post-discharge services and supports, including housing and provider supports.

Other notable barriers identified by DDA staff include high behavioral support needs of the individual referred followed by unmet mental health needs or the program's inability to meet the mental health or medical needs of the individual as the most common barriers they encounter when working with clients in need. DDA staff reported that location of stabilization services or travel distance required to access them was identified as a barrier to accessing those services less than 25% of the time.



What we learned from clients and caregivers

We surveyed adults eligible for DDA services, caregivers, family members and guardians regarding their experiences accessing respite and stabilization services. We also asked them if additional respite days were needed. We received over 1,600 responses statewide. Approximately 50% of respondents were parents, family members or close friends of a person receiving DDA services.

Respite Key Themes from the client and caregiver survey

Why respite is needed:

Clients and caregivers gave a variety of reasons why they consider or access respite services. The people who receive DDA services may seek out respite for other reasons besides providing a break to their caregiver. They shared they have tried to access respite to:

- Try a new type of housing.
- Gain more independence.
- Explore a new location.
- Attend to a personal need.

The majority of caregivers stated they need respite to relieve stress or prevent burnout. This is closely followed by caregivers needing respite because of physical or emotional exhaustion. A smaller, but still notable portion of caregivers report they use respite for emergencies or to support physical safety needs of others in the home. An overview of this data indicates that respite is necessary to retain caregivers and support adults to safely reside in the community.

Reasons given for trying to access respite services

Clients

%	Reason
38%	Give my caregiver a break.
13%	Meet new people.
38%	Try a new type of housing support.
13%	Learn new skills.
25%	Explore a new location.
38%	Attend to a personal need.
50%	Mental or behavioral needs.
38%	Other reasons.

Data source: DDA Staff Respite and Stabilization Survey, May 2023

Caregivers

%	Reason
78%	Relieve stress or prevent burnout.
63%	Physically or emotionally exhausted.
21%	Need to help a family member or friend.
62%	Attend to personal needs.
30%	Complete household tasks.
11%	Participate in caregiving support groups/training.
30%	Caregiver emergency health needs.
25%	Planned healthcare needs interfering with caregiving capability.
33%	Family emergencies, such as a death in the family.
12%	Physical safety needs of anyone in the home.

source: DDA Client and Caregiver Survey, July 2023

Barriers to accessing respite services:

Some respondents reported their requests for OPRS or RHC Planned Respite were denied. When this happened, 60% said they handled things the best they could at home. However, nine percent reported their loved one was hospitalized and three percent reported the individual went to jail.

Responses from this survey were consistent with the staff and provider surveys; location and scheduling issues are barriers to accessing the services. Caregivers also noted that clients' behavioral and supervision needs that exceed the respite setting remain a serious barrier. The largest barrier identified was the need for additional information on respite services. This year we will work to fill this need and provide an update on our progress in the final report next year.

Stabilization Key Themes from the Client and Caregiver Survey

Barriers to accessing stabilization services:

Responses from clients, caregivers and guardians surveyed regarding barriers to accessing stabilization services support similar themes about a lack of available stabilization resources statewide and the ability of those services to meet the support needs of the individual.

We also received feedback that more than 50% of respondents were unaware that stabilization resources such as diversion or SAIF are available and that additional education about these services, what they can provide and how one should go about requesting access to them would be of great benefit.

In addition to a lack of resources, many families and guardians shared concerns about sending their loved one to someplace far from their home and from those that they typically rely on for support. Many shared that they were uncomfortable with the thought of allowing caregivers who do not know their loved one well to provide for their care. This is especially true if the individual:

- Is not stable.
- May experience significant mental health or behavioral challenges.
- May not be able to communicate verbally with interim caregivers.

Twenty-seven percent of respondents stated that there either weren't enough staff available to provide stabilization services or that the programs or staff that are available are unable to meet the individual's support needs for a variety of reasons. Additionally, they shared the need to be able to access these services in or near one's home community. This would ensure distance to the service didn't prevent them from accessing it and minimize further disruption to the individual.

Caregiver identified barriers to stabilization services

- **53%** Need more information.
- **31%** There is no stabilization service near me or I don't have transportation to access them.
- **8%** The person I support refused help from others or is unable to leave home to access services.
- **12%** The person I support has needs that can't be met by others.
- **32%** Staff don't have the training to provide for our medical or behavioral needs.
- **35%** There aren't enough staff to meet the needs of the person I support.
- **7%** Nursing care isn't available.
- **9%** The person I support doesn't qualify for stabilization services.
- **37%** Care is not available when we need it.
- **14%** Stabilization locations can't meet our supervision needs.
- **11%** Stabilization locations can't meet our communication accessibility needs.
- **14%** Stabilization locations can't meet our accessibility needs.

Data source: Client and Caregiver Respite and Stabilization Survey, July 2023

Key themes from initial listening sessions with tribal partners at the Indian Policy Advisory Committee's DSHS subcommittee

We engaged in a listening session with our tribal partners at IPAC and subcommittee members regarding access to respite and stabilization services. Here is our synopsis of the key themes we heard.

More information

We heard tribal members' need for more information about respite and stabilization services, including how to request them or who to contact for help. We were encouraged to have a local point of contact to build strong relationships and share information about programs and services that meet the individual needs of each tribe.

Streamline the process

We heard that services for people with IDD can be complicated to access. When there are multiple steps to access a program, clients or their caregivers may feel overwhelmed and give up. Simplifying the process to request services would make them more accessible to tribal members. Participants also recommended decreasing wait times in accessing respite or considering specific types of more emergent respite options. Wait times can be difficult for families and clients, who may not feel comfortable asking for help until their need is immediate or urgent. The complicated process and the wait time are both separate barriers, each of which may discourage someone from pursuing the services they need.

Additional, more rural locations

We heard the need for tribes to access respite and stabilization services in their communities. They shared that the locations of existing services tend to be targeted toward the more populated areas, while services are harder to find in more rural areas, such as the Olympic Peninsula.
Lack of transportation is a barrier to accessing services in both urban and rural areas. Even for those willing to travel, the distance and limited transportation options are challenging. Tribal member caregivers and adults need either support with transportation directly or locations expanded statewide so that travel outside of the local community is minimized. When exploring opportunities for tribes and tribal members to be contracted providers for DDA services, it was suggested we use the government-to-government approach in DSHS administrative policy 7.01.

Key themes from initial listening sessions from Self-Advocates Guiding Council.

We engaged in a listening session with the Self-Advocates Guiding Council regarding self-advocates' experiences accessing respite and stabilization services. Here is our synopsis of the key themes of their feedback.

Self-Advocates Council Key Themes on Respite

Self-advocates highlighted how maintaining caregivers was critical when it came to ensuring stability of adults receiving DDA services. There were concerns about caregiver retention considering the nationwide shortage. Making sure respite and stabilization services are available when needed is necessary to maintain service continuity and ensure individuals do not lose their housing.

They would like to see an increase in the amount of respite hours/days available for adults and their caregivers. Providing appropriate levels of respite support can help with caregiver retention and maintain stability for adults living in their community.

Self-advocates gave examples of enjoyable experiences accessing respite, including meeting and making new lifelong friends.

There is a critical need for respite for individuals who have higher medical acuity, behavioral or mental health needs. Adults who need enhanced supports struggle to access respite or find qualified providers that have enough highly trained staff, the location, space or modifications necessary to provide the service, and within areas of the state that allows for ease of access for the individual.

Self-advocates asked us to think about expanding a variety of respite settings statewide for individuals, including in-home respite services and out-of-home respite services that are available in the local community where the individual resides.

Self-Advocates Council Key Themes on Stabilization

Self-advocates encouraged us to think about the national shortage of caregivers and how that is contributing to individuals in crisis needing stabilization services. This group shared concerns around individuals having to leave their home to access services and potential impacts such as a loss of residence, loss of employment, loss of rental assistance or housing vouchers and caregivers or staff who may seek other employment opportunities during their absence. The coming expansion of mobile diversion services may be one way to address these concerns and mitigate subsequent issues by bringing the person support in their current setting rather than necessitating a move, even temporarily, to another setting to access these supports.