



## ADSD Olmstead Community Workshop

### Summary Report

#### Methods

Community Workshops were held with consumers, caregivers, family members, and advocates at multiple locations in the north, south, and rural areas of Nevada. The purpose of the Community Workshops was to gather feedback directly from people with lived experience (PLEs) to include ADSD service recipients, family members, care providers, and advocates about what is needed to improve community-based services and supports to people with disabilities across the lifespan.

Workshops lasted approximately 90 minutes at each site. Each workshop began with a description of the Olmstead decision, the ADSD Olmstead planning process, and an explanation of how the workshop information was relevant to planning efforts.

#### Workshop Logistics and Number of Participants

There were a total of nine workshops conducted that hosted a combined total of 128 participants. The location, date, and number of participants for each of the nine Community Workshops are provided below.

- The Reno workshop occurred on February 21, 2023, and had a total of 10 participants.
- The Fallon workshop occurred on February 21, 2023, and had a total of 12 participants.
- The Winnemucca workshop occurred on February 22, 2023, and had a total of 1 participant.
- The Elko workshop occurred on February 23, 2023, and had a total of 19 participants.
- The Mesquite workshop occurred on February 27, 2023, and had a total of 5 participants.
- The Pahrump workshop occurred on February 28, 2023, and had a total of 6 participants.
- The Las Vegas workshop occurred on March 1, 2023, and had a total of 21 participants.
- A virtual workshop occurred on March 6, 2023, and had a total of 35 participants.
- A virtual workshop occurred on March 10, 2023 and had a total of 19 participants.

#### Summary of Workshop Discussions

The workshop discussions were structured around 11 questions that were developed to assess the extent that people knew about the Olmstead decision as well as the services available to support community integration. The bulk of each workshop focused on what services were needed for community integration purposes and how well the existing service systems met such needs.

The structure of the workshops was consistent across all in-person gatherings. To ensure sufficient time for all participants in the virtual settings, the structure for input was slightly modified. Input received from the in-person gatherings was summarized and then presented to participants in the virtual settings. Participants in the virtual settings were then asked to indicate, through polling, the extent to which they agreed with what had already been identified. Following polling, participants were offered the opportunity to add any additional thoughts they had on the subject either verbally or through use of the chat function within Zoom.

The summary of input received across all workshops is provided on the following pages.

## Understanding of the Olmstead Decision

Participants were asked to describe to what extent people with lived experience and their family members understand the Olmstead decision.

**People have a limited to non-existent understanding of the Olmstead Decision.** While a handful of workshop participants indicated a moderate to deep understanding of the Olmstead decision, the vast majority indicated a limited to non-existent awareness. There was recognition that while individuals may not know about the term “Olmstead” specifically, there was some understanding of “waiver” services and the availability of supports to assist with independent and integrated living options.

During the two virtual workshops, polling was offered that asked people to rate their level of understanding of Olmstead on a scale between one and five. Of the 44 people who participated in the poll, the results were as follows:

- 32% (14/44) rated themselves as a “1” indicating they know nothing about Olmstead.
- 59% (26/44) rated themselves as a “2” indicating they know a little, but not much.
- 7% (3/44) rated themselves as a “3” indicating they knew a reasonable amount.
- 2% (1/44) rated themselves as a “4” indicating they know a good amount.
- Not a single participant that responded to the poll rated themselves as a “5” indicating they knew a lot.

Some contextual themes came up throughout the discussion on this topic and are summarized below.

- There are differing understandings of Olmstead between those with developmental delays (and the individuals that care for them) and those from populations of individuals that are aging, and/or that are experiencing Alzheimer’s and/or dementia. Workshop participants indicated that the aging population as well as those individuals with dementia or Alzheimer’s may be less informed than the other populations impacted by the Olmstead decision. Reasons offered for this included the belief that the aging population did not grow up with the benefits offered by the ADA or the Olmstead decision.
- While service provider workshop participants indicated a greater knowledge than people with lived experiences, they still indicated a low level of awareness about the decision or its implications to service delivery. Furthermore, there were comments made at two of the workshops proposing that with a higher level of awareness about Olmstead, providers, specifically those conducting functional assessments, may conduct their business in a manner that provides greater access to Olmstead driven supports.
- Some participants indicated a greater knowledge of the Olmstead decision in other states and associated this to lawsuits that have been levied against those states, bringing the issue to the forefront of the service delivery system.

“People don’t understand the far-reaching things that Olmstead impacts - things like transportation and access. Furthermore, service providers don’t know the 10 waiver services, placing people [with lived experience] in the position of having to ask for them.”

~Workshop participant, and service provider~

“This is the first time I am ever hearing about anything called the Olmstead Decision.”

~Workshop participant, and father of a child with severe functional disabilities~

## Knowledge of ADSD Service Availability & Identifying Where People Get Information

Participants were asked to identify where they got information the first time they accessed support through ADSD or other state divisions.

Peer-to-peer information sharing, self-directed internet research, and service providers were most often the sources that people identified as having provided information about available services and supports. Other sources of first-time information included schools, hospitals, and regional centers. Specific service providers referenced at least once but no more than twice during workshops included the Autism Network, Care Chest, the Douglas County Public Guardian, Nevada Early Intervention Services, the Nevada Care Connection, Nevada Pep, and 211.

During the two virtual workshops, polling was offered to assess the degree to which people agreed with the sources of first-time information that had already been identified. While a total of 38 people participated in the poll, respondents were offered the option to agree with as many of the locations as they saw fit. The results demonstrate the percentage of those that participated in the poll's agreement with the locations where people most often get their information from when accessing ADSD or other state sponsored supports for the first time.

- 26% (10/38) agreed that peers were their first source of information about support options.
- 26% (10/38) agreed that self-directed research efforts were what led to accessing first time supports.
- 26% (10/38) agreed that service providers were their first source of information about support options.
- 16% (6/38) agreed that schools were their first source of information about support options.
- 8% (3/38) agreed that hospitals were their first source of information about support options.
- 8% (3/38) agreed that regional centers were their first source of information about support options.

Some contextual themes came up throughout the discussion on this topic and are summarized below.

- Peer-to-peer information sharing is where many people receive information about ADSD.
- Hospitals will provide information to parents if they have a child born with a disability or if a person has shown up at the hospital and is being discharged with a functional limitation.
- Schools were noted as a place where people often first encountered ADSD services, however they noted that the information shared was not universally distributed.
- Sometimes service providers will offer referrals to ADSD services, but that is very dependent on the individual as there is no systems wide approach to service connection.
- Many folks stated they first learned about ADSD services through their own internet research but stressed that the information was hard to find or understand.

"I am one of those parents who is tired. It takes so much energy to get information, and I need that energy to care for my 38-year old son."

~Workshop participant, and parent of an adult child with severe functional disabilities~

"I called every state number I could find online... I continued to call until I got directed to call Sierra Regional Center, which is how the ball got rolling for my daughter. The process took eight months."

~Workshop participant, and parent of a child with a disability~

**Participants were asked to share their perspective about the extent that people with lived experience (and their family members) know about services that provide community integration supports?**

**People with lived experience, as well as their family members do not know much about what services are available to support community integration.** There was a variety of perceived reasons offered to explain this circumstance which included high turn-over rates of ADSD staffing, intentional withholding of information by service providers, and a constant churning of available services/service providers. These reasonings and more are more fully summarized below.

- People get information in bits and pieces, and usually from other service providers. The amount of information you get and the quality of that information is largely dependent on the individual service provider.
- Because of the high turn-over at ADSD, it is not common to find an employee that has a deep understanding about the variety of services available through ADSD. This leaves PLEs with the responsibility of knowing the key terms or the right things to ask for, to get the help they need.
- Sometimes providers intentionally do not share information with PLEs about what services are available either because they are competing against other organizations to provide such services, or it is not in their organization’s best interest to share such information.
- Because people are on long waiting lists, sometimes they just give up on trying to understand what services are available. They feel hopeless about getting their needs met.
- Because things change (due to legislation or provider turn-over), many people do not know the full range of services available or who can provide services to them.

“I work for the NCED Family Navigation Network and find that families who contact us have heard that there are some kind of support/services out there, but they don’t know what they are let alone how to access them.”

~Workshop participant, and service provider~

**Participants were asked to share their perspective about where people with lived experience (and their family members) get information?**

**Peer-to-Peer information sharing, self-directed internet research and service providers were identified most often as the places where PLEs get information about available services and supports.** Advocacy organizations and doctor’s offices were also identified. Other sources with greater specificity included:

- Tv news segments and newspapers: Older people were identified as accessing information through more traditional mediums.
- Referrals and transfers from other states: People who move to Nevada from another state will often seek out similar services as a component of their move.

“The NCED Family Navigation Network helps in connecting families with resources. They have been very helpful for me in getting resources and information for my daughter. They got me help with medical connections, community resources and assistance for things for her to participate to the fullest extent possible in school”

~Workshop participant, and mother to a child with a disability~

Lastly, participants were asked what they would recommend to help ensure that information is readily available about the services that are available through ADSD.

Workshop participants made several suggestions regarding how ADSD could increase knowledge and awareness of its service options. Suggestions identified in at least two of the nine workshops conducted are described below.

- **ADSD Website Improvements:** Improvements to the ADSD website were almost universally requested in the community workshops conducted. Suggestions such as the use of simple language, comprehensive service listings and descriptions, and navigational ease were identified as needed improvements.
- **Targeted Messaging:** It was recommended numerous times that ADSD develop targeted messaging to each of its service populations. Specific recommendations included:
  - Utilizing tv ads, billboards, and direct mail for seniors. Sending information within utilities billing was also identified as a potential strategy to spread information to seniors.
  - Utilizing specific social media platforms for targeted age ranges and demographic profiles.
- **ADSD Staff Trainings:** Regular and ongoing training for ADSD staff to ensure they understand the full range of services available throughout the agency, regardless of population being served, and can act as a “no wrong door” portal to all available assistance was recommended in most workshops conducted.
- **Provider Outreach and Education:** There was a wide consensus that ADSD should conduct regular outreach and education efforts with partners that most intersect with the work they do. Hospitals, schools, contractors, first responders, public health nurses, and other social service entities should receive regular (one person suggested quarterly) updates about service offerings.
- **Promotion of 211:** Workshop participants were of mixed opinions about the value of 211. While some participants considered the state resource outdated and limited in its helpfulness, others felt like it had existing value or at least the potential of usefulness but only after the successful deployment of necessary improvements.
- **Pro-active Client Communications:** A variety of suggestions were offered regarding pro-active client communications, each of which are provided below.
  - Assigning transition coordinators to families that are leaving one system and entering another to ensure they have the information needed to successfully access all available services within the new system.
  - Each ADSD caseworker should, when working with a family, go through a checklist of other services that they may also benefit from.
  - Upon initial eligibility determination, send families information about other service options available and their contact information.
  - Centralize information about community service provider options, capacity, and quality of care.

“We have been hearing about No Wrong Door for years, and there is still no progress. I was just in a meeting before this about No Wrong Door, but nobody can get the right information from ANY Door. Things are not getting done.”

~Workshop participant, and service provider~

## Needs to Keep (or Support) Individuals Living within Integrated Settings

**Service Enhancements:** Participants were asked to describe what services are most needed to ensure community integration opportunities.

Housing, transportation, in-home care, personal care attendants, and respite care were the services most referenced as needed to support and sustain community integration options for individuals with disabilities.

Expansion of the following services was described in many of the community workshops held:

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|---|---|
| ✓ Affordable Housing Options & Modification     | ✓ Peer Support Network                  |
| ✓ Crisis Supports                               | ✓ Personal Care Attendants              |
| ✓ Day Care Services                             | ✓ Personal Support Assistance           |
| ✓ Durable Medical Equipment                     | ✓ Primary Care (In-Home and Community)  |
| ✓ Home-based Therapies                          | ✓ Respite for Families                  |
| ✓ Job Training Programs and Providers           | ✓ Social and Recreational Opportunities |
| ✓ Life Skills Training and Financial Counseling | ✓ Supported Living Arrangements         |
| ✓ Mobile Crisis Services                        | ✓ Transportation Options                |

“The number one issue we always hear about is housing and supported living arrangements. There is a homelessness problem. People are stuck in institutions. Real estate has skyrocketed. There are advocates with money to move folks out of institutions, but no money for housing after that.”

~Workshop participant, and service provider~

Other suggestions made at least once during workshops included:

- |  |                                 |
|--|---------------------------------|
| ✓ Behavioral Health Care   | ✓ Life Skills Training          |
| ✓ Community Inclusion Training for Employers and Providers Servicing Individuals with Disabilities | ✓ Mental Stimulation Activities |
| ✓ Competitive Employment/Job Placement   | ✓ Self-Advocacy Training        |
| ✓ Expanded Resource Navigation   | ✓ Social Security Advocates     |
| ✓ Gambling Support   | ✓ Special Dental Clinics        |
| ✓ Host Home Program  | ✓ Supported Decision Making     |
|  | ✓ Supported Employment Options  |
|  | ✓ Volunteer Opportunities       |

**Geographic Specific-Enhancements:** Additionally, participants were asked if there were any geographical considerations that should be considered as a component of the planning process.

- **Incentives for Services to Rural Populations:** Workshop participants expressed a significant need to incentivize providers to service rural areas. Without an incentive, providers are not able to sustain the cost of service provision, contributing to high turn-over and low quality of care.
- **Weather-based accommodations:** Multiple providers identified the implications for service populations living in Las Vegas and some of the adjacent communities that experience high temperatures in the summertime. Activities requiring outdoor participation are not always an option as high temperatures are known to be a seizure trigger for some developmental conditions. Additionally, the high cost of air conditioning during these months to host additional indoor activities should be accounted for.

**System Enhancements:** Participants were asked to identify the one thing they would change about the current service system particular to ADSD.

Several suggestions were made regarding the changes needed within the ADSD service system, all of which are summarized below.

- Assign a universal navigator to families that stays with them throughout their lifespan.
- Center the person in service delivery instead of the division, program, or funding stream.
- Decrease bureaucracy for family members caring for their loved ones.
- Decrease staff to client caseloads so more person-centered and pro-active service delivery can occur.
- Establish more public/private/family partnerships to ensure long-term sustainable service system.
- Improve ADSD staff knowledge of full-service spectrum and require person-centered care practices.
- Increase flexibility in service offerings and eligibility requirements.
- Streamline application process and information sharing across State departments and divisions.

**Participants were asked if there was any other information that they felt critical for the planning group to understand.**

- **Workforce Compensation:** Participants described a reality in which provider rates and reimbursements are so low that the field cannot sustain a sufficient workforce in quantity, quality, or longevity.

## Barriers to Accessing Supports

**Participants were asked to share the primary barriers to accessing community-based supports through ADSD.**

The primary barriers to accessing community-based services through ADSD include 1) the system being difficult to navigate, 2) long wait lists, 3) inflexible eligibility requirements, and 4) an insufficient workforce within ADSD and throughout industries that provide community-based supports.

Other barriers noted during workshops included:

- A lack of knowledge about what services are available or what exactly to ask for serves as a barrier for PLEs.
- Stigma and fear of PLE's personal autonomy being taken away from them.
- Distrust of state system. People get frustrated with the system and just give up.
- Sometimes the lack of culturally appropriate care or language barriers prevent people from getting the help they need.
- It is hard to get a diagnosis that makes people eligible for support.

Beyond the barriers to accessing supports through ADSD, multiple workshop participants referenced the difficulty in accessing supports as an individual who does not qualify for Medicaid. There was also a note made of individuals who are outside the geographical boundaries of the major population hubs being unable to access services only because of the regional center that was servicing them.

“People don't know that there are advocates out there to speak up for their needs...there are people you can call on when your case worker is not listening to you. Agencies don't want you to have an advocate because it means it keeps them on their toes.”

~Workshop participant, and individual with a disability~

**Participants were finally asked whether it was easy or difficult to navigate the ADSD service system.**

Participants noted that there were both assets and gaps experienced when navigating the ADSD service system. While the gaps were more often referenced, several participants in multiple workshops shared that they appreciated ADSD for a variety of reasons. The list of both assets and gaps have been summarized below.

**Strengths** of Navigating the ADSD Service System include:

- Some service providers noted having an open line of communication with individuals at ADSD who are responsive.
- Some ADSD state staff are knowledgeable and care about people.
- The co-location of services makes it easier for people to get all their needs met in one place.

“ADSD is the best of the state divisions. They just need to make information more accessible and the process a little bit easier”

~Workshop participant, and service provider~

**Gaps** in Navigating the ADSD Service System include:

- Service providers are always changing, making it hard to get services and nearly impossible to build community knowledge of who to contact for support.
- The application process is cumbersome and time consuming. The requirement to go through “due process” for everything was also noted as a difficulty.
- The systems in the various parts of the state are different, making it hard for people to know what to do when they move.
- Staffing levels are low resulting in people being served at a slower pace than what would be considered reasonable and the division lacks an overall depth of knowledge to do the job effectively. Both of these leave PLE independently responsible for their own care or reliant on the grace of a loved one to make sure they are okay.
- The lack of cell service in the rural areas of the state can make it difficult to access the care you need if it is dependent on telecommunications.
- There are few transitional supports offered for people as they age into or qualify for other services. This is especially true for those young adults with disabilities that are transitioning out of school-based supports.
- Participants raised the issue of not knowing which community-based providers to choose from and not having access to quality assurance information makes it difficult to determine best options.
- COVID-19 and the transition to virtual therapies was identified as a concern regarding the diminished value of that needed service.

“I work in the system and it is hard for ME. You have to know who the correct staff and departments are. The names of the department don’t always align with what they provide. People get bumped from place to place because none of us know what the other people do. You keep hitting barriers.”

~Workshop participant, and service provider~