2024

Enhancing Services for People with Co-Occurring Intellectual and Developmental Disabilities and Mental and/or Behavioral Health Supports in Washington

Report of Individual, State, and National Experiences, Models of Support, and Recommendations

NATIONAL LEADERSHIP CONSORTIUM
ON DEVELOPMENTAL DISABILITIES

WADDC

The National Leadership Consortium

Leadership, Values, and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.

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REPORT SUMMARY

What is the WADDC?

WADDC stands for the Washington State Developmental Disabilities Council. It is made up of people with disabilities, their family members, advocates, and representatives from state departments. They work to improve the lives of people with developmental disabilities in Washington state.

What is the NLC?

NLC stands for the National Leadership Consortium. This group provides training, support, and research for leaders in the field of disabilities.

What Happened?

The WADDC gave a grant to the NLC to research how Washington state can make its services better for people with both disabilities and mental or behavioral health support needs. This research was also interested in finding out what people from different groups, like minority racial groups and people who live in rural areas, liked and did not like about their services and what would help them get better services. The research had four parts:

Part 1: Researchers from the NLC looked up a lot of information about what Washington state was doing to make services better and how more people could get services.

Part 2: In July and August of 2024, people who get disability and mental or behavioral health services answered an online survey, took part in a virtual focus group, and took part in interviews. They talked about what was good and what was bad with their services. They also gave recommendations about how to make their services better and how more people could get services.

Part 3: Researchers from the NLC looked up information about what other states were doing to make their services better and get services to more people. Researchers from the NLC also interviewed experts from different states to find out what was working in other states to make services better.

Part 4: NLC created a report and two plain language documents about what people in Washington said about their services and about what they learned from other states. The NLC also created a plan for a statewide event to continue this work to try and make disability and mental health services better.

Recommendations

Based on what people shared, NLC came up with recommendations to improve services in Washington.

1. Make systems that support people with disabilities and mental or behavioral health support needs work together. Many people shared that it is hard to get services for having a disability and services for having a mental health support need. Many support coordinators, support staff, and medical professionals do not understand how to support both types of needs. More training and working together across systems is needed.
2. Make sure there are enough staff to support people with disabilities and mental and behavioral health support needs. Make sure that staff have the training and support they need to provide good services.
3. Make sure there are enough services for people with disabilities and mental and behavioral health support needs. Make sure that people living in rural areas have the transportation and services they need.
4. Train and support service coordinators, support staff, and medical professionals to support people with disabilities and mental and behavioral health support needs. Make sure that staff use person centered practices to provide great services.
5. Help people who live in institutions because of their mental or behavioral support needs live in the community. Help community service providers so that they can provide services that people need.
6. Support advocacy for better mental and behavioral health supports for people with disabilities. Hold an event so that people can come together to talk about the next steps to improve services for people with disabilities and mental and behavioral health support needs.

INTRODUCTION

A 2022 report from the Washington State Department of Social and Health Services Developmental Disabilities Administration (2022) has found that 37% of people with intellectual and developmental disabilities (IDD) living in Washington also have a co-occurring mental and/or behavioral health support need. Around the United States, systems have invested funds, resources, and efforts into improving access, availability, and quality of services for people with co-occurring support needs. However, people in Washington (DDA, 2022) and around the country consistently report struggles with getting and maintaining needed services. Further, people with co-occurring needs who do access services often share that their service providers are ill-equipped to support them, lacking awareness of the mental and behavioral health needs of people with IDD. Research consistently shows that these issues are even greater for people from traditionally underserved populations, including BIPOC, LGBTQIA+ people, and rural communities.

People with co-occurring support needs are people with intellectual and developmental disabilities (IDD) who also have mental health and behavioral needs; often, people use or attempt to use services that meet their IDD support needs and services that meet their mental or behavioral health support needs.

The state of Washington has created programs, set policies, and funded several initiatives to improve services for people with co-occurring support needs. However, according to 2020 data from the Residential Information Systems Project, more than 500 people still receive services in state-operated institutions (not including people living in private institutions that do not receive Medicaid funds), and the state is planning to build more institutional facilities. In 2020, the state also had a waiting list of more than 14,000 people who continue to need services. It is certain that a high proportion of people who are currently institutionalized and people who do not yet receive services have co-occurring IDD and mental and behavioral health support needs. There is a great need for statewide efforts to improve services for people with IDD and mental and behavioral health supports, particularly for those from traditionally underserved communities.

To better understand the need in Washington, the National Leadership Consortium, with support from the Washington Developmental Disabilities Council, conducted a three-part study of Washington and national perspectives to understand

1. The current landscape of policies, programs, services, and practices in supporting people with IDD and mental and behavioral health support needs in Washington.
2. The experiences, needs, and expectations of people with IDD and mental and behavioral health support needs in Washington.

3. Current policies, programs, services, and promising practices in other states and nationally that can inform the future efforts and direction of Washington.

This report outlines the findings of the three-part study and ends with recommendations to improve the Washington service system. The recommendations were designed to inform people with lived experiences, professionals, and advocates who can determine how Washington can move forward to ensure that people with co-occurring IDD and mental and behavioral health support needs can access and benefit from the services they need and want.

PART ONE WASHINGTON BEST PRACTICES AND STATE OF THE SYSTEM

This part of the report reviews recent Washington-specific literature and data to examine existing policies, programs, models, and disparities within state service systems.

"I am a single father of 2 adults with autism, live at home with both and have no family support and caregivers are only paid for 1. We need a break and someone to actually see them and give them the help they need."

I am a 50-year old adult female with ADHD, autism, PTSD, and a multitude of severe physical conditions. I am unable to get almost any help due to age, gender, and insurance being Medicare."

"I'm a 71 year old, gay, autistic man with mobility issues and terminal cancer. I have yet to find a single medical or mental health professional with ANY experience, knowledge or training in the needs of the autistic. I have trouble taking care of myself at home. I am completely isolated with no social support. I've talked about this with at least four major medical institutions, but they can do nothing but try to refer me to Autism Speaks, a group of parents of Autists, focusing on their own needs and ignoring all over 18. UW focuses on using behavioral therapy to make me hide my autistic characteristics. I've been to a dozen social service organizations. They take my information and that's the last I hear from them. No wonder why the average lifespan of autistic people is 39."

"I am an immigrant and although I speak English, it is not my first language. I'd rather prefer to receive services in my language, but that become secondary once we start considering costs and location, those are barriers more difficult to overcome for me, so I sacrifice my cultural needs just to receive what I can even if it is far from what I want."

"I was laid off from a mental health care organization for having ADHD and probably autism. That shows you how bad our services are here in Washington."

Introduction to Part One

Over the last few decades, the state of Washington has progressively transitioned toward a more supportive and comprehensive alignment between the Intellectual and Developmental Disability and the Mental and Behavioral Health Systems. The strategic work and collaboration of the Developmental Disabilities Administration, the Behavioral Health Administration (BHA), and other public organizations have aimed to set Washington up to be responsive to the needs of people with intellectual and/or developmental disabilities (IDD) and mental and/or behavioral health support needs across the state. Key legislative transformations, such as the implementation of Medicaid waivers and the adoption of the Olmstead Decision's mandates, have also laid the foundation for policies promoting inclusion and independence for people with IDD and co-occurring mental or behavioral health needs (Sulewski & Timmons, 2019). Further, Washington's current policies focus on improving service accessibility and quality through initiatives such as fully integrated managed care, crisis intervention programs, and telehealth expansions. While these policies have addressed many barriers, challenges such as long waiting lists for services, workforce shortages, lack of culturally competent providers to support historically underserved communities, and regional disparities persist.

Assessment of Relevant Washington Policies, Practices, and Data

During the summer of 2024, the National Leadership Consortium conducted an in-depth analysis of current Washington policies, programs, and models of support related to intellectual and developmental disabilities and mental and behavioral health supports.

Part one of the report offers a comprehensive analysis of current policies, revealing successes and prevailing gaps in meeting the needs of people with IDD and mental and/or behavioral health support needs. As the state continues to refine these service delivery systems, there is a growing need to assess the effectiveness of current programs and address the remaining obstacles to diverse, equitable, inclusive, and high-quality support.

Assessment of Current Policies and Programs

The Consortium team, with the support of Washington disability system experts, reviewed current policies and legislation related to human rights, service regulations, and access to support for people with IDD and mental and behavioral health support needs. They also reviewed existing models and programs in Washington to gather relevant information about the systems practices that inform, regulate, and fund services. Available literature, policy reports, and relevant information about the impact of policies and programs were also reviewed to determine their current and potential efficacy and implications.

Assessment of Washington-Specific Data from a National Dataset

A secondary data set analysis was performed using National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD) data from the state of Washington (See Appendix A for a description of the methodology). The subsample analyzed contained 29 variables on Background Information, Health, Behavioral Support Needs, Staff, and Access to Needed Services/Supports. These variables were selected for this analysis because they provide relevant information regarding IDD and mental/behavioral health diagnoses, quality of services (including support staff respect and communication), and access to needed services and supports. A total of 346 observations were recorded, with frequencies and percentages calculated for each indicator within the variables.

The analysis highlights the diversity of the population and underscores the various levels of support and services accessed or needed by people, especially those with co-occurring support needs. Understanding this data is crucial for informing policies and services to enhance the quality of life for people with IDD.

The National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) is a national data set designed to measure, monitor, and improve the performance of developmental disabilities agencies. NCI®-IDD was developed by the National Association of State Directors of Developmental Disabilities, the Human Services Research Institute, and state intellectual and developmental (IDD) agencies. Currently, most state agencies in the country participate in the NCI-IDD initiatives and collect data through an Online Data Entry Survey Application (ODESA). The NCI-IDD surveys provide a comprehensive overview of people's experiences receiving services, focusing on multiple domains such as health and wellness, residency, employment / other daily activities, support and services, behavioral support needs, rights and privacy, and staff (HSRI & NASDDDS, 2022).

The Washington IDD and Mental/ Behavioral Health Service System: Policy and Literature Analysis

Overview of Washington State Policies and Programs

Policies, Programs, and Initiatives Impacting Service Accessibility and Quality
Washington has implemented a range of policies aimed at improving both the accessibility and quality of services for people with IDD and co-occurring mental or behavioral health support needs. These policies focus on expanding community-based care, integrating behavioral health services with developmental supports, and providing crisis intervention to reduce hospitalizations. While these initiatives have made strides in enhancing the state's care system, significant challenges related to workforce shortages, geographic disparities, and service availability persist. Some of the most impactful policies and programs implemented in Washington are outlined below (see DDA's 2022 Report to the Legislature for a comprehensive list of other initiatives).

Home and Community-Based Services (HCBS) Waivers

One of the cornerstone policies impacting service accessibility in Washington is the use of Home and Community-Based Services (HCBS) waivers (*Home and Community Based Waivers (HCBS) | DSHS*, n.d.). These waivers allow people with IDD and co-occurring mental health needs to receive personalized services in their homes and communities rather than in institutions. Two significant waiver programs in Washington are the Individual and Family Services (IFS) waiver (Individual and Family Services, *2023*) and the Community First Choice (CFC) waiver (WAC 388-106-0270*,* n.d.). The IFS waiver offers support services such as respite care, assistive technology, and behavior management therapy for people living with their families, helping to prevent institutionalization and alleviate sole reliance on caregivers for support. The CFC waiver focuses on providing personal care services, such as assistance with daily activities, to support autonomy and independence.

While these programs have enhanced accessibility to necessary services, they are often affected by long waiting lists. For example, families seeking behavioral therapy under the IFS waiver frequently face delays due to the high demand for these services. Additionally, access to services under HCBS waivers varies by region, with rural areas often facing a shortage of providers, leading to inequitable service availability (Washington State Department of Social and Health Services, 2018). These disparities have left many families in underserved regions without timely access to critical services, forcing some to rely on institutional care or private pay options (Developmental Disabilities Administration, 2022).

Fully Integrated Managed Care (FIMC) and Behavioral Health Integration

Washington's move toward Fully Integrated Managed Care (FIMC) in 2016 marked a significant shift in the state's approach to service coordination for persons with IDD and mental/behavioral service needs (Thriving Together, n.d.). Under FIMC, Managed Care Organizations (MCOs) are responsible for coordinating comprehensive physical health, behavioral health, and developmental services (Center for Health Care Strategies, 2020). This model was designed to streamline care delivery, improve health outcomes, and reduce the fragmentation of services, which historically left people with co-occurring support needs bouncing between different service systems (Centers for Medicare & Medicaid Services, 2021).

The implementation of FIMC in Washington has impacted the integration of mental health supports into Washington's Supported Living programs, which provide residential services to people with IDD. With the FIMC model, these programs now include behavioral health supports, such as access to mental health counseling, crisis intervention, and medication management, allowing people to receive holistic care in residential settings. Despite these improvements, the model faces challenges in its capacity to provide specialized care (Mancuso, 2017). Many behavioral health providers within the MCO network lack the training or experience to address the

unique needs of people with co-occurring support needs, particularly for people with higher medical and behavioral support needs, resulting in gaps in service quality. This has led to concerns about whether the integration of behavioral health services is truly effective for people with complex support needs (Bittinger, Court, & Mancuso, 2019; Center for Health Care Strategies, 2020).

Crisis Intervention and Community-Based Stabilization

Another crucial area of focus in Washington's current policies is crisis intervention for people with IDD and mental/behavioral support needs. A decade ago, Washington expanded Community Crisis Stabilization Services (CCSS) to provide immediate, short-term residential care for people in crisis (Washington State Department of Social and Health Services, 2013). This program is designed to prevent psychiatric hospitalizations by stabilizing people in their communities. When a person with IDD experiences a psychiatric or behavioral crisis, they can access CCSS for intensive support and stabilization, allowing them to avoid the more restrictive setting of a hospital or long-term care facility (Developmental Disabilities Administration, 2023).

In addition to crisis stabilization services, Washington has also developed Mobile Crisis Response Teams, which are dispatched to people experiencing behavioral health emergencies in their homes or community settings (Washington State Health Care Authority, 2023). These teams are trained to work specifically with people with IDD and mental health support needs, offering crisis de-escalation, safety planning, and short-term case management. While these programs have improved Washington's ability to respond to crises, access remains uneven. Rural areas often face shortages of crisis response teams and stabilization facilities, leaving people in these regions at greater risk of hospitalization or more severe crises due to the lack of timely interventions (Developmental Disabilities Administration, 2023).

Employment and Service Accessibility

The state's Working Age Adult Policy also has a profound impact on service accessibility and quality for adults with IDD (Washington State Department of Social and Health Services, 2023). This policy mandates that employment services, including job coaching, vocational training, and workplace accommodations, be the primary focus for adults with IDD receiving services from the state (Clark County Community Services, n.d.). The policy promotes independence and inclusion by encouraging adults with disabilities to pursue meaningful employment in their communities. An example of this in practice is the development of Individualized Employment Plans (IEPs), which include support such as job training, career development, and assistance in navigating workplace challenges (Mank, 2018).

However, people with co-occurring IDD and mental health support needs often face additional barriers to accessing these services. Mental health diagnoses, such as anxiety or depression, can make it difficult for people with co-occurring needs to thrive in traditional work environments, and

the availability of mental health support within employment services is often limited. Furthermore, many people in rural areas have limited access to employment opportunities or the supports necessary to sustain a job, further compounding disparities in service accessibility. Addressing these barriers is crucial to ensuring that Washington's employment policies fully benefit people with complex needs (Tichá et al., 2018).

Telehealth and Digital Equity

The expansion of telehealth services during the COVID-19 pandemic has been one of Washington's most recent innovations aimed at improving service accessibility, particularly for people in rural or underserved areas (Washington State Department of Health, 2023). Telehealth has enabled people with IDD and co-occurring mental health support needs to access services such as counseling, crisis intervention, and case management remotely (Washington State Legislature, 2020). This has been especially beneficial for those in remote locations or for whom transportation presents a barrier to care.

However, telehealth has also highlighted issues of digital equity. Many people with disabilities, particularly those living in poverty or rural areas, lack access to the necessary technology, good internet services, or technical support to fully benefit from telehealth services (Washington State Department of Health, 2023). People with complex disabilities may also face challenges navigating telehealth platforms without proper assistive technologies. While Washington has begun to address these gaps by promoting initiatives aimed at expanding broadband access and offering training for people using telehealth, ensuring equitable access to these services remains an ongoing challenge (Eberle, 2021).

Challenges and Barriers to Accessing Quality Support

The challenges faced by people with co-occurring IDD and mental and/or behavioral health needs are complex and multifaceted, significantly impacting access to quality supports and services (Developmental Disabilities Administration, 2022). Understanding these obstacles is essential for developing effective interventions. These challenges are mainly categorized into three primary areas: systemic barriers, clinical barriers, and social and awareness barriers. Each category of barriers reveals specific issues that providers must address to create a more inclusive and effective support system for those requiring integrated care.

Systemic Barriers

A critical challenge impacting the support provided to people with co-occurring IDD and mental and/or behavioral health needs is the shortage of qualified professionals equipped to address both sets of needs (Carbonell et al., 2020). Recent findings from the National Core Indicators State of the Workforce Study (2023) show that the average national turnover rate of Direct Support Professionals (DSPs) is 41%. Further, about one-third of DSPs have a tenure of less than one year at their organizations, and of those that turnover, almost two-thirds do it within the first year. This

means that organizations providing services struggle to even train and equip many frontline staff with the skills and resources they need to support people well before they leave. This lack of provider capacity often results in long wait times for appointments and limited access to essential services, which can hinder timely and appropriate interventions (Fantuzzi & Mezzina, 2020). Additionally, existing service delivery systems frequently suffer from fragmentation, with a lack of effective cross-system collaboration. This disjointed approach to care makes it difficult for providers to deliver holistic support, ultimately failing to address the complex needs of people with co-occurring diagnoses. To enhance support, it is crucial to improve provider availability and create integrated service models that facilitate coordinated care (Fantuzzi & Mezzina, 2020).

Finally, one of the most pressing issues affecting both service accessibility and quality in Washington is the shortage of cross-trained professionals in the IDD and mental health sectors. Behavioral and mental health specialists who are trained to work with people with co-occurring support needs are in short supply, and vice versa, particularly in rural and underserved areas. The general direct support workforce shortage has resulted in longer wait times for services, reduced continuity of care, and challenges in providing person-centered, high-quality support for people with complex needs (Developmental Disabilities Administration, 2022). Compounded with a shortage of qualified professionals across services that people need, lack of qualified support is a critical issue for people with co-occurring IDD and mental/behavioral support needs.

Clinical Barriers
Clinical barriers also play a significant role in limiting the effectiveness of support for people with co-occurring IDD and mental/behavioral health needs. One major issue is the phenomenon of overshadowing, where challenging behaviors are often attributed solely to a person's disability, neglecting the potential presence of underlying mental health needs (Walton et al., 2022). This oversight can lead to missed opportunities for essential assessments and treatments that could significantly improve a person's well-being. Moreover, people with IDD may present atypical symptoms that do not align with conventional diagnostic criteria, complicating the ability of providers to accurately diagnose and treat their mental health needs (Bond et al., 2021). Such complexities highlight the necessity for providers, medical practitioners, and all professionals who impact a person's life and services to adopt a more nuanced understanding of the interplay between IDD and mental health, ensuring that all relevant conditions are adequately addressed.

Social and Awareness Barriers
Social and awareness barriers further exacerbate the challenges faced by people seeking support for co-occurring IDD and mental/behavioral health needs. Stigma surrounding mental health can deter people and their families from seeking necessary help, leading to the underutilization of available services (Carbonell et al., 2020). It is essential for stakeholders in the disabilities and mental health sectors to work to actively combat this stigma and foster a supportive environment where seeking help is encouraged. Additionally, many people may not recognize the symptoms

they are experiencing or lack the support needed to navigate the complex service systems effectively. This includes insufficient access to information regarding available resources and the importance of pursuing mental health care (Bond et al., 2021). Increasing awareness and providing comprehensive support can help mitigate these barriers and improve access to quality services for those in need.

Culturally Relevant Interventions in Washington

Washington aims to address the systemic barriers that have historically hindered access to quality services for traditionally underserved populations. Various interventions, such as integrating mental health services, promoting educational equity, and engaging communities in the development and delivery of programs, have been implemented to enhance access to services and support for BIPOC (Black, Indigenous, and People of Color), rural, and underserved communities. Statewide efforts have focused on reducing disparities in mental health care, improving educational outcomes, and increasing community engagement.

Mental Health and Behavioral Health Interventions
One notable intervention is the Integrated Behavioral Health (IBH) model, which seeks to provide comprehensive care by integrating mental health services within primary care settings (Washington State Legislature, 2020). This approach is particularly beneficial for BIPOC and rural communities, where stigma surrounding mental health has deterred people from seeking help. By embedding mental health professionals in familiar healthcare environments, the IBH model has started to reduce barriers to access and encourage people to address both physical and mental health needs in a single visit. Additionally, culturally competent care initiatives offer training for providers to better understand the cultural contexts of their patients, enabling them to deliver services that resonate with the unique experiences of BIPOC communities (Washington State Medica Home, 2017).

Educational and Community Support Programs
Educational initiatives such as the Washington State Equity in Education Partnership focus on promoting equitable access to educational resources for students from underserved communities [Washington INCLUDE (wainclude.org)]. Such programs emphasize the importance of culturally responsive teaching and the recruitment of diverse educators to reflect the demographics of the student body. This relevant initiative can be an exemplary practice to improve the quality of mental health services. Another relevant educational initiative was the "Home Survival Guide" webinar, which was developed and presented by DDA in May 2020 to over 400 participants. The webinar provided practical tips for adapting to the requirements of being locked down during the COVID-19 pandemic, including opportunities for mental health services when needed. The webinar was offered in three virtual Town Hall meetings after the initial broadcast and is available online ("Home Survival Guide" webinar in May 2020).

Community Engagement and Empowerment

Community engagement is another critical component of effective interventions in Washington. Initiatives like the ECHO IDD Wraparound [ECHO IDD Wraparound – Washington INCLUDE (wainclude.org)] aim to empower BIPOC and underserved populations by involving them in decision-making processes related to their healthcare and social services. This approach not only builds trust between communities and service providers but also ensures that interventions are tailored to the specific needs and preferences of the populations served. Similarly, programs like The Washington State Flex Program encourage and support the development of cooperative systems of care in rural areas. Such programs aimed at supporting rural communities currently work to increase the availability of educational resources and healthcare services in remote areas, addressing the geographical disparities that often exacerbate inequities (Rural Health Systems, Washington State Department of Health).

Secondary Data Analysis: Outcomes for Washingtonians with IDD and Mental/ Behavioral Health Support Needs

Overview of the National Core Indicators® (NCI) Data

Demographics

Figure One reveals the demographic composition of people with IDD in Washington who responded to the analyzed variables from NCI®-IDD (approximately 220 people). Most participants resided in metropolitan areas (84.1%), with smaller proportions in micropolitan (8.67%), small towns (5.2%), and rural areas (2.02%). The largest age group was 18-30 years (36.05%), followed by 31-40 years (25.58%). The population decreased with age, with only 9.88% aged 61 years or older. This distribution shows a relatively young population among respondents, with three-fifths having ages between 18 and 40 years. The majority of participants were male (58.77%), with females making up 41.23% of the sample. A significant majority of participants within the sub-sample identified as White (84.68%). Other racial groups included Asian (4.91%), Black or African American (6.94%), and smaller proportions of American Indian or Alaska Native (3.76%) and Pacific Islander (0.58%). The Hispanic/Latino population was 2.31%.

Figure One Demographic Composition of NCI-IDD Respondents

Rural/Metro classification	n	%
Metropolitan	291	84.10
Micropolitan	30	8.67
Rural	7	2.02
Small town	18	5.20
Age	n	%
18-30	124	36.05
31-40	88	25.58
41-50	56	16.28
51-60	42	12.21
61+	34	9.88
Sex	n	%
Male	201	58.77
Female	141	41.23
Race	n	%
American Indian or Alaska Native	13	3.76
Asian	17	4.91
Black or African-American	24	6.94
Pacific Islander	2	0.58
White	293	84.68
Hispanic/Latino	8	2.31

IDD and Mental/Behavioral Health Diagnostic

A majority of respondents (75.15%) identified as having intellectual disabilities, while 24.85% do not and are caregivers such as family members or guardians. (See Figure Two)

Figure Two Has an Intellectual or Developmental Disability Diagnosis
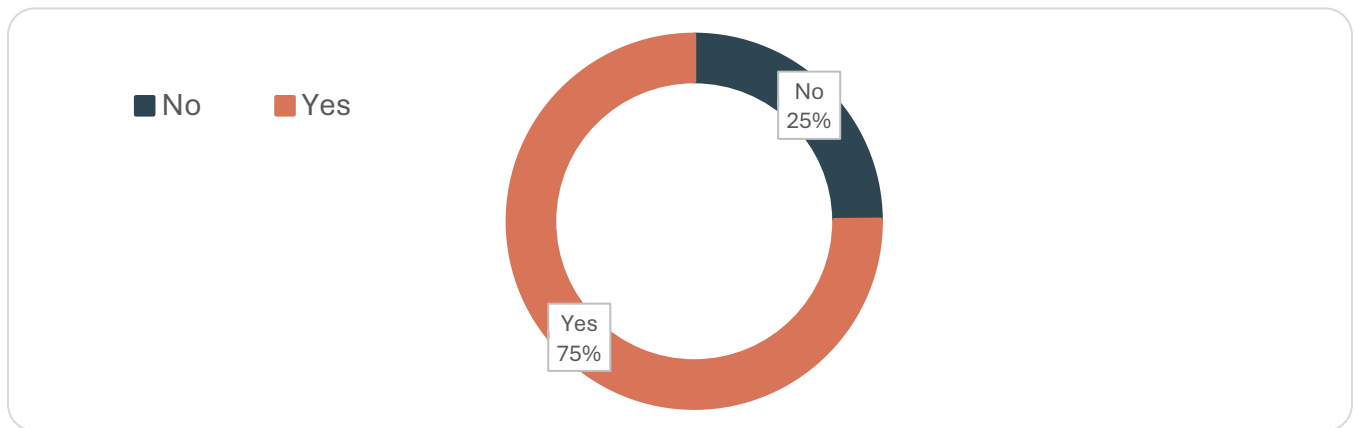
Approximately two out of three participants reported having mental and behavioral health support needs. Figure Three shows that 21.6% of participants reported having mood disorders like depression or bipolar disorder, while 27.16% had anxiety disorders. Also, 7.41% of the

respondents reported presenting behavior challenges, 6.48% psychotic disorders, and other mental illnesses (4.32%).

Figure Three Mental/ Behavioral Health Diagnosis
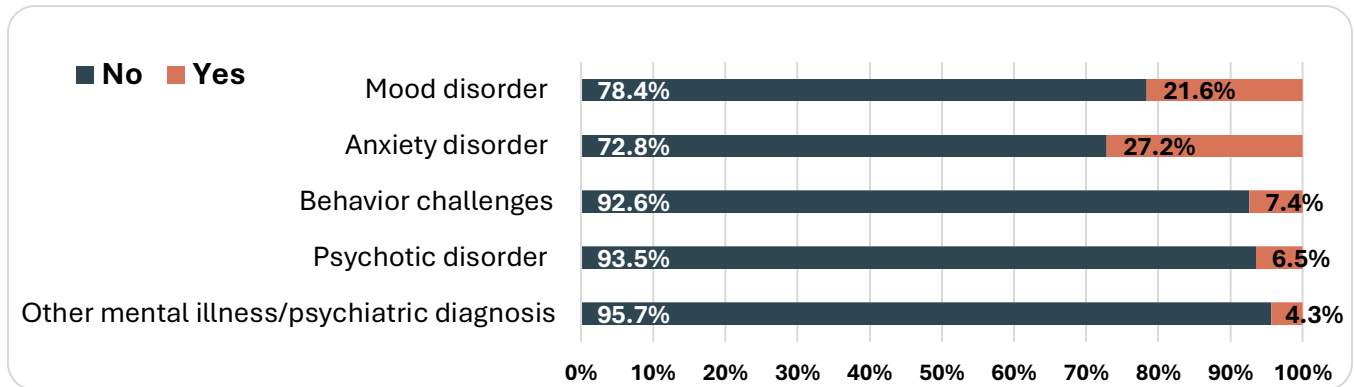
Figure Four shows that nearly half of the participants (46.44%) take medications for mood, anxiety, and/or psychotic disorders, while 20.43% take medications for their behavioral needs. Recent studies have shown that people with disabilities tend to be medicated at higher rates, particularly with psychotropic medication to manage challenging behavior, more than people without disabilities (Deb et al., 2023; Glover et al., 2015; Oswald, 2023). At the same time, 21.1% of the respondents said they have a current behavior plan in place.

Figure Four Mental/ Behavioral Health Treatment
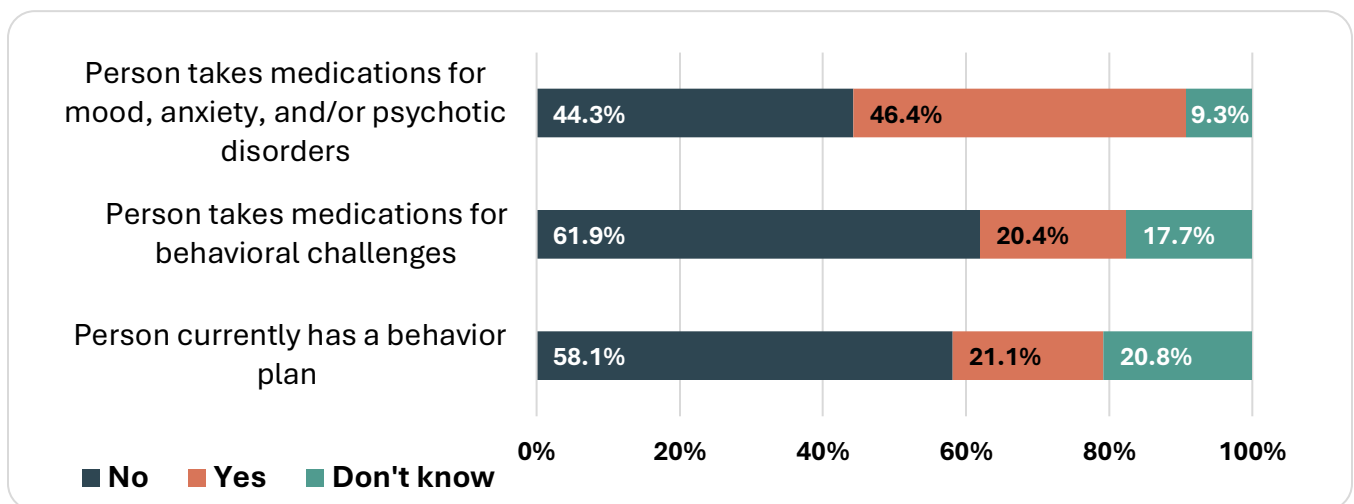
Access to Needed Culturally Competent Services and Supports

Support Staff

The analysis of support staff interactions for all respondents highlights a positive trend in cultural respect and communication overall (see Figure Five). Around 42% of participants felt that "*All Staff" were "Always"* respectful of their cultural and religious preferences while 3.3% indicated

that "*Sometimes or Some Staff*" were respectful. Similarly, 40.94% of participants stated that *"All staff, Always"* treat them with respect, while 4.7% selected that "*Sometimes or Some Staff*." Staff communication in preferred language was the highest positively rated indicator, with 44.59% of respondents confirming that they can always communicate with staff in their preferred language. However, over half of the participants indicated that these three questions were not applicable to them, potentially because they do not interact with support staff regularly, or were not comfortable answering due to the lack of privacy when responding to these questions.

Figure Five Support Staff Respect and Communication
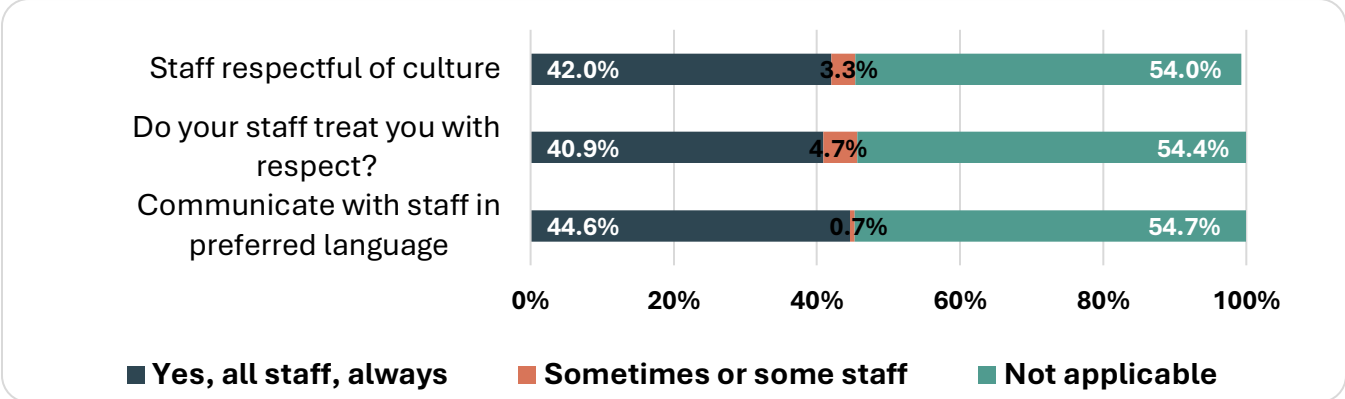
For the sub-sample of people with co-occurring support needs, the data showed a relatively higher level of satisfaction related to staff respecting cultural differences (see Figure Five). Among those with co-occurring support needs, 55.36% report that staff are always respectful of their culture. However, there is also a higher percentage of people with co-occurring support needs reporting that only sometimes or some staff are respectful of their culture (including religion, beliefs, preferred food, or celebrated holidays). People with co-occurring support needs reported positive and respectful treatment as the lowest among these practices, with 50.91% of participants saying that all staff always treat them with respect. Communication in the preferred language is also higher for people with co-occurring support needs. Three out of five people (60%) confirm that communication in their preferred language is always possible with all staff. Nevertheless, slightly more people (61.8%) with co-occurring support needs also indicated that they can communicate in their preferred language only sometimes or only with some staff.

Figure Six Support Staff Respect and Communication for People with Co-occurring Support Needs
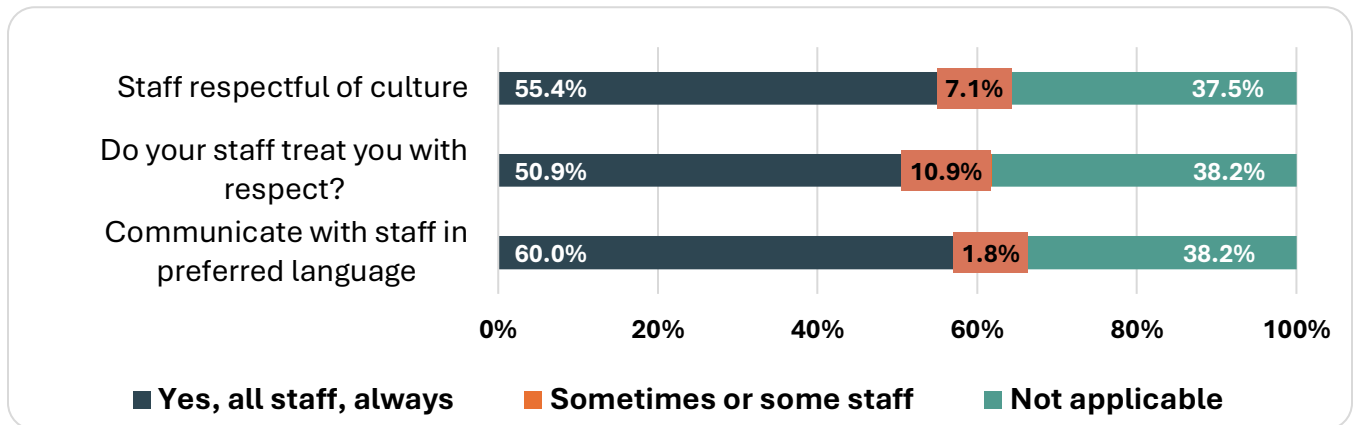
Service Access

Access to services is a crucial aspect of support for people with IDD. The data in Figure Seven indicate that while a majority of NCI respondents did not seek help with transportation (88.27%), technology use (89.51%), or understanding medication (92.9%), gaps in service delivery and support needs persist. Transportation was the highest area of services needed with 11.73% of participants expressing a desire for help with finding or getting more reliable transportation. Similarly, 10.49% indicated that they would like assistance with using technology for daily activities. A smaller proportion of about 7.10% of participants reported that they require help understanding medication related to what medication is used for, side effects, and how to take medication safely. A small proportion (6.48%) also said that they could use help finding, getting, or setting up behavioral or mental health supports. Even fewer (3.40%) sought help with healthcare, such as finding a doctor or making appointments. While this data may suggest that most participants had their needs met, it could also reveal a lack of knowledge of service options.

Figure Seven Supports and Services Accessed
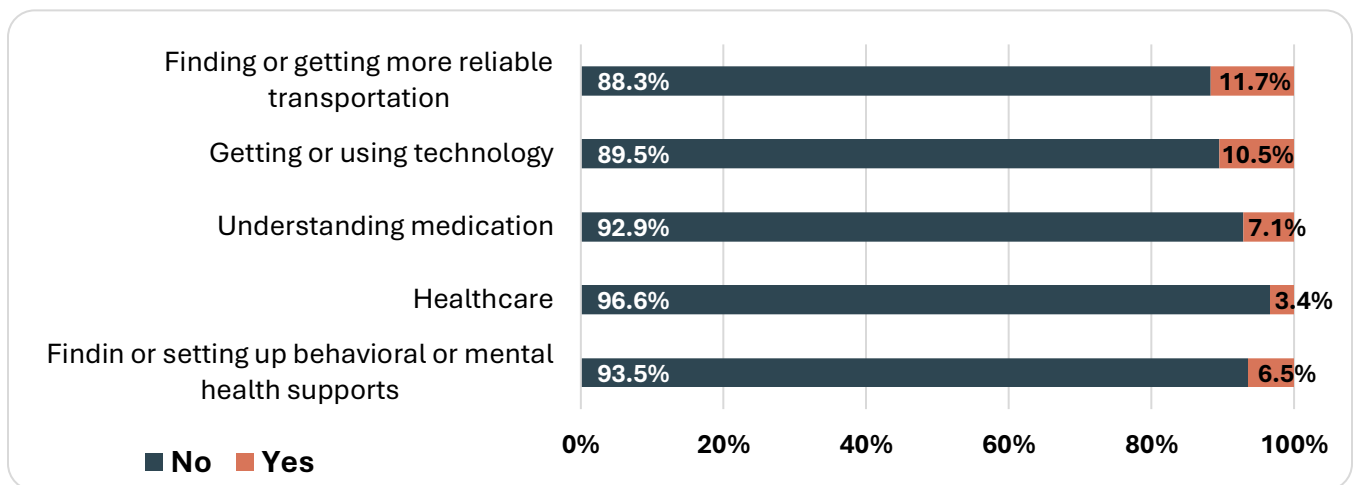
Participants with co-occurring support needs reported less desire for help in all areas of needs and supports (see Figure Eight). Only 5.77% of participants indicated that they needed help finding or getting more reliable transportation, while 8.65% said that they want assistance getting or using technology to help in everyday life to do more things on their own (like apps to get around, alerts to get reminders of things to do like take medication). As little as 3.85% said that they need help understanding medication and what medication is used for, side effects, or how to take medication safely. Just 5.77% indicated desired help finding, getting or setting up behavioral or mental health supports. Finally, only 1.92% stated that they need help with healthcare, such as finding a doctor or making appointments.

Figure Eight Supports and Services Needed by People with Co-Occurring Support Needs

Finding/ getting more reliable transportation: No 88.3%, Yes 11.7%
Getting/ using technology: No 89.5%, Yes 10.5%
Understanding medication: No 92.9%, Yes 7.1%
Healthcare: No 96.6%, Yes 3.4%
Finding/ setting up behavioral/ mental health supports: No 93.5%, Yes 6.5%

■ No ■ Yes
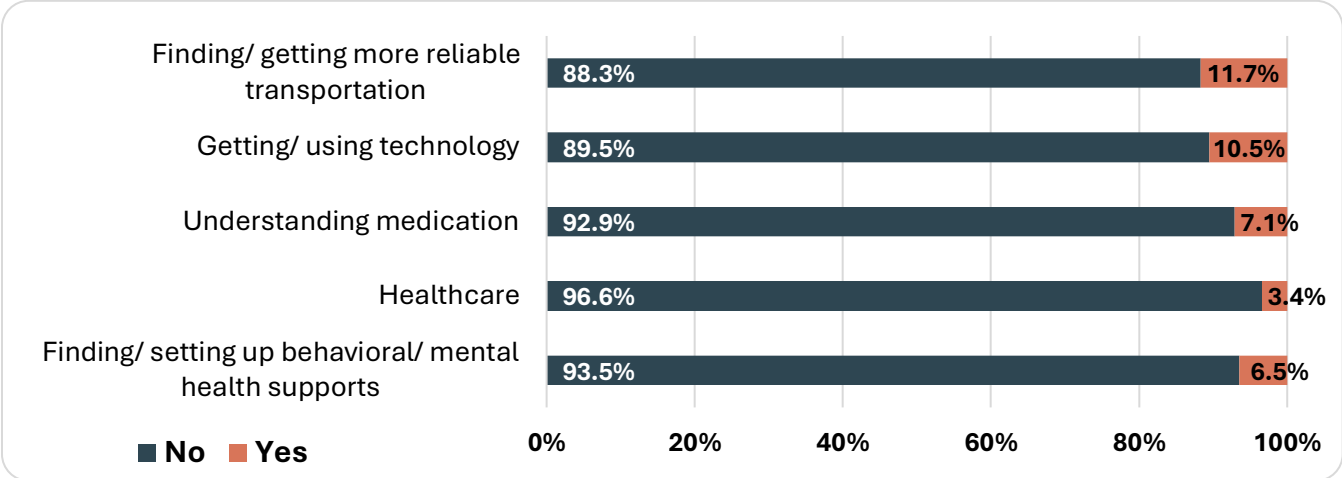
Notable Limitations Participants residing in metropolitan areas (84.1%) are overrepresented in this sample, which may underrepresent the needs of people from small-town and rural areas and mask challenges faced in less populated areas, such as limited access to specialized services. Additionally, 84.68% of the sample identified as White, limiting the ability to generalize findings to minority groups who face unique barriers in accessing services. The low percentage of Hispanic/Latino participants (2.31%) also restricts the analysis for this community. These limitations highlight the challenges of working with secondary data sets. However, this secondary data set analysis using a valid and reliable tool like the NCI-IDD allows for the identification of trends, gaps, and opportunities for improvement in service systems within Washington.

The analysis conducted for this report did not include differences in where people with disabilities live and receive services. Previous research has demonstrated that people living in their own homes and receiving supports in their communities tend to have higher quality of life outcomes and are more satisfied with their services. However, people living in group and institutional settings generally receive medical supports, interventions, and preventative appointments at higher rates. The impact of residence or type of support was not considered for this study, but it may be important to see how the types of services received impact support satisfaction, professional cultural competence, and access to needed services and resources.

Strengths of the Washington Service System

The NCI data highlights a significant need for support for people with intellectual and developmental disabilities (IDD) and mental/behavioral health support needs in Washington State. With 21.60% of participants experiencing mood disorders, 27.16% dealing with anxiety disorders, and 7.41% showing behavioral challenges, it is evident that there is a need for an integrated approach to care. Many strengths of the Washington Service System were highlighted in the results of the analysis; they are highlighted in Figure Nine.

Areas for Improvement in the Washington Service System

The NCI findings also clearly identified areas of need in the Washington service system. Many people with co-occurring IDD and mental and/or behavioral health support needs would benefit from policies, regulations, and practices that ensure access to needed supports and transportation, utilize positive behavioral interventions, and treat service professionals respectfully. Figure Ten highlights opportunities to improve the Washington service system that emerged from the NCI data.

The Washington service system shows several strengths, particularly in service availability in metropolitan areas, staff respect, language accommodation, and access to transportation. However, gaps in rural service coverage, mental health and behavioral support, staff respect consistency, and the need for better medication understanding indicate areas for improvement. By addressing these weaknesses through targeted policy changes, staff training, and expanded service delivery, Washington can improve outcomes for people with IDD and co-occurring mental and behavioral health needs.

Conclusion

Washington State's policies have made significant strides in improving service accessibility and quality for people with IDD and mental and/or behavioral health support needs. From the expansion of HCBS waivers and the integration of behavioral health services into Managed Care, to the development of crisis intervention programs and the promotion of employment services, these initiatives have helped move the state toward a more inclusive and person-centered service system. However, challenges such as long waiting lists, regional disparities in service availability, workforce shortages, and digital equity gaps continue to limit the effectiveness of these policies. Addressing these barriers will be critical in ensuring that all people with co-occurring disabilities receive the high-quality, accessible care they deserve.

Figure Nine Strengths of the Washington Service System

Policy Area	Strength	Implication
Service Availability in Preferred Language	A significant proportion (44.59%) of people reported that all staff always communicate with them in their preferred language, which is critical for ensuring service effectiveness and client satisfaction.	This reflects a positive capacity for language accommodations and culturally responsive service delivery.
Respectful Staff	Over 40% of people reported that staff consistently treat them with respect and accommodate their cultural preferences (e.g., religion, food, holidays).	This indicates that the staff are largely respectful and responsive to individual cultural and personal preferences, which enhances service satisfaction and adherence.
Limited Need for Transportation and Technology Support	A majority (88.27%) of people reported not needing help with transportation, and 89.51% did not require assistance with using technology in everyday life.	This suggests that many people have stable access to transportation and technology or that the system is currently meeting these needs well.

Figure Ten Areas for Improvement in the Washington Service System

Policy Area	Issue	Recommendations
Services for people in Rural and Micropolitan Areas	Only 2.02% of people lived in rural areas, and 8.67% in micropolitan regions. While metropolitan services may be more robust, people in less populated areas could face challenges in accessing necessary services.	Expand outreach and resources to rural and micropolitan areas to ensure equitable service delivery and access to mental health and behavioral supports.
Mental Health and Behavioral Health Services	A significant percentage of people had mental health diagnoses, including mood disorders (21.60%), anxiety disorders (27.16%), and psychotic disorders (6.48%). Yet, gaps in behavioral support remain, with 14.85% requiring extensive support for self-injurious behavior, and 26.97% for disruptive behavior.	Increase specialized training for staff to support people with co-occurring mental health and behavioral support needs. Expand the availability of behavioral support plans and access to psychiatric care.
Behavioral Health Plan Coverage	21.10% of people currently had a behavioral plan in place, meaning a significant portion of people with behavioral needs are either unsupported or unaware of available support options.	Conduct assessments to identify unmet behavioral health needs and ensure that people who require a behavior plan receive one.
Medication Management and Understanding	While 46.44% of people took medications for mood, anxiety, and psychotic disorders, 7.10% of people expressed a need for better understanding of their medications.	Implement educational programs focused on medication management to ensure people are empowered to understand the purpose, usage, and side effects of their medications.
Cultural Responsiveness of Staff	A notable 54% of respondents indicated that they do not have staff or their situation was not applicable, and only 42% reported that all staff are respectful of their cultural and religious preferences.	Enhance cultural competency training for all staff to improve respect for diverse backgrounds and focus on increasing the availability of culturally responsive staff across all service settings.

Figure Ten(Cont.) Areas for Improvement in the Washington Service System

Policy Area	Issue	Recommendations
Access to Behavioral and Mental Health Supports	While the majority did not seek additional help, 6.48% of people desired better access to behavioral and mental health supports.	Increase outreach efforts to ensure that people in need of behavioral and mental health supports are aware of available resources and can easily access them.
Respect from Staff and Language Services	While 44.59% of people always received services in their preferred language, there is room for improvement in ensuring staff can consistently meet language preferences. Similarly, while 40.94% of people reported that all staff treat them with respect, there was a gap in consistent staff respect across the board.	Prioritize staff training to ensure that all people, regardless of their language or cultural background, receive the highest standard of respect and communication. Expanding interpreter services could also help address these needs.
Desire for More Reliable Transportation	11.73% of people expressed a need for help in finding or obtaining more reliable transportation.	Improve transportation services for people who struggle with reliable access, especially in less urbanized areas. Investing in transportation vouchers or dedicated transportation services could help bridge this gap.
Support for Disruptive and Harmful Behaviors	There is a significant number of people (38.18%) who required occasional assistance with disruptive behavior, and 26.97% needed regular assistance. Similarly, 14.11% needed extensive support for behaviors harmful to others.	Increase the availability of behavioral intervention specialists and crisis management resources. Providing more comprehensive behavior management plans, ongoing staff training, and emergency behavioral support could help mitigate these risks.

PART TWO EXPERIENCES OF WASHINGTONIANS WITH IDD AND MENTAL AND/OR BEHAVIORAL HEALTH SUPPORT NEEDS

This part of the report provides an in-depth discussion of study findings from interviews, focus groups, and an online survey of Washington residents who experience or support people who receive disability and mental and/or behavioral health supports.

"Although I had the assistance of an insurance case manager with Molina and had my daughter on waitlists with every ABA agency we could identify that accepted this insurance and would serve adults, after more than 18 months, we still have been unable to access services. Low Medicaid reimbursement rates and a lack of providers qualified to work with adults, particularly in supported living settings, have proven to be an insurmountable barrier condemning my daughter to a life of suffering from the hardship and isolation her behavioral challenges cause. For all the glib words our state agencies use about the dignity of people with IDD, their actions show differently. She is 25 years old and has no future of growth and community connection to look forward due to the gross underfunding and neglect of services to people like her."

"I have no idea what I can qualify for. Every time I call an agency I hear "oh we don't do that" but then they can't tell me who does. I'm already beyond exhaustion caring for myself and my family, on top of masking to keep my three jobs. I don't have any spare time to research more of this."

"We're taking time off of work to travel to Seattle for different specialists my son sees about every other month. In the month of May this year, we traveled six times to Seattle, and unfortunately, we had to almost max out our credit card to cover expenses."

"Not one time have I been able to get the correct help and been shuffled along to no real solutions and support."

Introduction to Part Two

During the summer of 2024, the National Leadership Consortium launched a mixed-methods study to investigate the perspectives of Washington residents with co-occurring support needs about their disability and mental and/or behavioral health services and supports. This study aimed to gain a deeper understanding of the current barriers and facilitators to disability and mental/behavioral health services in the state of Washington, with a particular focus on the accessibility of services for historically underserved populations (including Black, Indigenous, and People of Color [BIPOC], people who live on a reservation, people who live in a rural area, people who are low-income, people who identify as LGBTQ+, etc.). The study collected data through three sources: 1) Interviews with people with co-occurring support needs and family members of people with co-occurring support needs, 2) A focus group with self-advocates with co-occurring support needs, and 3) A statewide survey of people with co-occurring support needs and family members or guardians of people with co-occurring support needs.

Interviews

In-depth interviews were conducted with 19 people - 14 parents of people with co-occurring support needs, three siblings of people with co-occurring support needs, and two people with co-occurring support needs, and six of whom identified as belonging to a historically underserved or minority population - via Zoom between July 15 and August 9, 2024. Participants were asked 14 questions about challenges, their experiences accessing services, things that helped them access services, and their recommendations for how to improve service access and quality across the state (see Supplemental Materials for the Interview Questions). Interviews lasted 1-2 hours and were audio recorded and transcribed for analysis.

Focus Group

Two focus groups were scheduled with self-advocate groups across the state. Researchers from the Consortium attended the Self Advocates in Leadership (SAIL) regularly scheduled meeting on July 9 via Zoom to tell attendees about the study and recruit participants for the upcoming focus group on July 23, 2024. Unfortunately, no one attended this focus group. Researchers also met with coordinators of the Allies in Advocacy Focus Group, who carved out time in their regularly scheduled meeting on August 9, 2024, and invited people with co-occurring needs outside of the group to attend the focus group portion of the meeting. Nine people with co-occurring support needs participated. Participants were asked nine questions about challenges accessing services, things that helped them access services, and their recommendations for how to improve service access and quality across the state (see Supplemental Materials for the Focus Group Questions). The Focus Group lasted about an hour and was recorded and transcribed for analysis.

Statewide Survey

A statewide web-based survey was developed by the Consortium with the goal of getting a snapshot of user perspectives from across the state about their disability and mental and/or behavioral health services and the barriers and facilitators to accessing those services. Survey participants included people with co-occurring support needs or caregivers of people with co-occurring support needs who currently live in Washington and who have ever received or tried to get formal services for their IDD and/or mental/behavioral health needs (see Appendix B for participant demographics). The survey contained 49 multiple-choice questions and two open-response questions about demographics, the types of services received, geographic accessibility of services, financial accessibility of services, language and cultural competency of services, appointment availability, accessibility of information about services, service quality, how all of their services work together, their satisfaction with their services, and the barriers and facilitators to services (see Supplemental Materials for Statewide Survey Questions). Participants were incentivized to respond to the survey by having the opportunity to enter into a drawing to win one of two $50 Amazon eGift Cards for completing the survey. The survey was open for responses between July 8 and August 18, 2024. There were 398 responses to the survey that were analyzed.

Recruitment

Participants for all parts of this study were recruited through the National Leadership Consortium's listserv, Community of Practice, and social media pages, some of our national partners, as well as several statewide and regional organizations that were recommended to the research team by the Washington Developmental Disabilities Council (WADDC), research consultants who work in the state, and listings found in the Behavioral Health Agencies Directory from the Washington State Department of Health.

Analysis

Thematic analysis was used to code data and identify emerging concepts and themes from interviews, focus group responses, and open-response questions on the survey (Braun & Clarke, 2006; 2021). First, the research team familiarized themselves with the data by reviewing transcripts and audio recordings. Researchers then generated initial codes of interesting features of the data and refined codes during a second round of analysis. Codes were then collated into potential themes, which were reviewed by the research team, and drafts of thematic maps arranging the themes and codes for each research question were generated. Themes were refined through the ongoing analysis of interviews and discussion within the research team, with a clear definition and names for themes emerging from the analysis process. The online qualitative platform Dedoose (www.dedoose.com) was used to facilitate analyses. Final themes and related content were organized into thematic maps or charts for key findings. Descriptive analysis, t-tests, and logistic regressions were used to analyze results from quantitative questions from the statewide survey. Analyses took place during August and September of 2024.

Section Two of the report outlines key findings from the interviews, focus group, and statewide survey data, starting with the challenges to accessing and maintaining services and then highlighting the facilitators to service access. Finally, Section Two summarizes recommendations from people with lived experience about how to improve service delivery across Washington.

User Perspectives about Barriers to Services for People with Co-Occurring Support Needs

People with co-occurring support needs and their family members participated in interviews and focus groups to share their experiences and perspectives about the barriers to IDD and mental and/or behavioral health services in Washington. Participants were asked, *"What are some of the challenges you have faced while accessing services for co-occurring support needs?"* as well as, specifically, if they have experienced any barriers related to location, cost, culture, or language, or issues accessing services due to belonging to a historically marginalized or underserved group. Challenges discussed by participants in interviews and the focus group were grouped into nine main categories: 1) Discrimination, 2) Financial, 3) Geographical, 4) COVID-19, 5) Lack of services for needs, 6) Service qualification, 7) Service navigation, 8) Caregiver burnout, and 9) Disconnected systems (See Figure Eleven). Further, much of the survey data, once it was analyzed, demonstrated that many of the indicators asked were barriers to people with disabilities and families.

Figure Eleven Barriers to Services for People with Co-Occurring Support Needs from Interviews and Focus Group

Barriers to Services for People with Co-Occurring Support Needs

Ableism
- Provider Stigma Toward Mediaid Users
- Descrimination Against People with IDD by
  • Mental Health Professionals
  • Medical Professionals
  • Employers

Cultural or Racial
- Racial Bias of Providers and Professionals
- Lack of Language Inclusivity
- Cultural Miasalignment Between Professional and Person Receiving Services
- Lack of Cultural Humility

Discrimination

Lack of Services for Needs
- Denial of or Removal from Services
- Mismatch Between Professional and Person Receiving Services
  • Uneducated about Co-Occurring Needs
  • Uneducated about Type of Intensity of Needs
  • Misaligned Values

Financial
- Can't Afford Services
- Make Too Much to Qualify for Funding, but Too Little to Pay for Needs
- Services Not Covered
- High Cost of Caregiving
- High Transportation Costs

Service Qualification
- Difficulty Getting Diagnosis
- No Clear Entry Point
- Lack of Knowledge About Entry Into Services or System
- Long Time Getting Medicaid Approval
- Lack of Initiation by Professionals
- Denial of Services Due to Needs
- Different Disagnosis Needed

Geographical
- Rural Areas Lack Services
- Lack of Services Overall Across State
- Inequity of Funding and Services Across Counties
- Transportation Challenges
  • Time and Distance
  • Cost
  • Lack of Public Transportation
  • Hard Commute for People with Needs

Service Navigation
- Lack of Knowledge About Services or System
- Lack of Outreach and Support by Professionals
- Lack of Providers or Services
- Long Wait Lists for Services
- Inconvenient or Impractical Services
- Overburdened or Ineffective Case Management

COVID-19
- Disruption of Services
- From In-Person to Virtual Services
  • Not Preferred
  • Community Isolation
  • Virtual Services Not Returning to In-Person

Caregiver Burnout
- Community Isolation
- Lack of Support for Families
- Burnout from
  • Caregiving
  • Service Navigation
  • Advocating for Services

Disconnected Systems
Between Disability, Mental Health, Education and Medical Systems
- Lack of Communication Between Systems
- Lack of Cross Education Between Systems
- Inadequate Crisis Response Due to Lack of Knowledge About IDD or MH
- Distrust of Systems
- Exclusion from Services Due to IDD or MH or Medical Needs
- Medicaid/Medicare Limitations: Diagnoses Do Not Support Services

Discrimination

Participants discussed the discrimination they experienced with providers in terms of ableism or stigma against people with disabilities, as well as the cultural or racial bias of providers that manifested in racism or a lack of cultural humility and led to services that were not a good fit.

"I can't think of a specific instance, but in a broader scope, we run into difficulty receiving services just because even service providers and government facilities are not accessible to our daughter. Unfortunately, there's a lack of willingness to make it accessible a lot of times. Sometimes there is willingness, but then no follow through. So, it's really frustrating to first apply for help, but then have to wait around wondering if they're going to cover a window in order for you to be able to receive services."

"One hundred percent, absolutely I would say that mostly the parents of kids of color, it's just heartbreaking the amount of times that I would have families come to me and be like, 'Can you please come to a doctor's appointment with me? Because if you're there with me, the doctors will listen to what I have to say.' And I would literally go to a doctor's appointment and mom would be sharing what's going on with their child and the doctor would be dismissive and then I would rephrase the exact same thing the mom just said and it would be like as if they never heard it before. Why can't you listen to this parent who was telling you what their child needs and what's going on with their kid? Why do I as a White woman need to be sitting in the room to get you to listen. This is ridiculous and there is your job. ... It's just heartbreaking to see families have to go through that, fighting to get the basic needs of their kids met."

Statewide Survey participants also highlighted some language and cultural accessibility and competency issues with providers, with some statistically significant differences between people from traditionally underserved groups and the general population. About 82.4% of traditionally underserved respondents said their IDD services were "*always*" (65.5%) or "*usually*" (16.9%) available in their preferred language and were 2.2 times more likely to say that IDD services are only "*sometimes*" available in their preferred language than others (see Figure Twelve). Similarly, about 85.5% of traditionally underserved respondents said their mental and/or behavioral health services were "*always*" or "*usually*" available in their preferred language, and were 4.9 times more likely to say that they're only "*sometimes*" in their preferred language.

Figure Twelve Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Services Available in Their Preferred Language

Are services available in your preferred language?

	Never	Sometimes	Usually	Always
All Other Respondents		6.7%	15.2%	74.6%
Traditionally Underserved		12.7%	16.9%	65.5%
All Other Respondents	2.6%	20%		74.2%
Traditionally Underserved	10.9%	21%		64.5%
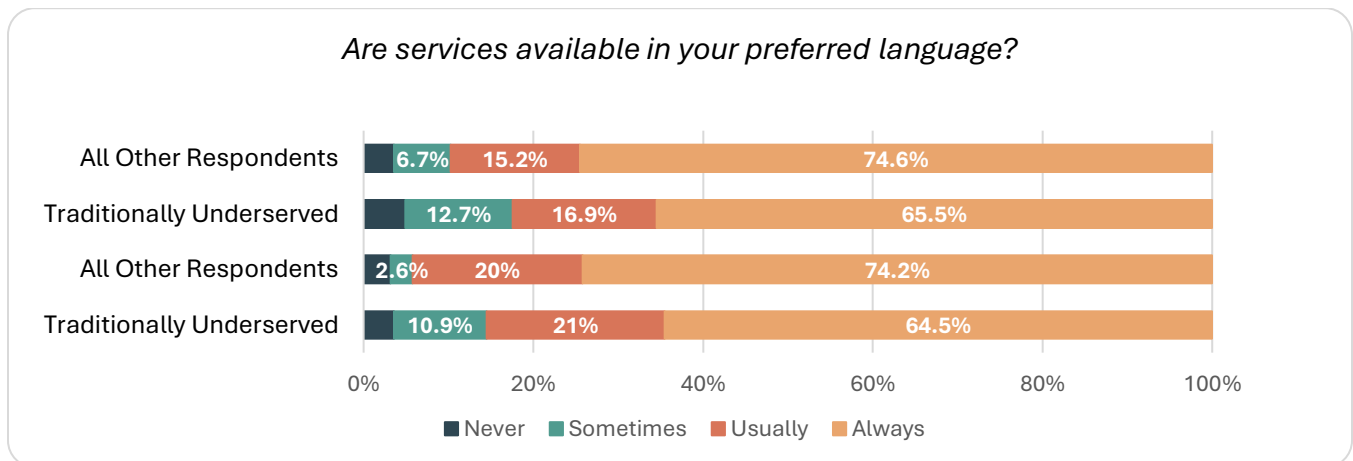
About 80.6% of traditionally underserved respondents said their IDD service providers respected their cultural background, religion, and/or values "*very well*" or "*somewhat well*," and were 3.1 times more likely to say that IDD providers only respect their culture, religion, and/or values "*a little bit*" (see Figure Thirteen). Traditionally underserved respondents were also 3.1 times more

likely to say that their mental or behavioral health providers only respected their culture, religion, and/or values "*a little bit*."

Figure Thirteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Service Providers Respecting Their Cultural Background, Religion, and/or Values

In general, do you feel that service providers respect your cultural background, religion, and/or values?

Category	Not At All	A Little Bit	Somewhat Well	Very Well
All Other Respondents	6.3%	23.1%		66.9%
Traditionally Underserved		15.8%	25.9%	54.7%
All Other Respondents	4.8%	24.8%		67.6%
Traditionally Underserved	13.7%	27.5%		55.7%
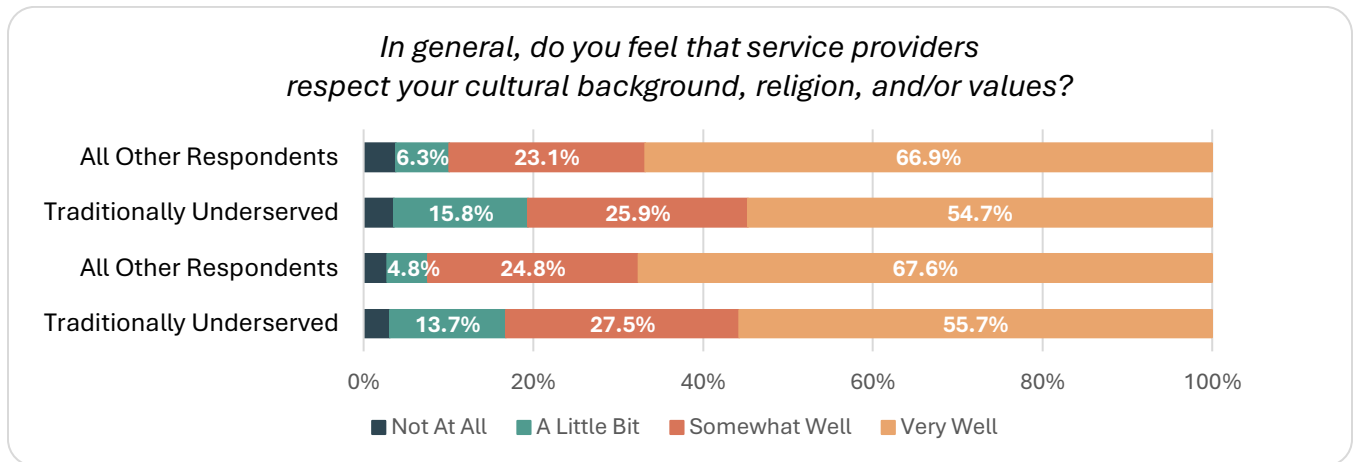
Fewer people felt providers aligned with their values, with about 69.8% of traditionally underserved respondents saying that their IDD service providers tried to offer services that aligned with their cultural background, religion, and/or values "*very well*" (41.1%) or "*somewhat well*" (28.7%) (see Figure Fourteen).

Figure Fourteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Service Providers Who Try to Offer Services that Align with Their Cultural Background, Religion, and/or Values

Do service providers try to offer services that align with your cultural background, religion, and/or values?

Category	Not At All	A Little Bit	Somewhat Well	Very Well	Service
All Other Respondents	7.9%	10.1%	34.5%	47.5%	IDD Services
Traditionally Underserved	13.2%	17.1%	28.7%	41.1%	
All Other Respondents	7.9%	9.5%	23.8%	58.7%	MH/BH Services
Traditionally Underserved	8%	19.2%	29.6%	43.2%	

Legend: Not At All, A Little Bit, Somewhat Well, Very Well

Financial Barriers

Financial barriers mentioned in interviews and the focus group related to the out-of-pocket costs of services, because some families made too much money to receive support from public services but not enough money to pay for services. Further, some services were not covered by public funding. Many participants also struggled to cover the high costs of caregiving and transportation needed to go to services and support.

"My husband works in a corporate job and makes six figures, and still, I can't afford to hire babysitters or people to help, and I can't find respite care because it takes a very special human being to be able to hang with my kids and it's hard to find that. And if I do find that, I need to pay them really well because it's a skill. But I don't have $30 an hour to pay somebody to care of kids. There's no room in my life. So yeah, it's crazy to have financial barriers when you make $170,000 a year. That's not right."

"I would put [my daughter] in much more things if I could afford them."

"Insurance companies make it impossible for providers, so they don't want to work with them. They would rather charge me less money upfront than have it paid for through insurance. That tells you so much, that they'd rather charge me a quarter of their rate than fight with insurance."

"[My son] has been on state insurance because our income is right at the level. But there are some local different therapy services, places that don't take his insurance. I feel like, gosh, if we had the money, I sure would love to look into that type of thing."

"On [name], where I live, nobody wants to work with the insurance companies because it's so much hassle and effort and work. So, I spent so many hours fighting with United Healthcare to try and get coverage for mental health therapy for my daughter and for my husband. … [My husband] did TMS therapy training for such bad depression that he was suicidal. And it's been so impossible to constantly advocate and fight with the insurance companies, who just push it back and say, 'Oh well, that's behavioral health, you need to go over there.' You get pushed around."

"We have a lot of out-of-pocket [expenses] from our private insurance. We're just not qualifying for state assistance in some ways, and then not getting assistance from our private insurance and it's all kind of piling up where it seems like we have a high income, but all of that just keeps going out. So, it's a bit of, I believe the expression is 'the donut hole,' where the coverage is — if you're too far over in one direction, but not far over enough in the other direction, then you're not fully covered on either end."

"Before [my daughters] turned 18, there were financial barriers to everything because my husband was retired and also partly disabled himself and so I had to take care of them. So, I was doing all

the parttime work I could, but the financial barriers came mostly in fuel costs. Driving cost too much money."

"We live on Social Security. She's a picky eater, but Washington just looks at the blank slate and goes, 'Here's what you get in food stamps. We don't care if your child's a picky eater. We don't care about any of that.' When she throws a fit and tosses the food across the room, oh well—there goes dinner. I can't make her another meal because then I'm spending more money. They don't look at those barriers, so I'm spending more on food than for the typical child. ... They give us less than $100 in food stamps. ... I'm grateful to have the government helping me, and I appreciate that more than anything. But they can't sit there and go, 'We're so great.' They can't do that because they're not. They're good, they've helped, but they can't praise themselves for being miracle workers because they're not. I don't think they're doing the best they can. They can do better and help us do better by looking at each individual family and looking at the needs of those families."

There were large differences between how traditionally underserved populations and how other respondents reported about the cost of their services on the survey. About 48.8% of traditionally underserved survey respondents said their IDD service providers were "*very expensive*" (21.9%) or "*somewhat expensive*" (26.9%), as opposed to 25% of the rest of the respondents (see Figure Fifteen). They were also about 2.8 times more likely to say that their IDD providers were "*somewhat*" or "*very*" expensive. Differences were also seen in the cost of mental or behavioral health services, with about 47.1% of traditionally underserved respondents saying their mental or behavioral health service providers were "*very expensive*" (21.1%) or "*somewhat expensive*" (26.1%), an almost 15% difference than the 32.6% of the rest of the respondents.

Figure Fifteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of the Affordability of Their Services
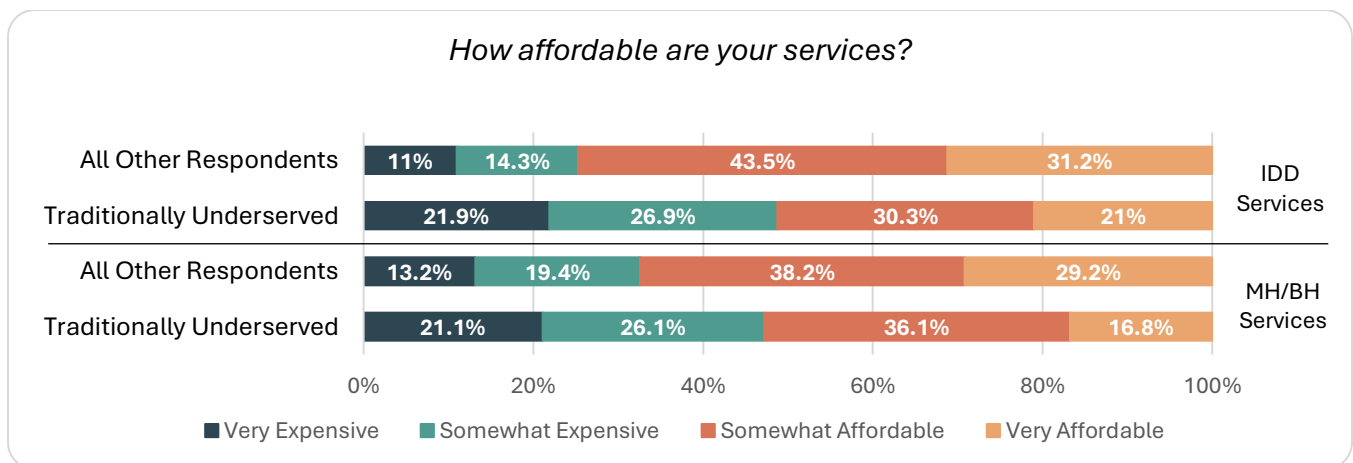
Geographical Barriers

Participants voiced many obstacles to services due to their geographical location, especially people who lived in rural areas. All participants noted the need for more services across the state, especially in rural areas, where some participants said that there were fewer service options available and less funding for services. Transportation was a large barrier for many participants.

"The barrier now is you can't get gas. You can't find the doctors. Washington won't help you with gas to go get to the doctors. And the time you spend going back and forth is hard and working parents can't get there."

"We are living in an area that we specifically stay because it's quite able to get [our son] to services. We're in this suburb in Lakewood, so urban/suburban. Getting him services isn't a problem—it's getting the appropriate services. If we had appropriate services, that'd be great. But we don't have services for [job] training him or things like that."

"Where I live is a small town 95 miles north of Seattle, so we don't have as many providers as I would like for my son."

"They probably have at least a good five different agencies that provide different types of programs for IDD adults where we are. We barley have any and the ones that we do have are at capacity and not taking any more clients in."

"We live in a small town in eastern Washington. There are some services in Pullman, which is not too far away, but too many of the services are located in Spokane and that's an hour away minimum. There is, of course, no public transportation between here and there. Driving wouldn't be a problem, except that constantly driving back and forth to a service that would end up being less time than the drive itself, plus having another daughter who needs completely different services and the inability to make that all work. It just hasn't been very conducive."

"Access to transportation is definitely an issue. Whether it's transporting [our daughter] to programs and services ourselves or paying a caregiver to do it, depending on what the situation is, or if she has to take our paratransit, which is called Metro Access in our area, it's a very stressful situation. It's stressful for her to take Access because of the uncertainty of the way Access runs. They've been working on it and trying to make things more reliable, but it's stressful. She does not want to use Access."

Differences were also seen in survey responses related to geographical access to services between those who belong to traditionally underserved communities and others. More than half (52.6%) of respondents from traditionally underserved communities said it was "*very hard*" or "*somewhat hard*" to get to their IDD service providers and their mental/behavioral health

providers (50.1%) because of the distance, versus 40.1% for IDD providers and 39.3% for mental/behavioral health providers for the rest of the population (see Figure Sixteen).

Figure Sixteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of the Distance of Service Providers from Their Homes

Considering the distance from home, how easy it is for you to access service providers?

	Very Hard	Somewhat Hard	Somewhat Easy	Very Easy
All Other Respondents	14.8%	25.3%	39%	17.6%
Traditionally Underserved	15.6%	37%	32.5%	14.9%
All Other Respondents	20.2%	19.1%	39.3%	21.4%
Traditionally Underserved	17.6%	32.5%	33.8%	16.2%
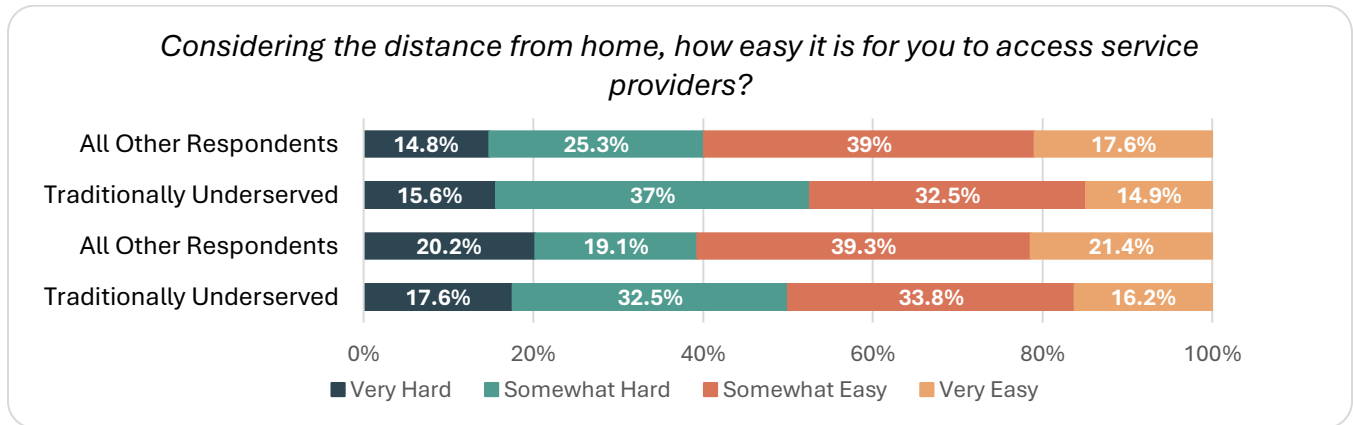
Similarly, more people from traditionally underserved groups found it "*very hard*" and "*somewhat hard*" than the rest of the respondents to get transportation to appointments, 45.2% versus 39.4% respectively for IDD services and 47.3% versus 35% for mental/behavioral health services (see Figure Seventeen).

Figure Seventeen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of the Ease of Getting Transportation to Appointments

How easy is it for you to get transportation to appointments?

	Very Hard	Somewhat Hard	Somewhat Easy	Very Easy
All Other Respondents	12.2%	27.2%	31.1%	29.4%
Traditionally Underserved	15.3%	29.9%	33.3%	21.5%
All Other Respondents	14.9%	20.1%	38.5%	26.4%
Traditionally Underserved	15.5%	31.8%	32.4%	20.3%
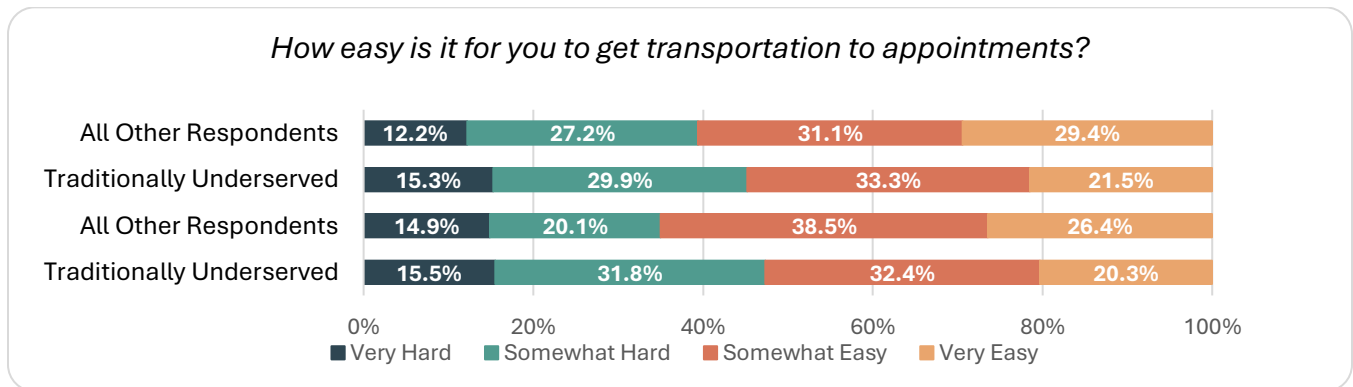
COVID-19 Pandemic

The COVID-19 pandemic also changed services and experiences for the people receiving services and families in the study. The pandemic disrupted services for many people with co-occurring support needs, and also transformed services to be more virtual, which is not preferred for many because it can contribute to feeling more socially isolated or it just is not the right fit.

"We were using a Medicaid medical transportation system in town called Hopelink — this is all pre-pandemic — and it was a crap fest. They contracted with cabs and the cabs would pick her up. ... Between her being unstable and doing things like yelling at cab drivers because she was in a paranoid state and thought they were glaring at her, and then the cab drivers, not knowing how to work with this population, would be offended about it and this and that, they would drop her off at the wrong location. It was just a hot mess, a hot, hot mess. ... And then the pandemic hit and all those services disappeared and lives changed. ... So, we end up paying a caregiver to take her places a lot of times because a lot of times with the mental health side of things, she's easily triggered and on the DD side of things, she has sensory issues so if there's strong odors and fragrances, all these things trigger her. So, I'd say that's the biggest issue for us — transportation. Any training that he had in high school and generalization of it is gone. COVID was a huge problem because there's two years of [my son] being happiest being in his environment that he is familiar with, which is part of the disability. So COVID was just what he wanted. ... I mean, there's probably six years of his life wasted. COVID was definitely one of the reasons we stopped [going to services at Easter Seals] because they stopped doing classes around that time, and we weren't real happy with what was going on there anyway, so we stopped. And they never reached out after COVID. I haven't heard from them in quite a long time."

Lack of Appropriate Services

Related to lack of appropriate services for their needs, participants spoke about being denied or removed from services and mismatches between the professionals they were seeing and the person receiving services due to professionals being uneducated about co-occurring needs, about the types or intensity of needs, or professionals having values that were misaligned with their own.

"[My son's] transition program just taught him to sit quietly for two years."

"What's really important for me on the dual diagnosis side of things is that there are not enough options inpatient and outpatient for our people. Our daughter, once she aged out of Seattle Children's and could no longer go to their units, she has been admitted to adult psychiatric units. She has the mind of, it goes between a four year old to maybe somedays she's kind of like a teen, giving you attitude. So, she's all over the map. She very immature, developmentally for her age, and yet, being admitted to adult units where she's can't even go there. It's just so heartbreaking. There are no options for our population. ... There was a small civil unit at the state psychiatric hospital that had the IDD population, but these were for long term admits. ... So, if you're admitted with some kind of severe mental illness, they're not really trained to deal with this population to help them and treat them and know how to navigate that. To me, that is the biggest, clear, glaring issue going on."

"I hate that if you bring your child in for early intervention ... you are instantly handed a prescription for ABA and told that there is a window of opportunity to fix these things. If I am handed a prescription by a doctor, I will go and fill that prescription, like if my child has an earache, I will go and get them antibiotics. So, if my child is handed a prescription by a doctor and they said, 'This is urgent, this is the gold standard of care, and this is what you should do and this is what insurance pays for.' And if I'm terrified and confused and panicked, I will go and do that and put my child through that instead of realizing that that is maybe not what my child needs. ... I want to stop looking at it as this medical intervention and let's fix it, and instead support it in the environment. If a flower doesn't bloom, you change the environment, you don't blame the flower, right?"

"To be honest, we really haven't seen much improvement in behavioral health. What we have seen with [my son] being gone three days a week is that it's not as frustrating [because we get a break], but it's not dealing with the issue. His behavioral issues are still there."

"I was trying to get [my daughter] on some SSRIs, some anti-anxiety medication to try to manage it, and then also maybe look at ADHD and at the advice of her therapist we went one of the few people who was willing to consider SSRIs for young children. She was a neuro psych who was like 60 years old and followed this really old school model. She was so off putting to [my daughter] from the get-go. She was like 20 minutes late, and [my daughter] was like marching around like, 'We were gonna start 20 minutes ago'; rigidity, right? And so, when it started out, [my daughter] was so high anxiety. And then straight out she asked her, 'Do you believe in neurodiversity?' And the provider was like, 'Well, I've read a lot about it. Yes, I believe I do.' And she said, 'Okay, I am autistic. You can't say I have autism.' And the provider said, 'Well, I like to see the whole patient, not just their disability. So, I say you are a young girl who has autism.' And my daughter was like, 'We're done. I'm not putting up with that.' And straight out, she goes, 'It's not like the flu—it doesn't come and go.' And the rest from that point on was a disaster. To have a provider talking to an eight-year-old child and argue with her about how my child wants to talk about her profile. ... And so, then she turned to me and goes, 'Mommy, I don't want to be here with this woman.' And I was like, 'Oh my god, we waited like three and a half months to get you in.' ... And at the time, I was so desperate and really needed her to write the script for the meds. And that prevented [my daughter] from seeing another doctor again for a year because I forced her through that experience and having the doctor talk about her to me and all these things. ... She's like, 'Why should I ever trust another doctor again? They don't know anything.' She could feel right away that this doctor wasn't with her on her side. And so, she's like, 'I'm out.' ... She wouldn't take any of the meds that this doctor prescribed because she didn't trust the doctor. We went another year before I could finally talk her into seeing a different doctor and taking some meds from a different doctor."

More than a quarter of respondents (28.1% of traditionally underserved people and 27.8% of other respondents) thought that disability service providers were not accommodating to their mental

and/or behavioral health support needs (see Figure Eighteen). Most respondents (44.6% of traditionally underserved people and 43.8% of other respondents) only "*somewhat agree*" that their disability service providers accommodate their mental/behavioral support needs, meaning that there is some room for improvement.

Figure Eighteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Disability Service Providers Being Accommodating to Their Mental and/or Behavioral Health Support Needs

In general, are DISABILITY service providers accommodating to your mental and/or behavioral health support needs?

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
All Other Respondents	12.4%	15.4%	43.8%	28.4%
Traditionally Underserved	11.5%	16.6%	44.6%	27.3%
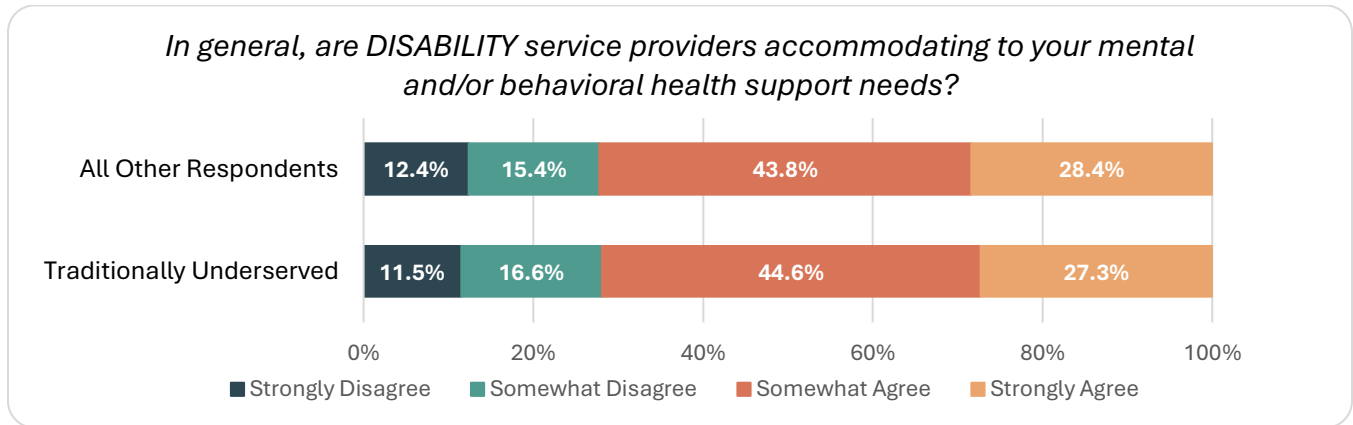
Similarly, 26.7% of traditionally underserved participants and 28% of other participants thought their mental/behavioral health providers were not accommodating to their disability support needs (see Figure Nineteen).

Figure Nineteen Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Mental and/or Behavioral Health Service Providers Accommodating Their Disability Support Needs

In general, are MENTAL and/or BEHAVIORAL HEALTH service providers accommodating to your disability support needs?

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
All Other Respondents	10.7%	17.3%	39.3%	32.7%
Traditionally Underserved	14.8%	11.9%	41.5%	31.9%
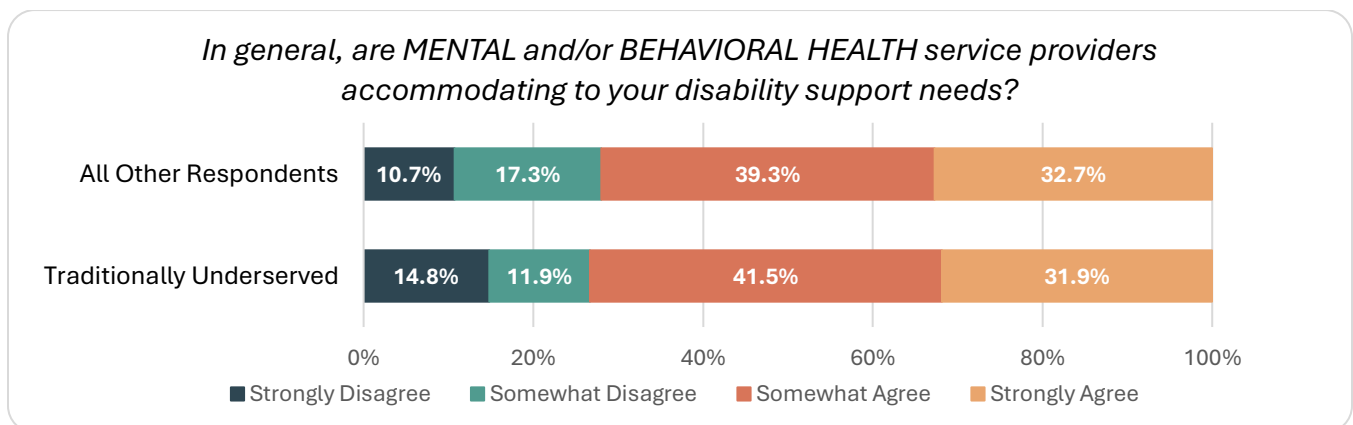
About half of respondents (45.9% of those from traditionally underserved groups and 55.6% of others) said that they've never been denied or removed from disability services because of their mental and/or behavioral health support needs, which is slightly higher than people who report being denied or removed from mental/behavioral health services due to their disability support

needs (44.6% for traditionally underserved people and 49.3% of others) (see Figures Twenty and Twenty-One). This may point to a number of factors such as mental health providers being slightly more accommodating to disability needs or slightly less likely to remove people from supports, especially for those from traditionally underserved communities who had lower averages of denial or removal from disability services (45.9% versus 55.6% of others) and mental and/or behavioral health services (44.6% versus 49.3% of others).

Figure Twenty Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Disability Service Providers Denying or Removing Them from Services Due to Their Mental and/or Behavioral Support Needs

Have you ever experienced a DISABILITY service provider denying or removing you from services because of mental and/or behavioral health support needs?

	I Don't Know	Yes, More Than Once	Yes, One Time	No, Never
All Other Respondents	9.9%	24.7%	9.9%	55.6%
Traditionally Underserved	15%	21.8%	17.3%	45.9%

Figure Twenty-One Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Mental and/or Behavioral Health Service Providers Denying or Removing Them from Services Due to Their Disability Support Needs

Have you ever experienced a MENTAL and/or BEHAVIORAL HEALTH service provider denying or removing you from services because of disability support needs?

	I Don't Know	Yes, More Than Once	Yes, One Time	No, Never
All Other Respondents	11.3%	24%	15.3%	49.3%
Traditionally Underserved	10.8%	20%	24.5%	44.6%

Many respondents, however, were concerned about being denied or removed from their services because of their co-occurring support needs. More than one-third (37.3%) of respondents from

traditionally underserved communities were "*very concerned*" that they may be denied or removed from their disability services because of their mental and/or behavioral health support needs, and 36.8% were "*very concerned*" about being denied or removed from their mental and/or behavioral health services due to their disability-related needs (see Figures Twenty-Two and Twenty-Three). Nine percent (9%) more traditionally underserved people were "*very concerned*" about losing disability services due to mental/behavioral health needs, and about 7% more were "*very concerned*" about losing their mental and/or behavioral health services than other respondents.

Figure Twenty-Two Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Concern about Disability Service Providers Denying or Removing Them from Services Due to Their Mental and/or Behavioral Support Needs

How concerned are you that you may be denied or removed from DISABILITY services because of mental and/or behavioral health support needs?

Figure Twenty-Three Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Concern about Mental and/or Behavioral Health Service Providers Denying or Removing Them from Services Due to Their Disability Support Needs

How concerned are you that you may be denied or removed from MENTAL and/or BEHAVIORAL HEALTH services because of disability support needs?
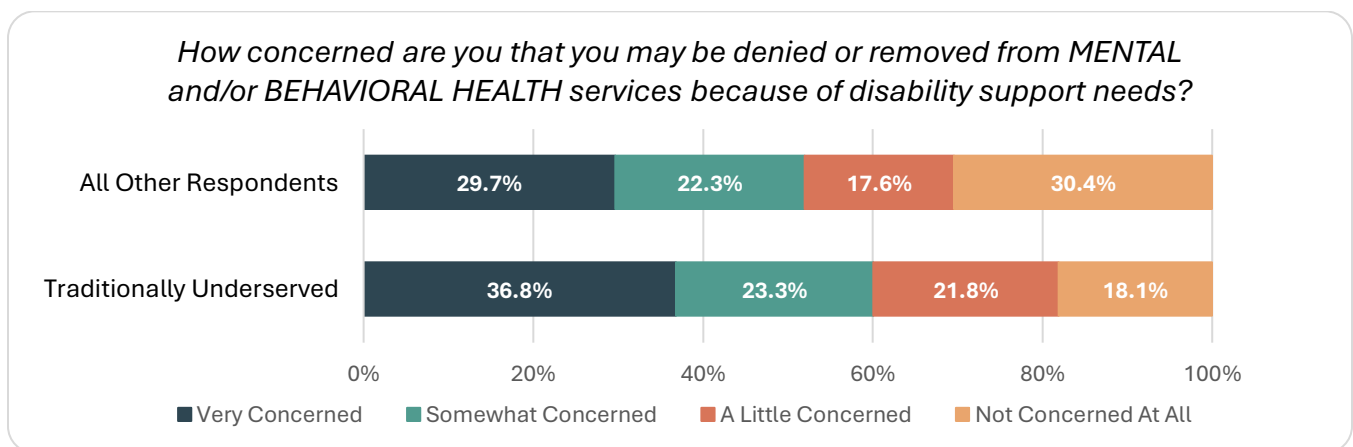
The Statewide Survey also asked participants about institutionalization due to mental and/or behavioral health support needs because community-based supports were not available.

Significantly more people from traditionally underserved communities (39.4%) have been institutionalized once or more than other respondents in the survey (22.2%) (see Figure Twenty-Four). Respondents from traditionally underserved groups are three times more likely to have experienced institutionalization once and 2.6 times more likely to have experienced institutionalization more than once because community-based supports were not available.

Figure Twenty-Four Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Institutionalization Due to Unavailable Community-Based Supports

Have you ever experienced instituationalization due to mental and/or behavioral health support needs because community-based supports were not available?

	I Don't Know	Yes, More Than Once	Yes, One Time	No, Never
All Other Respondents	6.4%	14.6%	7.6%	71.4%
Traditionally Underserved	8.7%	22.7%	16.7%	52%

People from traditionally underserved groups are also 2.6 times more likely to be "very concerned" about institutionalization because community-based supports were not available, and were significantly more "*very concerned*" (36.9%) about institutionalization in the future than others (24.6) (see Figure Twenty-Five).

Figure Twenty-Five Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Concern about Institutionalization Due to Unavailable Community-Based Supports

How concerned are you that you may be institutionalized due to mental and/or behavrioal health support needs because community-based supports were not available?

	Very Concerned	Somewhat Concerned	A Little Concerned	Not At All Concerned
All Other Respondents	24.6%	17.5%	21.1%	36.8%
Traditionally Underserved	36.9%	19.8%	22.8%	21.5%
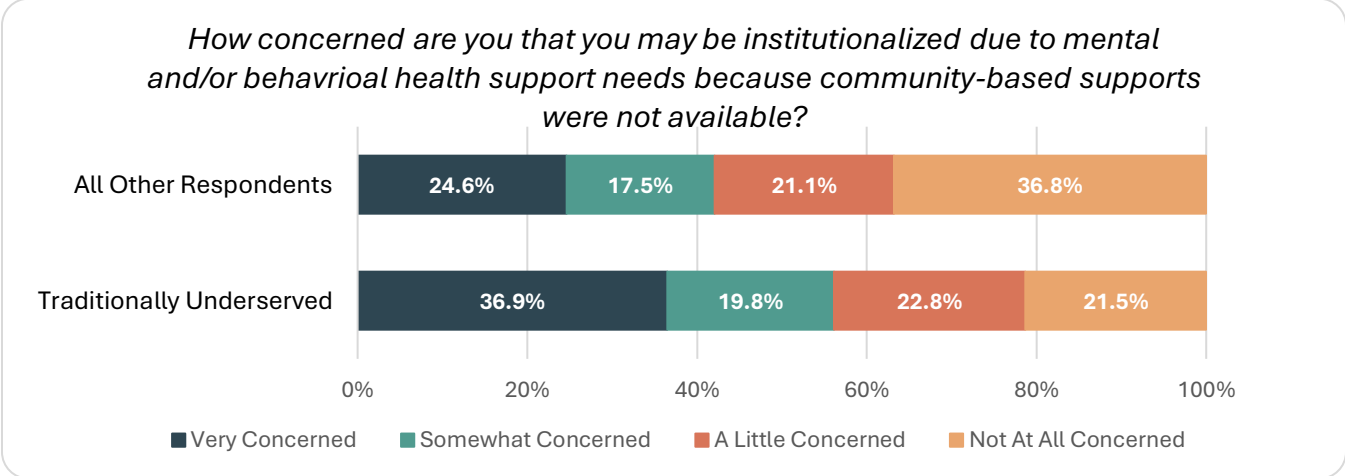
Service Qualification and Navigation

Many stories were shared about issues with qualifying for services and service navigation, including difficulty navigating the disability and mental and/or behavioral health systems; difficulty getting the appropriate diagnoses; lack of knowledge about what services are available and how to apply for them; lack of initiation of knowledgeable professionals to help them navigate systems and programs; and denial of services or funding of services.

"Here's my challenge with the Developmental Disabilities Administration: Our daughter was unable to get the services. There are services that she needed with her dual diagnosis, but that she is unable to get. We can't even access them using private pay because the providers only contract with DDA. … Our daughter has been denied eligibility twice in the past because of her IQ score."

"Going straight to the state, if you don't know what you're looking for at first [it's hard]. I know we need services but I don't know what they are. And there's not much outreach from the state first, it's finding the people who provides the state services and then getting connected with them."

"In Washington, we didn't have anybody reaching out to us. The school district wasn't providing county information on county services to us, and so it was more up to us to figure out where we needed to go and who we needed to talk to try to navigate things, versus when we were in California, it was actually the school district that first contact us and said, 'We understand that you have a daughter that's going to be coming into the school,' and it was two years from then, but they wanted to make sure that we were getting the services that we needed so that she was set up the best way possible to enter kindergarten. So, it was surprising to me when I moved to Washington, where the first place we contacted was the school district and they didn't give us any additional information for the county or for any other resources."

"The first challenges were proving that she needed the services when she was younger. Getting all of the documentation so that the state would provide the services, getting the doctors proof, getting the teachers, getting the psychiatrist or the pediatric developmental specialist, getting all of that and getting my daughter's autism diagnosis. She is profoundly autistic, but back in the early 2000s, they wouldn't give [the autism diagnosis] to a girl, especially one who had fairly good eye contact. Finally, a psychiatrist who was doing a study at Gonzaga said, 'What's going on here? This girl is autistic.' And once we got that diagnosis and he signed off on it, and the behavior was obvious from the school district and her pediatrician, once we got all of that into the system, it became easier to access services—the ones that were available, of course. Every now and then, her behavior would cause problems and she would be removed from certain services because the behavior was too extreme."

"A lot of families just don't have the ability, knowledge, or those advocacy skills to [navigate these systems]. That's where a lot of people fall through the cracks; that's the biggest challenge."

"It's hard figuring out where to start and then where to go after that first start because [my son] has a number of disabilities and a number of diagnoses. Do you start with the autism diagnosis? Do you start with the seizure disorder first? Do you start with the behavioral challenges? Do you start with the sensory processing disorder? Just getting all those services in place takes time."

"You don't know where to go, who to contact, and who to work through. And then the waiting — the waiting was the hardest part, just being on the wait list."

"I don't even know how we did it because there are days it's hard to keep your act together. I can't imagine how we did it in those early days. Somehow, we survived it because we didn't know what we didn't know. You make mistakes because of that lack of knowledge. And in our case, our child is the one who's bearing the negative effects of that because you don't know to sign up for something by a certain time, or whatever it is. It's just a very complex system, which is a surprise to no one."

"Part of it is that you don't always know the right way to navigate these systems right and you don't know the right words to use that get you services."

"There are families who are going to struggle a lot harder [navigating the systems] in terms of where their life is, what their situations is, and their capacity for understanding all that."

Statewide Survey respondents also expressed difficulty getting and understanding information about services. Sixty-three percent (63.4%) of participants said it was "*very hard*" or "*somewhat hard*" to get information about IDD services they can use, and about 57% said it was "*very hard*" or "*somewhat hard*" to get information about mental and behavioral health services (see Figure Twenty-Six).
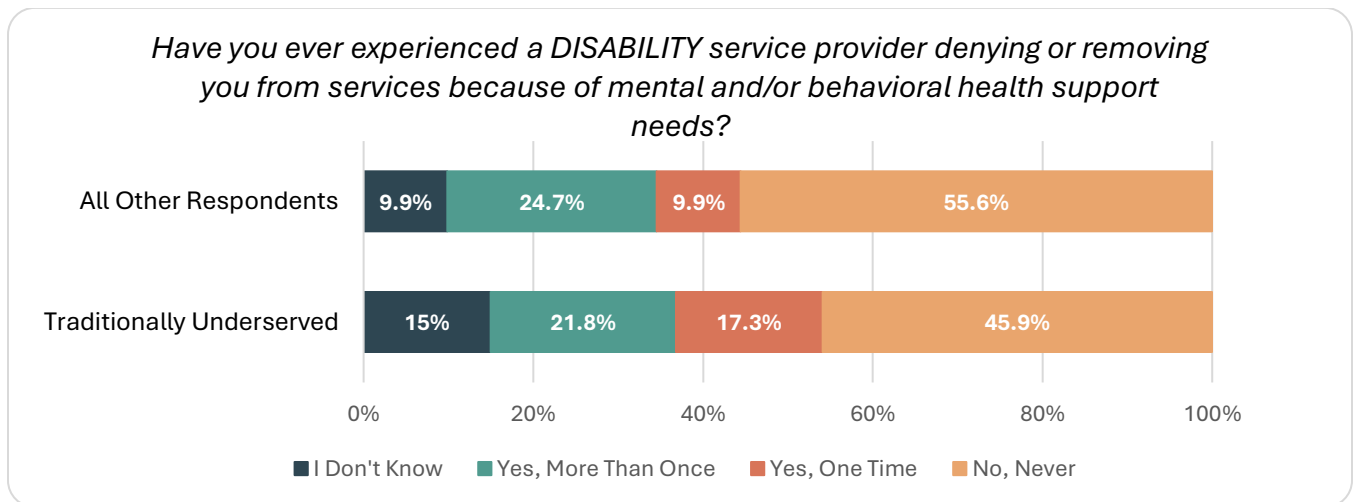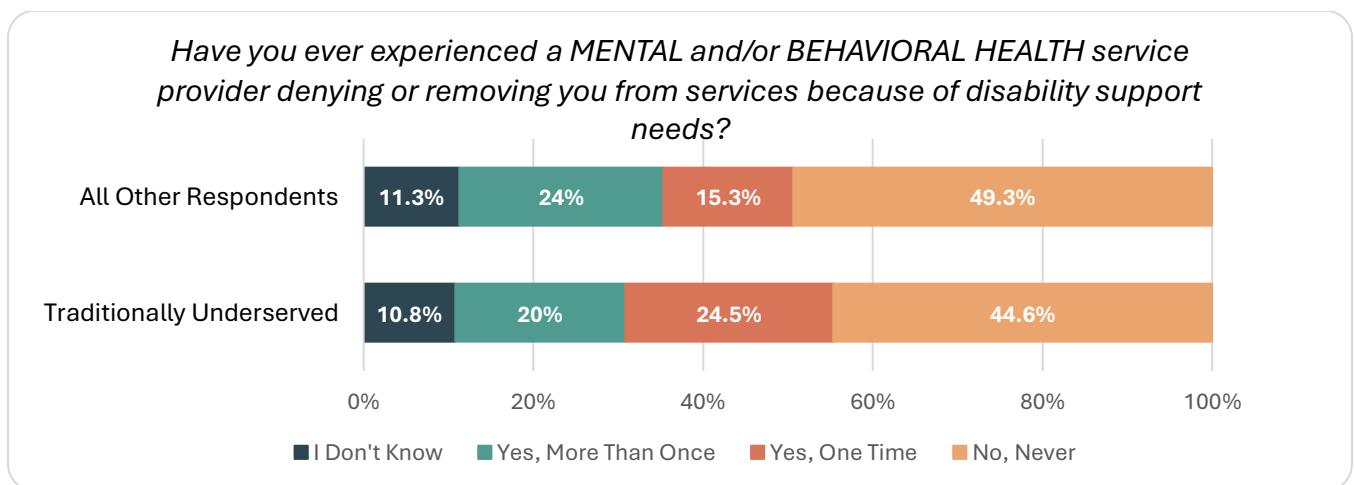
Figure Twenty-Six Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Ease of Getting Information about Services They Can Use

How easy is it for you
to get information about services you can use?

	Very Hard	Somewhat Hard	Somewhat Easy	Very Easy
All Other Respondents	24.7%	38.5%	27.6%	9.2%
Traditionally Underserved	30.1%	33.3%	28.2%	8.3%
All Other Respondents	24.1%	32.4%	34.7%	8.8%
Traditionally Underserved	23.4%	35.1%	34.4%	7.1%
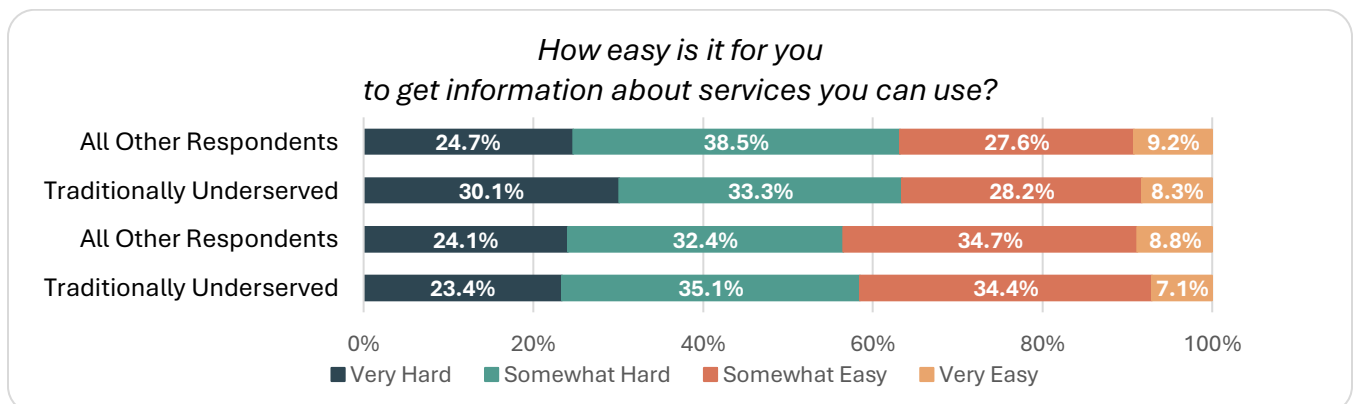
Similarly, more than half of survey respondents had difficulty understanding the information they found about eligibility, services offered, and how to seek help (see Figure Twenty-Seven).
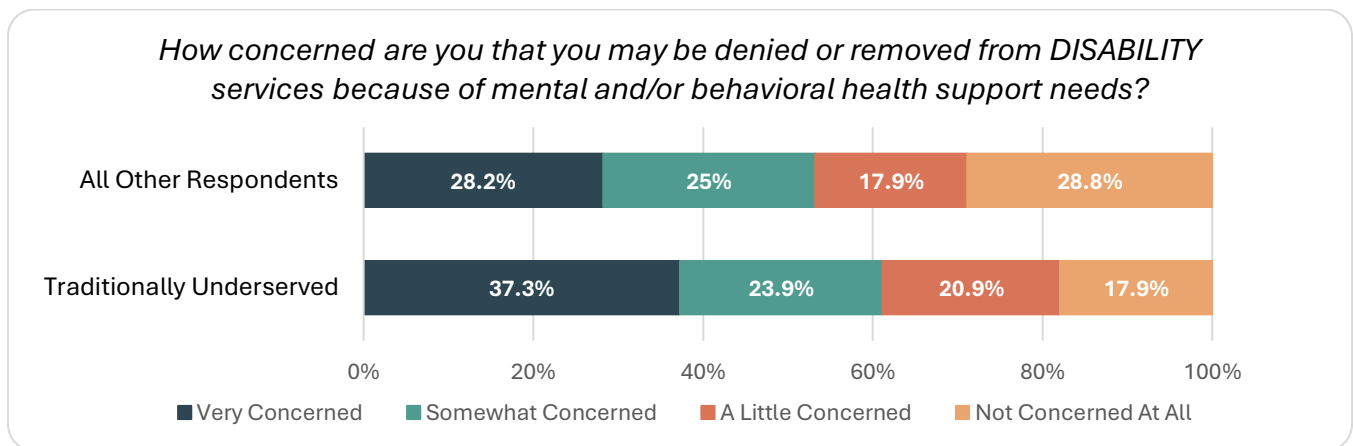
Figure Twenty-Seven Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Ease of Understanding the Information and Resources about Eligibility, Services Offered, and How to Seek Help

How easy is it for you to understand the information and resources about eligibility, services offered, and how to seek help?

	Very Hard	Somewhat Hard	Somewhat Easy	Very Easy
All Other Respondents	21%	40.9%	28.4%	9.7%
Traditionally Underserved	27.6%	30.1%	33.3%	9%
All Other Respondents	24.7%	29.9%	36.2%	9.2%
Traditionally Underserved	22.9%	34.6%	34%	8.5%
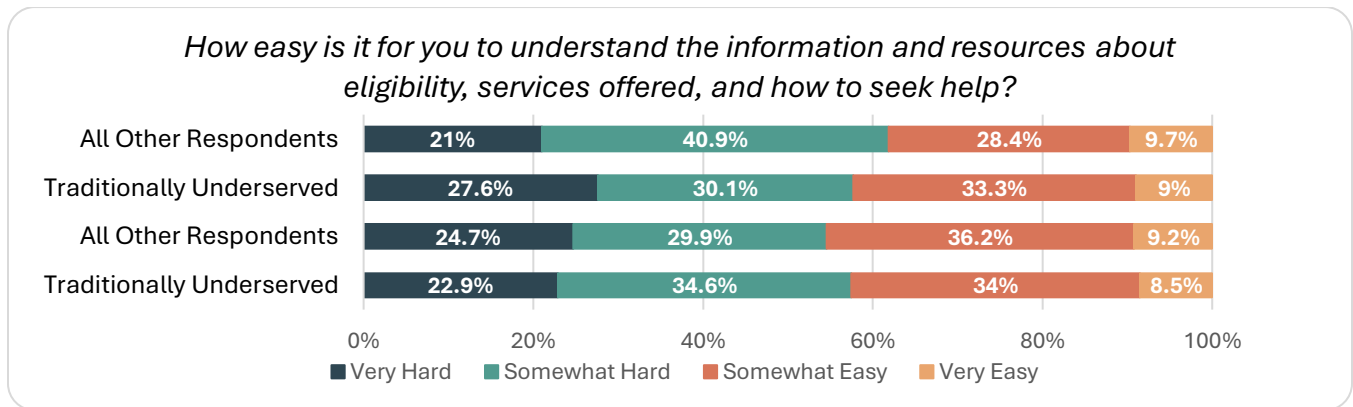
Survey respondents were also inconsistently confident about how to find and access the services they needed, with only 17-23% of respondents knowing how to access all the services they needed (See Figure Twenty-Eight). While most people knew how to access "some services," it may fall short of meeting their needs for both disability and mental/behavioral health support. Substantially more people from traditionally underserved communities (27.6%) said they did not know how to access IDD services than other respondents (15.8%), but more respondents who were not from traditionally underserved communities (23.6%) said they did not know how to access mental/behavioral health services than those traditionally underserved (21.8%). Both populations would benefit from more guidance about how to access the services they need.
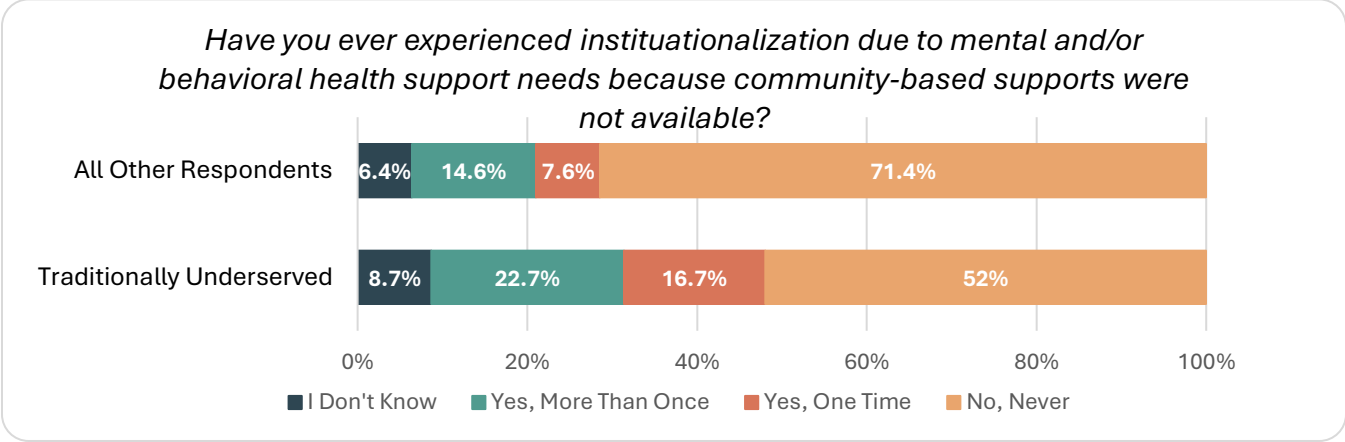
Figure Twenty-Eight Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Knowledge about How to Access Services

Do you know how to access the services you need?

	No	Yes, Some Services	Yes, All Services
All Respondents	15.8%	67%	17%
Traditionally Underserved	27.6%	54.5%	18%
All Other Respondents	23.6%	53.5%	23%
Traditionally Underserved	21.8%	59.6%	18.6%
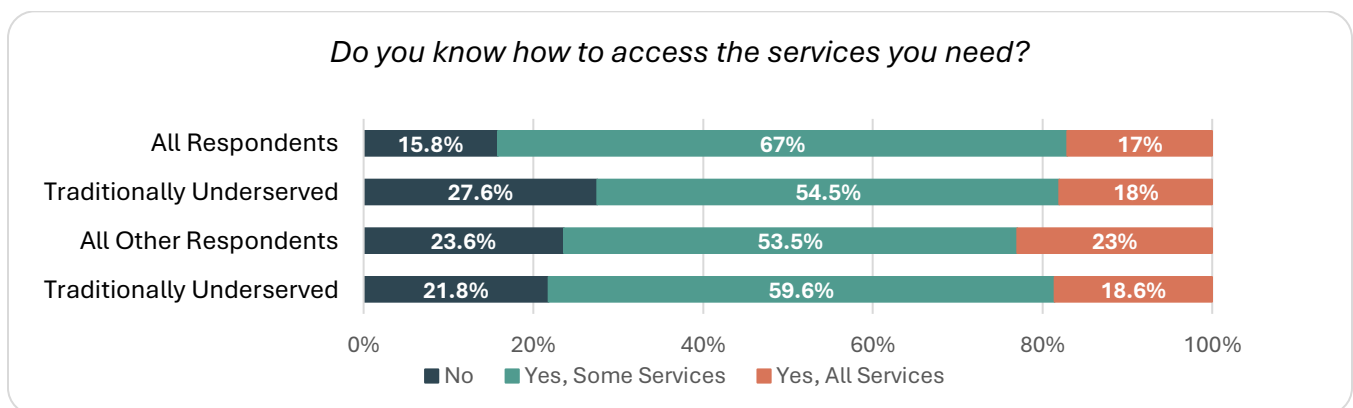
Survey responses related to service coverage mirrored concerns voiced in the interviews and focus group, with less than 50% of respondents saying they got all their services covered by insurance, Medicaid, or Medicare (see Figure Twenty-Nine). These numbers were substantially lower, about 10%, for those in traditionally underserved groups. Only 36.7% of people from

traditionally underserved populations said their insurance or public funding covered their IDD services, while 46.7% of other people reported having costs covered, and only 35.6% of people from traditionally underserved populations said their insurance or public funding covered their mental/behavioral health services, while 45.5% of other people reported having costs covered.

Figure Twenty-Nine Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Insurance, Medicaid, or Medicare Covering the Cost of Their Services
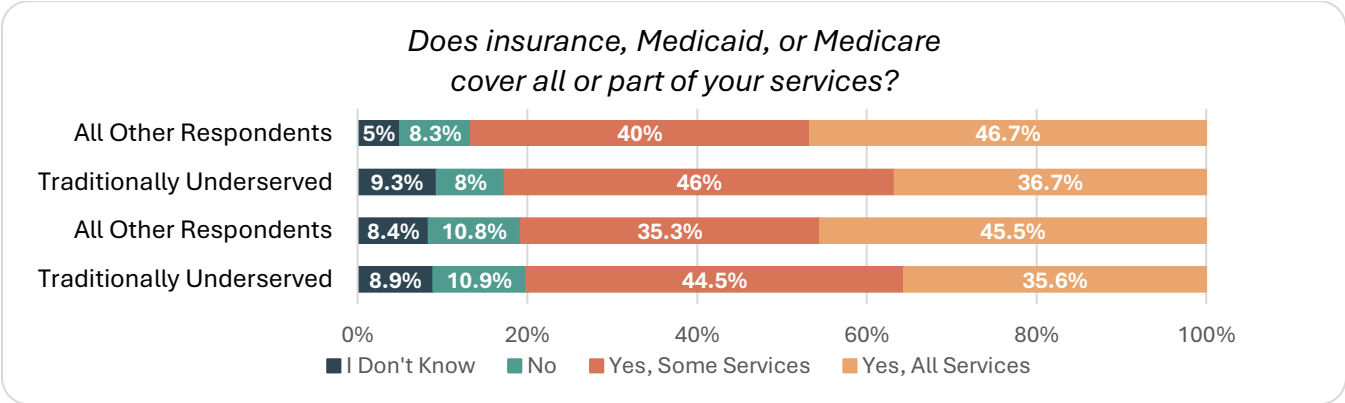
Caregiver Burnout

Difficulty navigating the systems and advocating for services while feeling unsupported in the process results in caregiver burnout and feeling isolated.

"As a parent, patience is required. I never thought I would need this amount of patience and how time consuming caregiving is. Being a single parent of a very high needs individual is very time consuming. … Being a parent of a very high needs individual takes a lot of creativity. How can I help him get through this anxiety? How can I help me get the strength to carry on and not give up? I said to his case manager one day long before he moved into supported living, I said, 'I'm about ready to drop him off at the institution with his meds and leave him with him with his name, his meds, and the name of his doctor and just drop and run.' She said, 'Oh, you can't do that. Do you know how bad that would be?' and I said, 'Yes, I do, but I'm letting you know that this is my level of frustration. I need help.' And I think as a parent, the parent has to find within themselves to say, 'I need help,' to be vulnerable enough to say, 'I need some help.'"

"I feel like the way the DDA system is set up, you have to fight tooth and nail just to show that your loved one needs supports and services. You can't focus on anything good that is happening, you have to focus on the worst of the worst in order to get the right help and that's very counterintuitive when we're trying to focus on person centered and very individualized and to have an increased positive outcome. Yet we're constantly having to focus on the negative and hope that our loved one stays in the negative to keep these services. It's very mind boggling in that way. The system is a set up a mess."

"There has not been really true success in getting supports or services. It's always been an uphill battle and fight. ... I sometime just give up because I can't keep moving mountains. It's exhausting. The constant advocacy work is so exhausting."

"I can't think of any [positive things to say] honestly. Maybe I'm not being fair, but you know, you just feel so worn down trying."

"There's too much burden on the families to fight through the system when we're already so taxed by just functioning within the system. I can't fight the system and try to survive in the system."

"It's been difficult reaching out [for support] because when you're a fulltime caregiver, plus I work fulltime, I don't really get to go to the support meetings and make those connections. When I've really needed to, there are lots of communities on Facebook that really help out with things like what I should be looking for with help and services."

Survey respondents were asked, "*Please pick the things that make it harder to access your or the person's current or most recent services*," and given eight possible responses and an opportunity to write their own response. The top selected barrier was "*Long wait times or difficulty scheduling*" (61%) (see Figure Thirty). "*Lack of knowledgeable support coordinator, support broker, or case manager*" was the next most popular barrier selected (45%), and following closely behind is "*Inconvenient location*" as the third most selected barrier (44%).

Figure Thirty Top Selected Barriers to Services from the Statewide Survey

Pick the things that make it harder to acces your current or most recent services
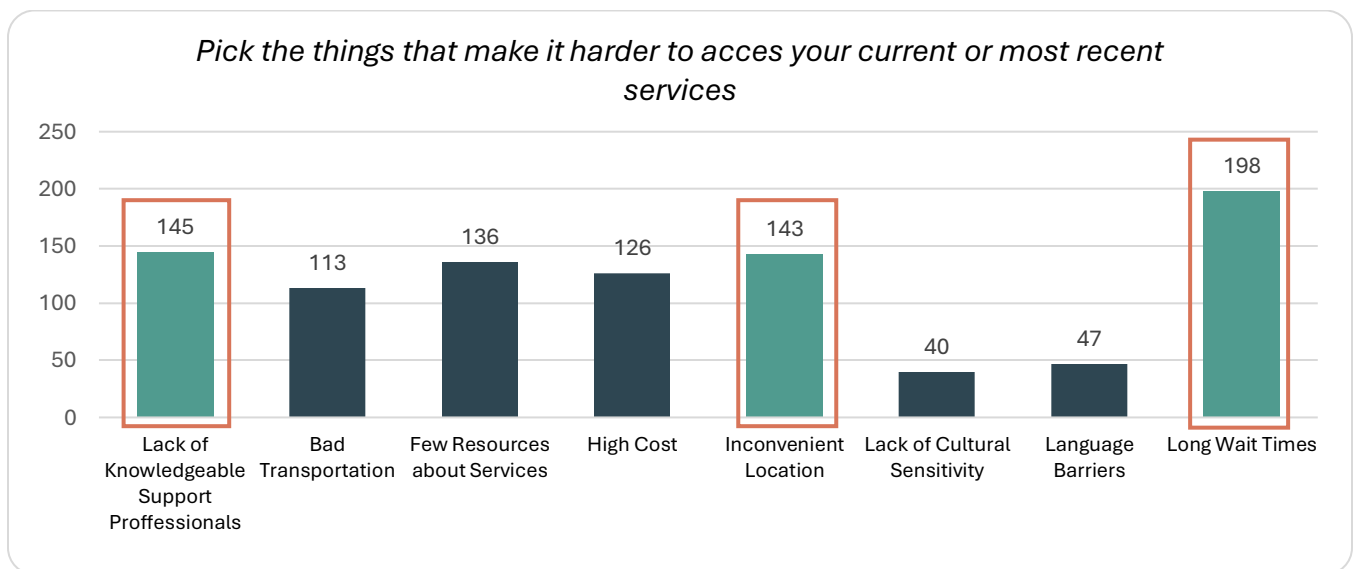
People also added the following barriers as "other" responses. Responses were grouped into the categories of waitlists, barriers to accessing services, insurance barriers, financial barriers, lack of mental health services, lack of disability services, unavailable services, lack of time or energy, negative stigma, health and behavior barriers, and other responses (Figure Thirty-One).

Figure Thirty-One Other Barriers to Services

Waitlists	Waitlists of up to two years for services when in crisis mode
	There aren't appropriate programs or services available, or there are long waiting lists
	It is so hard to find BCBA for my son. We been waiting for years and all they do put as on the waiting lists then finally tells us that they don't offer services in the area anymore. It's been an ongoing problem here in King County. We need a BCBA therapist.
Barriers to Accessing to Services	Very confusing how to get access to services, to even learn what is available and how to take advantage of services. What is the pathway to determine that my child qualifies for services.
	Not KNOWING what resources are available. They're out there, but how does a person know?
	Lack of personal willingness to seek help or lack of knowledge in what is actually available
	Case managers do not offer or ask what may be available
	Case workers who have no knowledge of the info or know very little
	Location, wheelchair accessibility, and transportation are major variable factors, depending on which service.
	Never find right resources
Insurance Barriers	Lack of providers accepting Medicaid insurance plans and serving adults
	So, FEW providers accept Apple Health.
	Not enough providers that take Medicaid.
	No psychiatrist available or willing to work with the patient because they do not accept Medicaid
	Lack of providers that take Medicaid
	Lack of in network coverage through my insurance plan. No one good wants to work with insurance
Financial Barriers	Being low income having the gas to get to appointments
Lack of MH Services	Lack of mental health living facilities and legal means to place people in care facilities when they need it.
	Services in the community are not available for mental health stability. Constant visits to hospital ED for behaviors.
	It's very hard to find mental health services that people who are dually diagnosed (IDD and mental health issues). Pretty much nonexistent or wait list are so full they don't even take help
	Lack of mental health providers willing to work with individuals who exhibit "behaviors"
Lack of Disability Services	There is a general lack of services for those not qualified for Path to Employment.

Figure Thirty-One (Cont.) Other Barriers to Services

Geographical Barriers	UW is the best place for most services I need but is 88 miles round trip
	The services we need don't exist or aren't in Kitsap
	Services are not available in my area. Adults with autism have no resources. They visited the house ONCE and never came back.
Services Not Working Together	Very hard to combine services from different "categories" (caregivers, community inclusion and engagement, other) to best meet real needs
	The mental health services always say they cannot provide mental/behavioral support due to his intellectual disability so they prescribe meds and request that his PCP manage his medications after initial prescribing.
	No communication between service providers to help bring it all together. Also, poor support.
	It's often hard to keep all providers on the same page as I don't necessarily automatically share information or have meetings to discuss. Patient care and best all providers can assist and serve the patient.
Services Don't Meet Needs	The waiting room is too chaotic & often disturbing/frightening to my special needs person
	Services, support, therapies, interventions, crisis services, short- or long-term inpatient, supported living, vocation supports, community participation, and residential habilitation/intermediate care facilities (even when it's desperately needed) are very difficult and more often ABSENT for those who are profoundly impacted. Providers are not trained, motivated, financially incentivized or mandated to work with individuals (children, teens, or adults) who have high needs/profound/IDD/harmful behaviors/co-occurring diagnoses. These services 'exist' but not for those with the highest needs and acuity. Systematic discrimination. Even this survey did not list or acknowledge "no access due to severity" as a reason or concern.
	Please include as one of the reasons my son is not able to access services and supports is because "PROVIDERS DENY SERIVICES, CLIAMING HIS NEEDS EXCEED THEIR MODEL OF CARE, STAFF ARE NOT TRAINED, WE DON'T GET REIMBURSED MORE SO WE CAN NOT SERVE THIS POPULATION." Why is this not listed as a reason? Our high needs/profound population are blanketly excluded for vital services and supports. HBCS, talk therapy, ABA, speech, OT, day programs, community participation ... all of these services and supports technically exist but our highest needs population is being excluded simply due to their high level of care needs, challenging behaviors, limited communication ability (not to be confused with those who can communicate using assisted tech), and intellectual impairment. Please acknowledge this discrimination. Filling out these surveys is even more isolating knowing those who advocate for our loved ones don't even acknowledge profound disability / high needs population exists or understand and identify the reasons they can't access vital services and supports.

Services Don't Meet Needs	No new suggestions for my dependent. They continue to struggle and at every appointment I am told "you are doing everything you should be doing keep it up" but my child is still suffering. We go to counseling and therapy to try to find new ways for her to cope and most times I walk out of there feeling discouraged because it is all things we have already done and have not worked. I just want to help my daughter but it is hard being told I am doing everything right but yet she is still struggling.
	It isn't easy - there are few if any sped personnel educated in comorbidities particularly those that are knowledgeable about neurodiversity
	No PDN AFHs that take medically intensive YOUNG adults with behavioral issues! The 2-3 are always full IR gave been told the liability insurance alone along with paying for an RN/LPN 24/7 isn't being adequately covered so they won't do it 24/7.
	Needed services are not available and supported living providers terminate with behaviors
	My son's school is perpetually out of compliance with his IEP. Yelm Middle School has the most awful SPED program I've ever seen.
	My family member has significant challenging behaviors that get in the way of accessing any community-based employment, day habilitation, recreation, residential and mental health counseling.
	Need access to psychiatric doctor to oversee medications who can work with non-communicative disabled patient.
	Never found any community respite or services that will take my daughter due to her high needs. DDA has zero options for us to use in our area
Services are Unavailable	Not having openings.
	Lack of providers with room
	Need more providers for mental and IDD supports
	Lack of service provider support staff is critical!!! Underpaid and under trained. Constant turnover of employees of caregiver organizations makes consistent quality care uncertain to impossible to depend on.
	Lack of staff to help with support needs!
Lack of Time or Energy	I'm just tired. Meds don't do much which means I'm stuck in jobs that exhaust me even more. You can't get time off to repeatedly go to countless doctors and psychologists when you're poor. Accommodations requires complicated evidence from the doctors they don't give you time off to see. So, one gives up.
	Help dealing with social security would be nice. I work full time job and taking care of disabled person is also full time job. Dealing with social security is a full time and Most stressful job.
	Because I work full time and have a developmentally delayed adult child, it is hard to get all the paperwork done.

Figure Thirty-One (Cont.) Other Barriers to Services

Negative Stigma	My daughter has seen counselors and psychiatrists in the past. Currently, she resists seeing mental health providers because she was tormented in school by kids who called her "crazy," "mental," and other slurs related to her behavior and learning disabilities. She desperately wants to be "normal" and resists the stigmatization that she associates with seeing a counselor, psychiatrist, etc.
Health and Behavior Barriers	My health
	High risk behaviors
	I get overwhelmed and have panic attacks which causes me to be unable to complete forms, especially ones like unemployment which have short time-frames and you have to start over if you don't complete them. Lost my entire retirement because I couldn't meet the deadline even though qualified.
	Difficulty with emotional response of person for whom I am caregiving
Other Responses	As a guardian, I am told after the fact of everything
	I maintain for my son the services and supports that he needs. I always go with him to his appointments to make sure he understands.
	Ignorance from medical professionals
	Immigrants
	Only able to see my PCP currently for my multitude of health concerns. This means we quickly and vaguely go over many things over many visits and she does not always retain all the information we review from appt to appt.
	We HAVE experienced difficulties at times in past; not now
	Client is very capable in many ways. Knows he needs services but frequently is out of town. We have been highly discouraged because DD Services and Housing systems seem to be eager to disqualify client. Guardian (parent) has serious health condition and can no longer manage client well. We have cared for him well for 48 years with assistance from Special Ed in public schools. His sibs live on East Coast have families and big jobs. I am REALLY frustrated and need help w my 48 y o son now.
	Familiarity breeds contempt.

Disconnected Systems

Interview respondents were also asked, "*Have you experienced a disconnect between the disability and mental health service systems? If so, how has that disconnect between the systems affect your access to services?*" Focus group participants and survey respondents spoke a lot about how disconnected disability, education, mental/behavioral health, and medical systems contribute to issues with accessing and maintaining services. Participants described a cycle of lack of communication between systems and providers, lack of available services, lack of or non-mandatory training across fields, and lack of guidance for families, all leading to delays in accessing services, lack of professional knowledge across fields, poor system navigation by people seeking services, and no seamless continuity of care across the lifespan. All of these elements contribute to the denial of services or service disruption, a lack of professionals who are qualified to work with people with co-occurring support needs, and caregiver confusion and exhaustion. Ultimately, people with co-occurring support needs are left with inadequate or inappropriate services for their needs or no services altogether, and a great mistrust of the system and of service providers (see Figure Thirty-Two).

"There's nothing but disconnects. There's no information sharing. The systems aren't set up to share information, like medical information and all of that. We actually carry a kit with all of [my daughter's] records, her guardianship papers, and her med list. I am the keeper of her medicines and I'd say that's the biggest risk factor because what happens is that lack of access to the history of her medicines could actually be dangerous because they always want to try something new and I'm like, 'No, actually she was on that three years ago and had a really bad reaction to it.' So, you are the historian and carry all that information around. So, I'd say those at the biggest disconnects."

"I feel like I'm stuck in the middle between my autism and my mental health because I have to get services for both of them. I feel like those are not coordinating very well because they're different."

"For the broad experience, things don't connect to each other, things don't communicate with each other and it makes it overall difficult."

"I've talked to people in other states, so I know this is not just a Washington issue. I know that this is an issue across the country, really across the world, because I've also been to conferences in England and in Australia and they're all dealing with the exact same thing. But that said, here in Washington, the biggest issue is everybody wants to point the finger. I feel like the mental health community loses sight of the fact that individuals with IDD present differently a neurotypical individual with a mental health disorder and so the things that they're seeing that they're chalking up to their disability. [For example] looking at self-harm behaviors or sexualized behaviors, I think that's one that we tend to see a lot is sexualized behaviors. And sexualized behaviors are not part

of IDD like that's coming from somewhere else. That's not directly tied to someone's disability. So, we need to look at where else is that coming from? … So, there's a huge disconnect with that mental health versus DD and people being willing to see where the lines cross and just accepting that. And sometimes it boggles my mind that we're in 2024 and people still struggle to even acknowledge that someone can have IDD, and have a mental health diagnosis and the prevalence of that is still ridiculously high, and it's like, how, how are we here? Maybe it's because I live it every day, both personally and professionally, but how can you deny that people can't be co-occurring? It's just astounding to me that people can't figure that out."

Figure Thirty-Two: The Danger of Disconnected Systems Based on Responses from Interviews, Focus Group, and Survey Responses

| Lack of Communication Between Systems

Lack of Communication Between Providers

Lack of State Supported Mental Health Services

Lack of or Non-Mandatory Training Across Fields

Lack of Guidance for Families | Delay in Accessing Services

Lack of Professional Knowledge Across Fields

Poor System Navigation

No Continuity of Care Through the Lifespan | Service Disruption

Denial of Services

Lack of Professionals Who Work with People with Co-Occuring Support Needs

Caregiver Confusion and Exhaustion | Inadequate or Inappropriate Services

No Services

Inadequate or Inappropriate Crisis Response Services

Mistrust of the System and Service Providers |

"I think the biggest problems I've ever come across would be that there is a lot out there, services for people who are disabled, like camps and things like that, but the moment you mention a behavior issue, they're not welcome. … The moment you say, 'Well, she does have some behavior issues,' they're like, 'Oh, well, we're sorry. We can't take care of that.'"

"Having a dual diagnosis have become even more complicated in our state because the behavioral supports really are not, for the most part, set up for residents who also have a developmental or intellectual disability."

"Finding a therapist that also understands developmental disabilities is almost impossible. State practitioners, their caseload is mostly mental health focused, but that's not helpful to [my brother] if they don't understand autism or developmental disabilities. It's probably the most frustrating piece of this puzzle."

"It's been a challenge of either getting services, continuing services, or getting people to understand that [my daughter] is one person dealing with two different issues and we have to treat her as one person, not as two different issues."

Survey data aligned with views from the interviews and the focus group; only about a quarter of respondents said they "*strongly agree*" that their different providers communicated with each other (30.2% of traditionally underserved people and 26.8% of others) (see Figure Thirty-Three).

Figure Thirty-Three: Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Whether Their Disability and Mental and/or Behavioral Health Provider(s) Communicate with Each Other
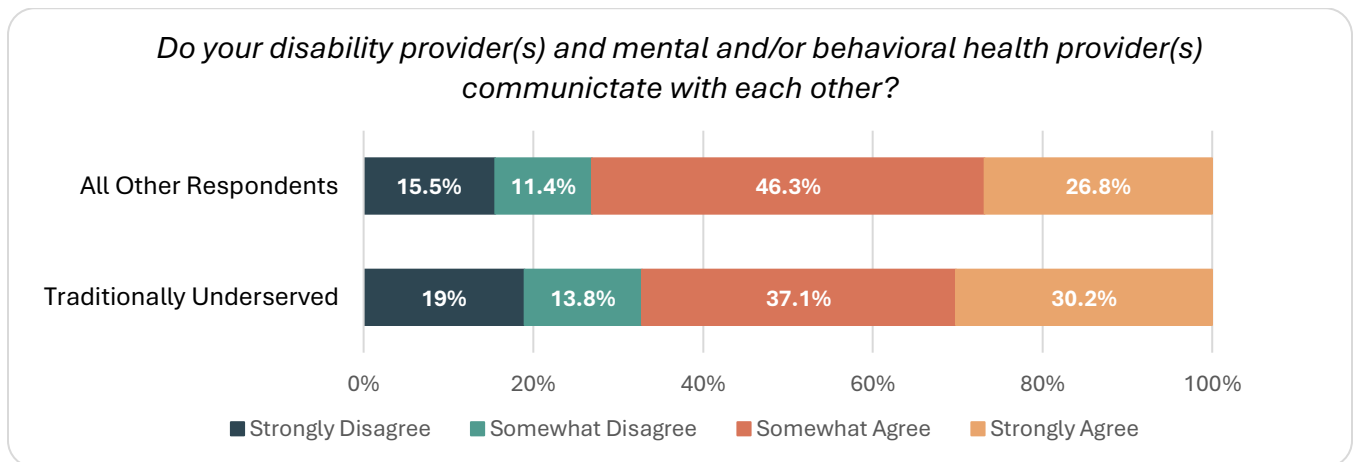
Similarly, only about a quarter of people thought their service providers worked well together (27.6% of traditionally underserved people and 26.7% of others), showing a disconnect between disability and mental/behavioral health providers (see Figure Thirty-Four).

Figure Thirty-Four Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Whether Their Disability and Mental and/or Behavioral Health Provider(s) Work Well Together
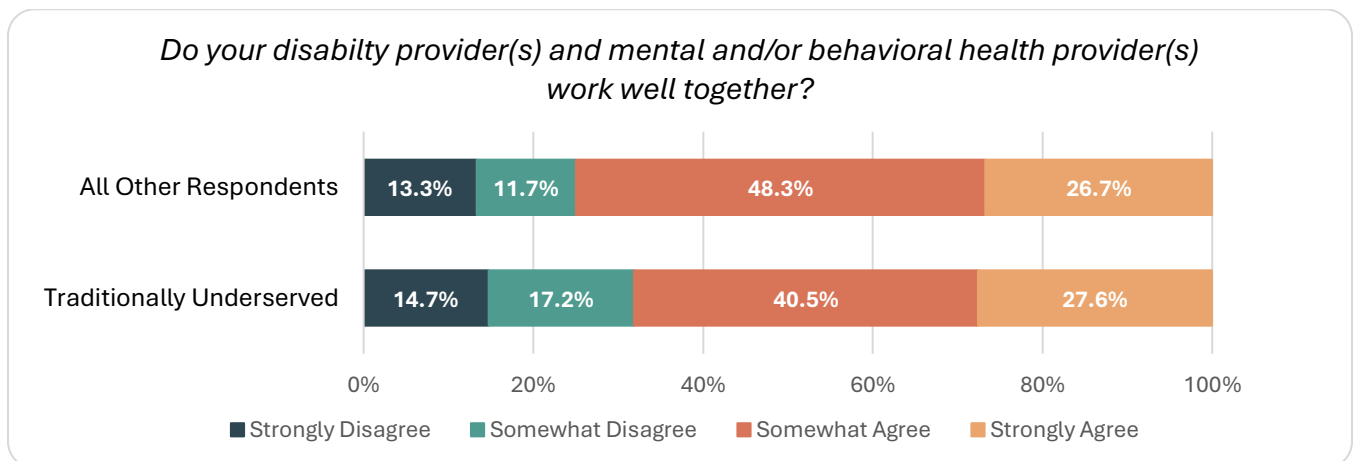
User Perspectives about Facilitators to Services for People with Co-Occurring Support Needs

People with co-occurring support needs and their family members participated in interviews and focus groups to share their experiences and perspectives about the things that help them get and maintain IDD and mental and/or behavioral health services in Washington. Participants were asked, *"What strategies have you used to access the services you need?"* and *"What are some of the things that have helped you to access services for co-occurring support needs?"* Facilitators discussed by participants in interviews and the focus group were grouped into five main categories: 1) Family support, 2) Available funding, 3) Available resources, 4) Provider support, and 5) System support. It is notable that far fewer facilitators were shared than barriers.

Figure Thirty-Five Facilitators to Services for People with Co-Occurring Support Needs from Interviews and Focus Group

-Competent Case Managers
-Government Support of Services (DDA, DVR)
-Government Support of Medical Needs (Medicaid, Medicare)
-School System Support for Services
-Respite Care

-Strong Relationship Between Provider and Family
-Providers in Close Proximity to Each Other
-Virtual Services
-Flexible Scheduling

-Family Insider Knowledge
-Individual Research (Online)
-Persistent Advocacy
-Family to Family Word of Mouth

System Support

Provider Support

Family Support

Facilitators to Services for People with Co-Occuring Support Needs

Available Resources

Available Funding

-Resource Fairs
-Non-Profit Organizations as Resources (Local Charities, The Arc, Parent to Parent, etc.)
-Providers Offering Referrals

-Ease of Becoming a Paid Family Caregiver
-Living Wage for Parents as Paid Family Caregivers
-Person Receiving Services as the Payee
-Insurance and Medicaid Coverage

Family Support

Related to family support, family insider knowledge from experience at jobs and careers in the disability field came in handy for many participants; many also relied on individual research and persistent advocacy, spending a lot of time online, on the phone, and in offices to make sure their loved ones got appropriate services; families also turned to other families for information that would help them navigate the system.

"I'm fortunate that I have a social work background. I've been in that field for quite a while, retired now, but I knew where to start. I know I had a jump start on some people who maybe don't know how to navigate our systems."

"I have the benefit of working for the Developmental Disabilities Administration, so I know what is out there and available, and yet, I still have to lean on my coworkers and be like, 'Okay, this is your area of expertise, lead the way for me because I don't know and I'm in mom mode right now and we're in crisis. Tell me who I need to be calling and what I need to be doing.'... That's worked really well in our favor. But no everybody has that in their back pocket."

"I was working for The Arc, so that's where I learned about Washington state services. ... I learned what [my son] could qualify for through The Arc, because that's something The Arc helps people to access. But until I worked there, I didn't really understand the DDA."

"I basically ended up going down the list and talking to them and then I went out in person and met with the people at the different programs. I narrowed it down to two and I went and I observed their program in progress."

"Luckily, because I'm a strong advocate, I was able to get my daughter into out-of-home placement and into supported living—but that's very hard to do."

"That's been our strategy — a lot of persistence."

"I advocate — calling around, searching online for services."

"Being a loud mouth — the only way you can get anything done in my area is being a loud mouth and demanding."

Available Funding

People in interviews and the focus group talked about how available funding was a big help to them and their families because it helped parents get paid a living to be caregivers. Private insurance also helped cover gaps or waiting times for public funding to pay for services, and Medicaid paid for many services, making them more attainable for participants. Participants also shared that becoming their own payee made getting the services they needed easier.

"Probably one of the most useful things is allowing me to be a paid care provider because that means I don't have to have an outside job. My job is to take care of my daughters. I get paid for it and that allows me to manage her. When people told me that was possible, that was the greatest news I ever got. It was fabulous news because it just made all of the stress of having to find a parttime job or substitute work [go away]. My daughters' disabilities meant that I couldn't be reliable and have a fulltime paid job because I was constantly having to pick one or the other of them up for different reason."

"I was very pleased that Medicaid covered all his services in terms of his medications, his doctor visits, his dental visits—they're all covered. He's had to have a couple of hospitalizations. He's had some MRIs; he's had some x-rays and things like that and Medicaid has covered all of that. So, I'm very grateful for that."

Available Resources

Many participants said that they would not have found appropriate community-based services if it were not for learning about them from places that provide available resources, like resource fairs, nonprofit organizations, and existing providers giving referrals.

"I always appreciate when whoever I'm working with recognizes if we need another referral or another person's assistance. That's when I really appreciate that first person. Because if they're saying, 'Oh well, this is my scope, but if you can talk to this department or this person, they can broaden the services.' That's what I appreciate the most, because as a parent that has no experience in these services, I don't know who else exists or what else could be provided to us. So, when those service workers give those referrals, gives those recommendations, that's the most help."

"There would be a fair once a year and all the different services would be there. I used to go to those. And DDA was there, along with other organizations, where people could come and get brochures and ask questions. But to be truly honest, to access and understand the services that come through the state, The Arc is probably the most substantial place to go and find out those services."

Provider Support

Participants in interviews and the focus group said that provider support, such as building relationships with them and their families, offering virtual services and flexible scheduling, and having providers who are close distance from each other, has helped facilitate successful services.

"We just went in with the idea that they were the professionals, and we were the parents and the sister and that everybody knows something about him and everybody was willing to listen to everybody's side."

"It's great if you're working with [providers] who are willing to do some financial adjustments and willing to be flexible with scheduling, and then just understanding that it's a whole system, it's a family system [that should be supported]."

"I have to say that telehealth is amazing, so I'm am so thankful that has come out of the pandemic."

"It's worked out well to have virtual appointments for [my son]. Sometimes he'll have anxiety. He'll be like, 'I don't know what I'm going to talk about today. I don't have anything to talk about. I don't feel like talking about it.' And I'm like, 'Then you need to call and change your appointment to virtual.' So, I feel like that's been helpful for him."

System Support

Participants voiced gratitude for system support when they got it, including competent and knowledgeable case managers, support from the DDA and DVR for services, public funding like Medicaid and Medicare, support from the school system for additional services or to transition to adulthood, and respite care.

"We're struggling how to best provide supports for him, but a lot of what I received as a strategy was to get respite care, which I was able to get, so I was grateful for that."

"[My daughter] gets respite care in house, so I do have a care provider that comes in. … She comes down here and helps, which does help me relieve my stress."

"DVR got me started with the whole process [of getting a job]. So, I have to give it up to them, because I don't know where I'd be without them."

"Looking into vocational rehab, the person I worked with and the voc rehab person hat [my son] was set up with was great."

"I think the state [professional] coming and seeing us at least once a year, making that personal connection is what helps drive the support through for us. He's good at getting back feedback if [my son] is struggling in a certain area. We've really been struggling for dental work and he was giving me places to look into."

Survey respondents were also asked to share what facilitated their services on the Statewide Survey: "*Please pick the things that make it easier to access your or the person's current or most recent services.*" They were given eight possible responses and an opportunity to write their own

response. The top selected facilitator was "*Convenient location*" (57.2%) (see Figure Thirty-Six). "*Knowledgeable support coordinator, support broker, or case manager*" was the next most popular barrier selected (51.6%), and "*Easy appointment scheduling*" was the third most selected barrier (50.4%).

Figure Thirty-Six Top Selected Facilitators to Services from the Statewide Survey

Pick the things that make it easier to acces your current or most recent services

People also added the following facilitators as "other" responses. Responses were grouped into the categories of: systems professionals or programs, Medicaid and public funding, providers, frontline professionals, other families, family support, virtual options, and other responses in Figure Thirty-Seven.

Figure Thirty-Seven Other Facilitators to Services

Systems Professionals or Programs	Excellent support in the RHC
	Currently, an EXCEPTIONAL DDA service coordinator and EXCEPTIONAL MH therapist
	A case worker who knows about all programs and help you not just tell you but engage and help. After the client turns 18 services seems too quickly not be available
	Immediate Crisis help
	In patient care facilities that are for low income and previously homeless
Medicaid and Public Funding	Available service providers accepting Medicaid insurance
	Current providers take Medicaid but they are leaving at the speed of light so soon will be none
	Housing! Live in support qualified to meet medical aspects of disability along with behavioral issues!
Providers	Providers who understand and accept to work with co-occurring IDD & MBH conditions
	Willing to work with insurance; willing to write DDA letters for specialized equipment
	The one provider has a flexible schedule
	More qualified providers willing and able to work with profoundly autistic individuals with limited language proficiency.
Frontline Professionals	Healthcare workers taking action to help me and being knowledgeable in general
	My daughter's Medicaid personal care assistant and her non-paid caregiver provide behavior support as needed during her daily activities.
Other Families	Info from other families who care for children with I/DD
Family Support	His provider, Uncle, has PTSD and understands the client's PTSD and is a great help in helping the client deal with and get through instances.
Virtual Options	Online meetings and appointments
	Online Services are appreciated (to save the time and hassle of transportation to appts)
	Covered through health insurance and provided online
Other Responses	More options for DME More contracted with DDA
	Resources are offered until I find them
	none

User Perspectives Recommendations for Services for People with Co-Occurring Support Needs

Participants of the interviews and focus group had many recommendations related to provider strategies and practices, improvements for future policy, and improvements for the disability and mental/behavioral health system improvements in general.

Provider Recommendations

Participants of the interviews and focus group were asked, *"What have you found to be the most useful thing that a service provider or state department has done to help people with co-occurring support needs maintain good health, wellbeing, and quality of life? Why?"* Their responses fell into three main categories of recommendations about ways to 1) Adjust approaches to service delivery, 2) Build a solid foundation for successful service delivery, and 3) Offer family support.

Suggested adjusted approaches to service delivery included having a broader spectrum of services for people with less needs and more needs, aspiring to have more engaging employees and programs, aiming for better coordination between different services, offering occasional counseling as needed, having a holistic approach that generalizes services and skills across environments, and having a better continuity of care across the lifespan.

Recommendations related to building a solid foundation for service delivery included providers having a better understanding of IDD and mental health, a better understanding and respect for family values to build trust, sharing resources with families, having plenty of engaged employees, using better matching practices of the person receiving services and the frontline employees, and offering more support for DSPs and frontline employees. those on the frontline.

Ways to offer family support were also recommended, such as helping with service navigation, offering support groups, offering programs for siblings or other family members, and taking the initiative to share programs and check in with families. Figure Thirty-Eight includes specific quotes and ideas that exemplify these recommendations.

Policy Recommendations

The National Leadership Consortium research team asked participants, *"What have you found to be most the useful thing that a service provider or state department has done to help people with co-occurring support needs maintain good health, wellbeing, and quality of life?"* Responses for policy related to funding, crisis services, extended timelines for services, protecting access to both disability and mental health services, following through with policy to ensure disability representation in policy making, and having more accountability for providers and the quality of their services (see Figure Thirty-Nine).

ADJUST APPROACHES TO SERVICE DELIVERY

Offer a Spectrum of Services

"[My son] is so high functioning because he has Asperger's or whatever they're qualifying it as now, that he doesn't need the specialized services."

Engaging Approaches to Services

"With [my son's] current therapist, he's meeting him where he's at and has that willingness to step outside of her box rather than him needs to conform what would typically be expected—sitting in an office, staring at her. ... She will start their session in her office and do a brief check in in the office and then they'll just go walk around the neighborhood and do the rest of their check in walking around outside. She knows he does better when he is not just sitting there face to face. But that took a long time to find someone who was willing to stretch beyond the traditional approach."

"[My daughter's therapist has] a strategy of building rapport and coming to a person's house. They have made the most progress in helping her. ... They don't tell me 'Oh, we can't help her; we can't serve her. They don't say that. So, to me, that's something that works with her."

"[My son] is engaged when he's there. He's doing the activities and he's interacting. He's definitely more engaged than he was in [the other program], absolutely. ... He wasn't making friends [at the other program] like he is at this program and now he actually has people he considers his friends, which is really good because he has a hard time making friends."

Better Coordination Between Different Services

"I feel like the mental health providers, and I don't know how this would even happen, but if they were working with maybe disability providers of DSHS providers, that would lead to a better quality of service. ... the disability services aren't necessarily connected with the mental health aspect of what he needs."

Occasional counseling as needed

"I think it would be nice if [my son] could get a counselor or somebody he can meet with a one-to-one basis to talk about the things he struggles with, because he does have some mental issues that he struggles with. It'd be nice if he could have one counseling session occasionally. I think it'd be helpful for him to talk about things and get things out because he doesn't have that right now."

ADJUST APPROACHES TO SERVICE DELIVERY

Services Across Environments

"Something with my VA therapists that was so amazing with [my daughter] was that, we live on a small island so she would see [my daughter] out and about in the community. And so, the insight that she would get of seeing others in the grocery store or at a school function or something when she was still going to school, and that willingness to break the isolation of that or that boundary … that has allowed the provider to see the bigger impact than when you're in a therapy room, one-on-one with an adult who's co-regulating you while they're trying to talk with you and work through stuff."

"I would love to see schools doing more wraparound work. I would love to see schools working with providers and having a community-based team, a school-based team and the family- based team all working to like improve things everywhere, because it's the same stuff showing up everywhere. And for a child who is heavily masked and can make it through the day at school, they're going to come home and implode. And then the parents get blamed for being bad parents, without realizing that effort of maintaining that whole day. And so, if the school can see what's going on at home, and then know that they're involved, you know, it's all connected."

More Continuity of Care

"[We need] more services for teenagers with intellectual disabilities because there are none. There are more services for them going into adulthood and into the workforce. But what if they're not at that point to go into the workforce? What if they're less than that ability? What can they do in the community? What if they're at the point to volunteer, can we get some programs to help them do that? But even before then we've got teenagers that are neurotypical who are working. Can we get programs to help in that area? … It's hard for them to make friends, and so they need to somehow get in the community. Not always is there a youth group that's available for them. Not always can they do Girl Scouts or Boy Scouts or 4H. When those are the only available groups, maybe there can be some sort of thing through DDA or through something that the state can provide, that they can come to that will help them with skills and will help them with communicating that isn't school based, that is more fun-based, community-based and so that they can learn some of those skills so that when they get older it will help them maybe get into the workforce."

BUILDING A SOLID FOUNDATION FOR SERVICE DELIVERY

Better Understanding of IDD and Mental Health

"Learn to truly understand the population that they're working with both mentally and on the disabled side. That's another thing I feel is hugely lacking. If they had more knowledge of and understanding, maybe they wouldn't treat their clients like crap."

"Have a little more passion and patience and more understanding of disabilities."

Understand Family Values

"We trust [our new psychiatrist]. He has taken the time to get to know us and know how we think and what's important to us. … [Previous psychiatrists] pretty much thought they were the doctors and we didn't know anything; their opinion was the right one. This doctor now confers with colleagues. He said that he's talked to people that he went to medical school with 20 years ago, he's talked to people across the United States because we can't seem to figure out how to help her."

Share Resources with Families

"[Our daughter's] case manager, she'll just send me something and she's like, 'I was thinking of [your daughter] and I thought this might be good for her,' and she sends it to me. … She's sent a bunch of different things over the years like that. And she just checks in, not just at the one year meeting, she's checking in other times just to see how we're doing."

More Engaged Staff

"It was an excellent program. They had a lot of structure, which my brother needs. And they did a lot of activities like exercise and programs where he could interact with other people. And they had plenty of staff per person, which I really liked because it looked like it was a very safe place where he would get supervision and fun activities. … They have a lot of people there [at the program]. Every time I've gone and observed, there's always been plenty of people helping and engaged with them on the activity they're doing. It's not just a few people and everybody's having coffee. They're engaged with them."

Better Matching

"The counselors are all older women, 20 plus years older than [my daughter]. It wasn't unsuccessful, but it's a different relationship. So, I would recommend probably same sex and closer to her age for rapport building. Once that rapport and trust is established, then she makes more progress."

FOUNDATION FOR SERVICE DELIVERY	**Support for DSPs** "I think focusing on the positive and rewarding employees for jobs well done, making sure they're well trained. … I think instead of going through the basic training of 'this is how you shower someone. This is how you change someone's incontinence supplies,' I think they need to go beyond those basics and make it more individualized. … How do we support those direct support for personnel? What tools can we give them to keep going? … I think part of the key to keeping direct support professionals engaged is ongoing learning—and it doesn't have to be textbook learning. Ongoing learning and positive rewards. Check in with them, maybe once a month."
FAMILY SUPPORT	**Help with Service Navigation** "If there were a private organization that was like a nonprofit and their job is simply to help you navigate the system, learn about your profile and have a modern understanding of autism and everything involved in it and they help you navigate the system and tell you, 'These are the things that you might be eligible for.' [That would be good.]" **Support for Parents** "My son lives in supported living now with two housemates and fulltime staff, but none of our agencies in town who provide residential support have a support group for us parents with older kids that I'm aware of. Most of the support groups are parents and families of younger children or early in their diagnosis stage or school age." **Support for Siblings** "If there's one autistic person or one person with a diagnosis, it's the entire family system that needs to be supports and treated. So, this idea of bringing the little sister in to help work during the big sister's appointments that are covered by insurance, that was so amazing." **Providers Initiate Service Navigation** "It would be nice if [the provider] would reach out and if we need any behavioral health or mental health … just contact us and say, 'Is this an area that you need help in?'"

Figure Thirty-Nine Policy Recommendations from Interview and Focus Group Participants

FUNDING	**Accept More People for DDA Funding or Allow More Diverse Funding for Services** "Right now, all roads lead to DDA, and if you're not on DDA, you are left out. At one point, our daughter was discharged from a hospital, and there was a program south of us that specializes in clients with IDD and teaching them DBT methods, and so is with so clients with severe mental illness and IDD, and we could not access those services because they only contract with DDA. I couldn't even privately pay. I was like, 'I will private pay you to help our daughter.' And we couldn't get to these services. We've run into it repeatedly with housing that only contracts with DDA. So, this is my biggest beef. We need to open up and let more of the thousands of people in our state who are being denied DDA services get them on DDA so they can then access these services in some way or say you can contract with multiple streams and you can take private pay. But we have so many things where we just hit barrier after barrier because she's not on DDA ... I'm assuming that it's going to start at a policy and a rule level." **Budget More Funding for IDD and Mental/Behavioral Health Services** "Make them a priority in the policies and in the budgeting process, and really acknowledge and say, 'What are the needs?' And do the planning around this population across all dimensions, whether it's about their social services, their programming, their housing, their primary care, their specialty care, their psychiatric care ... because I feel like rights are being violated repeatedly in so many different ways and in a lot of cases, they can't advocate for themselves at the level that other populations maybe can. So, I think that's it's got to start at the policy level and in the programs." "We need more funding for these children, because it seems to be that year after year we're having more children with disabilities, and these kids are growing up to be adults. These kids are going to be adults in our community and we need to make sure that these people are taken care of in our community. We need to take care of our neighbors. We need to take care of people, and we need to have policies in place that protect them. We need to have policies in place that provide the care they need. We need to have policies in place so they have the funding year after year, not one year we have the money, and one year we don't have the money, because they need consistency year after year."

Figure Thirty-Nine Policy Recommendations from Interview and Focus Group Participants

CRISIS SERVICES AND SUPPORTS	**More Non-Medical Crisis Services Support** "We do not in Washington state have a building that provides care for parents when a parent is overwhelmed by a child who has behavioral issues and needs to put their child in a place besides a hospital, like an actual ER hospital that takes care of medical people. There is not a place in Washington state that you can put in a person or child when they're having behavioral issues. We do not have a building. So, if you have a child who's 13 or 14, who is bigger than you, who is hitting you and you are overwhelmed, you have no place to put that child to have a break, to have a moment, to decompress for a day or two. There is nowhere to put them except to go to the emergency room and put that child in an emergency room in a mental hospital. ... If you are getting injured by your child who was having an outburst, and it's a teenager who is bigger than you, you could not call the police to have them come and help you. They did not come and do that anymore. Our governor changed the laws on that one and they would not come and help anymore. Now, the police would want to come, but they legally could not come and help you get protection from your child." **Adopt a Trauma-Focused Approach** "I really want to shift to a more trauma focused approach in all of our children's residential programs. I would love to see that in our adult residential program. I would love to see that in all of our programs across the board. ... Things are too negative and punishment focused. By the time kids and adults are in residential programs, they have been through so much and most, if not all, have experienced trauma. The last things we want to do is create more trauma, so any policy or rule around that would be a huge step in the right direction."
EXTEND TIMELINE FOR SERVICES	**Extend Mental Health Services Timelines** "I get you have to have boundaries, and they've got a lot of people to serve. But to realistically think that a person with a developmental disability and a mental health disability is going to be turned around in 90 days is ridiculous. Who thinks that?" **Extend Special Education Eligibility** "Moving here from Michigan, I was surprised we had more services in Michigan than we did in Washington state. Michigan has a special ed program up to age 26, but in Washington, as in most states, the students age out of most programs at 21."

Figure Thirty-Nine Policy Recommendations from Interview and Focus Group Participants

PROTECT ACCESS TO DDA & MENTAL HEALTH SERVICES	"When families are trying to qualify their kiddos or their loved ones for services [through DDA], they are open and acknowledge that mental health or behavioral health could be a part of their disability. But when I first got my daughter on [DDA services], I was told by multiple people that you can't say that she has mental health issues because once you say that, then she gets kicked out of the DDA system. So somewhere along the line that needs to be part of the policy or some type of law to acknowledge that co-occurring existence."
FOLLOW THROUGH WITH POLICY FOR REPRESENTATION	**Nothing About Us Without Us Act, House Bill 1541** Intending to access and representation in policy-making processes for people with direct lived experience and set to take effect in January 2025. "This past legislative session, a group of self-advocates from all over the state of Washington and myself were able to get HB 1541, the Nothing About Us Without Us Bill, passed into law and that took four years to get that done. It's about making your own choices as a person with a disability. … I haven't seen anything changed since that Bill became a law, but I'm hoping that people with mental health get the changes or get the help that they need with their mental health."
MORE PROVIDER ACCOUNTABILITY	"You have to hold programs and services and agencies accountable to walk the walk."

System Recommendations

Interview and focus group participants were asked, "*Based on your experience, what changes do you think are necessary to improve services for people with co-occurring support needs in Washington*?"

Their responses fell into five main categories of recommendations about how the system could be easier to access and use for people with co-occurring support needs 1) More Training, 2) Support for people receiving services and their families, 3) More communication across systems, 4) Improved Services, and 5) Easier access to services. There were also a few recommendations that did not fit into these categories, including addressing turnover and workforce issues, examining the budget, and increasing lobbying.

More Training

Recommendations to improve systems related to more training referred to more training for emergency response and medical professionals to be more knowledgeable about disability and mental health needs, for IDD professionals to be more knowledgeable about mental and behavioral health, for mental and behavioral health professionals to learn more about disabilities, and more training and professionalization of the DSP position.

Support For People Using Services and Families

Related to support for people receiving services and their families, participants suggested there should be more support services and groups for caregivers, greater outreach to families, a dedicated professional whose role would be to help families navigate services, and more advocates to improve policy that would help people with co-occurring support needs and their families.

Communication Across Systems

People receiving services and their families also had recommendations related to more communication across systems, such as coordinating across providers, fostering public partnerships that actively work to integrate IDD and mental health systems, recognizing the intersection of IDD with other needs, and building a continuum of care across the lifespan for people with co-occurring support needs.

Improving Services

Regarding improving services, families suggested more transparency about the services that are available, a more individualized approach to funding and services, increased employment training for people with co-occurring support needs, and addressing employee turnover and workforce issues.

Easier Access to Services

Finally, participants recommended working toward easier access to services by expanding access to services and DDA, reducing red tape and processes for getting services, and having multiple ways to apply for services. Quotes from the interviews and focus group providing additional context and examples in these areas of recommendation are included in Figure Forty.

Figure Forty System Recommendations from Interview and Focus Group Participants

MORE TRAINING	**Training for First Responders** "Better training for police and fire and EMTs as to how to respond to people with both intellectual disability and mental health issues [is needed], because if someone is stressed, they've got both the inability to fully understand as well as the mental health issue of whatever's going on, and they're in an emergency situation, so they're not going to understand what someone is trying to tell them to do. So, I think training for people in those areas for first responders is essential so that nobody gets hurt, and so that there aren't any misunderstandings." "I think first responders really need to have that training. I don't know how well they're trained. … I think all first responders definitely need to have awareness that there's all types of people; that epilepsy doesn't look like drunkenness, that neurotypical people react differently to different situations. You know, all people, each individual is an individual."
	Improve Medical Professional Outreach and Training "More information [should be] given at doctor's offices, more information on now to access and what is there would be really helpful, because you're going in with your kid, and you're saying, 'Something's up, something's going on. I don't know what to do.' So, to have that person say, 'Well, here's a pamphlet on what our county can do or what your state can do for you, how we can provide well rounded services for you and your family,' That would be really helpful, instead of having to find that out from a friend or stumble across it in internet research." "We need more doctors that know and are trained in challenging behaviors." "I feel like the primary care provider of people, there needs to be something in place there in these offices so instead of saying or writing down, 'Okay, well, here's a website you can go to,' or 'Look into this,' they're actually being helpful. I feel like regular doctor's offices don't have anything like that in place to help you walk you through the steps of and help you troubleshoot things on, 'Where can I go for this? Or what do I ask for?'"
	Training for IDD Providers in Mental Health "I feel the first step is for DDA, since they are the state's administrators for disabilities, is to truly partner with all behavioral health sectors and start looking at ways where they can coexist and how they work together and build upon understanding, education, and training those who work on both sides of the aisle. With this population, I think that is first and foremost. And I feel like because that has never truly happened, and even though it's starting it's like, literally in its baby stages. This is why we are the way that we are in some counties like ours."

MORE TRAINING	**Training for Mental Health Providers in IDD** "We need to incorporate more education and training because our population is pretty large. [We need people] who can work in the behavioral health sector with the intellectual population." "If there were more [mental health providers] that were more specialized with dealing with autistic individuals would be very helpful."
	Training for Educators "Low funding of our schools in general impacts the services for kids with special needs in a big way. Teacher education is needed for the teachers, particularly if they're gonna be working in special education, but actually all teachers to have more in depth training about what they're potentially facing in a classroom where there's going to be kids with those mental and developmental disabilities needs."
	Professionalization of DSPs "'Caregiving,' I think societally is seen as an entry level job — a job for somebody that can't do anything else. And I think that's really unfortunate, because there are so many components to caregiving that people don't know about. People who are not in the field don't know the training that a caregiver needs, the lived experience of a caregiver. It can be very rewarding but it can be very difficult. It can be very frustrating. We need to change the perspective of 'a caregiver.' We need to see it as a career. … They're kind of a nurse, they're kind of a doctor, they're kind they're a therapist, they're a chef, they're, they're a housekeeper, they're a mediator, they're an investigator. There's just so much that is involved with caregiving." "Improve workforce development and get more people into the workforce. Not just more people, but support training."
SUPPORT FOR PEOPLE USING SERVICES & FAMILIES	**Support Services for Caregivers** "More services for the caregivers of children [are needed] to help them cope, because raising a child who has both an intellectual disability and major behavior problems is very difficult and very stressful, and if you don't have a lot of supports because you don't have family nearby, or if you're a single mom or a single dad, if you are living in an area that that doesn't have a lot of services, then that can be really bad for both the child and the parent."
	Intermediate Professional to Help Navigate Services "If there were an external person, not from the DDA, who could help work with the DDA I would trust that more, because I feel like the system is so slow and so dysfunctional. maybe that person could help smooth some of the way. And they could be like, 'I'll reach out to the neuro psych and get a copy of that,' instead of you reaching out to the neuro psych to get a copy and photocopying and printing it and sending it here or whatever. Maybe some of the effort that's involved in the process that paperwork [could be shared].

SUPPORT FOR PEOPLE USING SERVICES &	**Greater Outreach to Families** "I think there needs to be more outreach and help for families, particularly when we're navigating the systems." "There needs to be better community communications and services for people with IDD and people who have mental health needs."
	More Advocacy "I think that the legislature needs to hear from citizens and from mental health professionals about what's missing, what needs are not met, and what's the impact on the state budget now, because of the vast number of people with mental health diagnoses who have no support whatsoever. So, I guess it starts with the legislature. They tend to be slow moving, though, in my experience." "We need advocates because I can't keep doing it. I just can't; it's too hard."
COMMUNICATION ACROSS SYSTEMS	**Coordinate Across Services** "I just feel like people need to coordinate, need to connect those two together, between both IDD and mental health, because we're all struggling with both of those. I notice people with disabilities and who will have a mental health problem — it's a challenge that we're all facing every day. And what's the sad part is, is that there's no cure for any of those, right?"
	Learn How to Coordinate Across Services Like the Hospital System "When you go to Seattle Children's, it seems like I can speak to anybody there, and they're all connected, whether it's his gastroenterologist, his neurologist, medication management, behavioral health, they all seem to be connected. They already have the information; I feel like they know him."
	Public Partnerships to Integrate IDD and Mental Health "Although I love NAMI, I don't think NAMI is doing enough for our population, the dual diagnosis population. I think that it would also help if the advocacy groups were in alignment and in partnership with the state on this."
	Recognize Intersect of IDD and Mental Health With Other Issues "You can tie it to the homeless population. They're always looking for solutions for the homeless and aside from drug addiction, lot of those folks on the street are mentally ill. If I go in town, there are people who are clearly schizophrenic just in the streets. My assumption is they have no supports or they end up in jail because of their mental disability. So that's a huge thing."

COMMUNICATION ACROSS SYSTEMS	**Continuum of Care**
	"It seems like the younger years, there was lots of services. But then as they get older, or even up to past adulthood, I don't see a lot of services from being provided at all in those rural like non-big city areas, right?"
	"Recently, having the same person has been helpful, and I do understand that there's a huge need for that. But it seems like as [my son] progressed and got older, it was almost every year was like a new person, and that's where we kind of started over again. But we've had our current caseworker probably three years now. So, it's like he knows [my son] and he knows what to look for, and recently suggested a different level waiver so that we can get more support. So, like a continuity of care may be a good way to look."

IMPROVING SERVICES	**Service Transparency**
	"If I was running it, there'd be written, clear transparency of the services your child is going to get, in bullet points, no more than a page. These are the timelines. This is what we can provide, this is what we cannot provide. The guessing game of who would be the best vendor and who will go and interview them [is awful]. And the method of, 'Here's 45 vendors and go and interview them,' and they're like a car salesman, and what do I know?"
	Individualized Approach to Funding and Services
	"I think that rather than DDA s and the government sitting and lumping everybody together, [they should] go out and visit these people and learn how they respond to things and that they are individuals — they're not a big lump. If you're going to work with people with disabilities, go out and visit them and see what each one needs and not assume that everybody needs the same thing. That would help a major amount."
	Increased Employment Training for People Receiving Services
	"I would say get it streamlined, get it institutionalized, and have a goal. And I know that everybody loves person-centered planning and things like this. But these people don't know. I mean, how many of us knew what we wanted to be? So, they need to be in a situation where they can experience these employment aspects. And not just go and do the job."
	Address Turnover and Workforce Issues
	"I know from other guardians that I've talked to that they can't keep staff. They would get them and train them, and then they would be gone, or sometimes the staff was abusing them behind closed doors, or that kind of thing. That's why I think I'm so leery that community placements."
	"Pay increases for the people who provide supports. That will improve the work because it would it would cause less turnover."

EASIER ACCESS TO SERVICES	**Expand Access to Services and DDA** "Another example would be supported employment. Because she needs a little extra help, her agency said, 'Is there any way you could go back and try and get her on DDA? Because then we could provide more help.' And I'm like, just throw salt in the wounds. Do you think I have not tried for years to get her on DDA? I cannot get her on DDA, until this IQ eligibility thing goes away. Then let's hope that she actually qualifies. So, the supported employment providers can provide more support if their client is on DDA and less support if their client is not on DDA. So DDA is so dominant in this landscape for our population, and we live it constantly. I mean, every week I'm like, God Almighty, what DDA conversation am I going to have today."
	Less Red Tape "It's harder when you're dealing with larger amounts of people, obviously, but the bureaucracy and the red tape that you have to go through — I would think it would be easier on everybody if there wasn't quite so much of it, it would be easier on the people who are doing the services, as well it's easier on the people who are trying to get the services. And the other thing is getting a call back sooner. With my local people, I get a call back within 24 hours unless they're on vacation, and their voicemail always tells me if they are regional, they're pretty good. But the state, sometimes that that can take forever. Luckily, I very rarely have had to deal with them. But I'll tell you that that can be a real that can be a real drag."
	Multiple Access to Apply "I would say that to prove your eligibility is very taxing for the people who have these disabilities. The effort to gather the medical records or the information or make the case — the expectations of executive function are so high in order to access any of these things that like. The nature of our disabilities prevent us from accessing that. You can't even apply because it's too [expletive removed] hard. So, there's got to be a different way; there has to be a different process. Whether it it's that some people would do better in person, some people would do better on Zoom, or if there could there be somebody who [could help] … my mother had breast cancer and she was assigned to cancer navigator who helped her figure out all the things you're supposed to do to meet all the needs of other things. Like could there be people that just help you navigate the system and could you just be assigned somebody who isn't overwhelmed and somebody whom I could trust?"

Washington Model Organizations Named by Participants

To understand which organizations were accomplishing the facilitators listed above, the Consortium research team asked interview participants, *"Are there any specific programs or services in Washington that you believe are exemplary (innovative, working really well, or an example that other states could use) in supporting people with co-occurring support needs? What makes them exemplary*?" Participants named many programs and service providers who they thought were exemplary in some way (See Figure Forty-One).

Figure Forty-One Model Organizations and Strengths that Facilitate Quality Services

Program	Strengths Noted by Participants
Foundational Community Supports Waiver Program *[Statewide]*	"Good assistance" with supportive housing and employment services
The Arc *[Statewide and Chapters Countywide]*	A one stop shop that had navigators to help newly diagnosed people navigate medical services, community groups, and support groups; also provides support in Spanish
Autism Center at Seattle Children's Hospital *[Statewide; Centers of Excellence Countywide]*	"Amazing" medication management specialists
Partners4Housing *[Nationwide]*	Helps families navigate housing and Medicaid to get funding for living in the community, provides education about types of housing and regulations
Sound Mental Health	Provides an array of IDD services, including intensive group therapy; a good provider for people with co-occurring needs
SEAS	Helps people navigate to resources
Boost Collaborative	Has a "wonderful" staff
Behavioral Bridges in Pierce County	Has professionals with understanding of both disability and mental health
Pacific Northwest Behavioral Health	Professionals are "great" at building rapport and will deliver services in a person's home
Children's Village in Yakima	Helps connect families to all types of services, including ABA, dental, play therapy, physical therapy, occupational therapy, and parent groups
Pierce County Specialized Recreation	Helps with volunteering opportunities for people with disabilities and is "well run"
Kristen Foster's Consulting	A job coaching program that provides "great tools" like scripts for customer service jobs

Participants also mentioned "Families Together," a nonprofit that used to support families but is no longer active since the COVID-19 pandemic, the first responders in Moses Lakes, special education paras who work with their children in schools, and a new pilot program on Bainbridge Island that is in the process of being set up to help support students with high social/emotional needs.

User Satisfaction with Services for People with Co-Occurring Support Needs

Overall, most participants of the Statewide Survey were satisfied with their IDD and mental and/or behavioral health services, however, there were significant differences in satisfaction ratings from traditionally underserved populations and other respondents of the survey, as well as a large chunk of respondents who gave their services poor ratings. Only 17.2% of respondents from traditionally underserved communities thought their IDD services were "*excellent*" and 18.3% thought their mental/behavioral health services were "*excellent,*" which was far fewer than other respondents; only 28% and 38.4% of whom rated the quality of their IDD services and mental/behavioral health services respectively as "*excellent*" (see Figure Forty-Two). Also, about 35% of people rated the quality of their IDD services "*fair*" or "*bad,*" and 37% gave the same poor ratings to their mental/behavioral health services.

Figure Forty-Two Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of Quality of Services
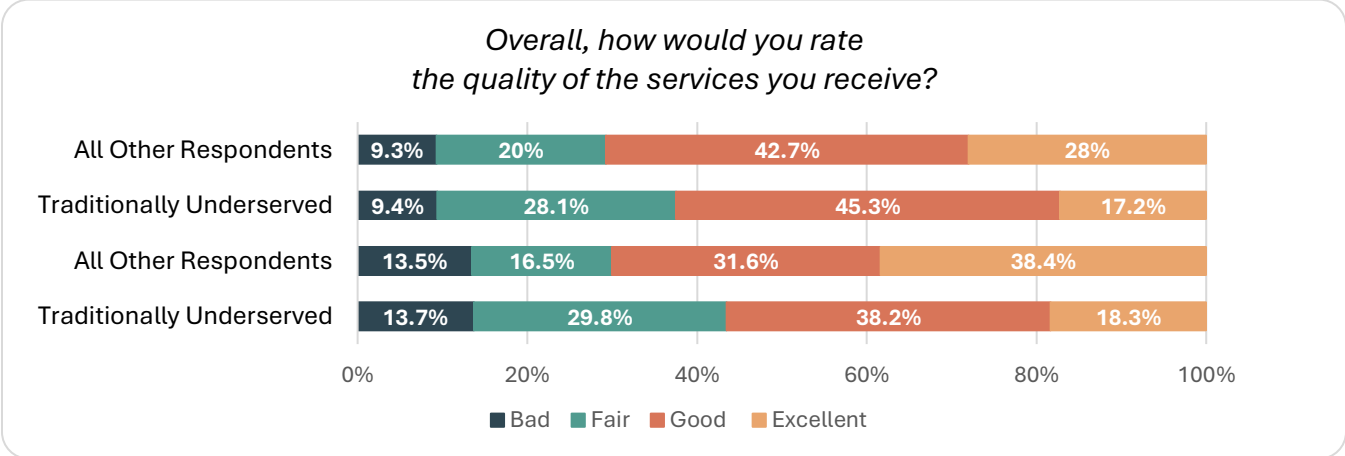
Similarly, about 31% of people rated their overall satisfaction with their IDD services as "*fair*" or "*bad*" and 36% of people rated their overall satisfaction with their mental/behavioral health services as "*fair*" or "*bad*" (see Figure Forty-Three). This means that overall, about one-out-of-three people are unhappy with services for their co-occurring support needs, with traditionally underserved respondents being noticeably less satisfied with the quality of their services and how well their services are meeting their needs.

Figure Forty-Three Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of How Well Services Meet Their Needs

Overall, how satisfied are you with how well services are meeting your needs?

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
All Other Respondents	11.9%	17.9%	41.1%	29.1%
Traditionally Underserved	17.8%	16.3%	41.9%	24%
All Other Respondents	14.7%	18.4%	30.9%	36%
Traditionally Underserved	18.3%	20.6%	34.4%	26.7%
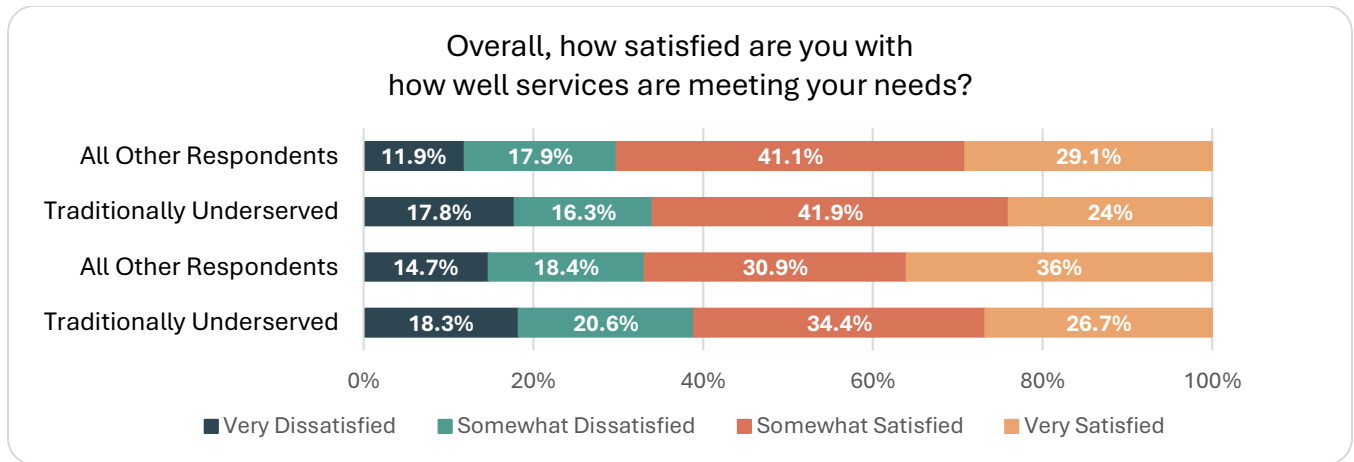
When survey respondents were asked about their satisfaction with how their services are supporting progress toward their goals, their feedback was similar. About 15% of respondents were "*very dissatisfied*" with the progress of their IDD services, and about 18% were "*very dissatisfied*" with the progress of their mental and/or behavioral health services (See Figure Forty-Four).

Figure Forty-Four Averages of Traditionally Underserved Vs Other Respondents on the Statewide Survey Reporting of How Well Services Support Progress Toward Their Goals

Overall, how satisfied are you with how services are supporting progress toward your goals?

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied	
All Other Respondents	14.3%	16.2%	39.6%	29.9%	IDD Services
Traditionally Underserved	15.4%	19.2%	40%	25.4%	
All Other Respondents	15.9%	17.4%	31.2%	35.5%	MH/BH Services
Traditionally Underserved	20.8%	17.7%	37.7%	23.9%	
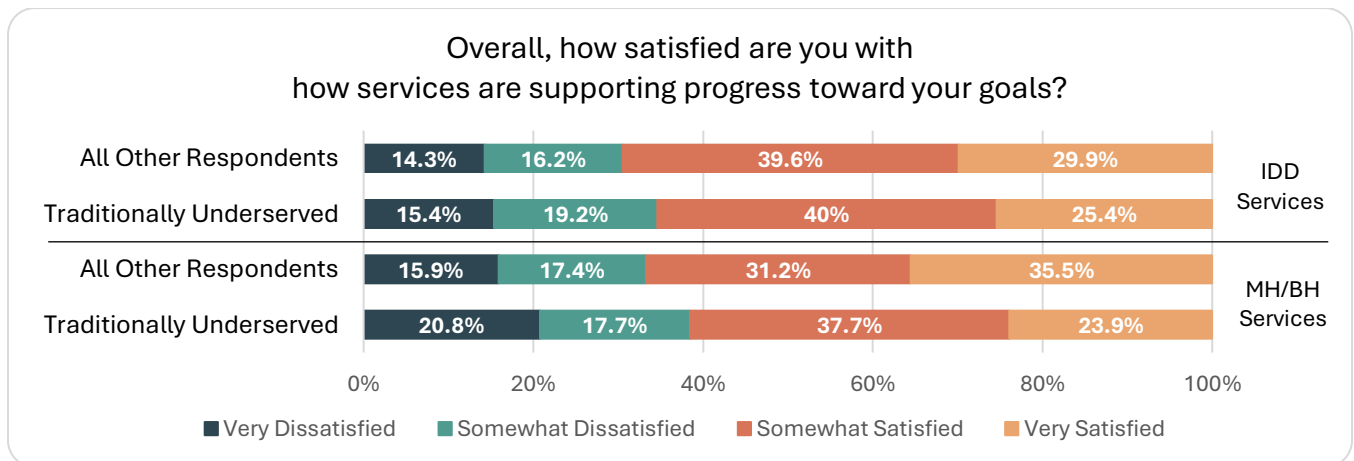
PART THREE BEST PRACTICES & THE STATE SYSTEM

This part of the report reviews national models and examples of best practices that can inform approaches for Washington to consider improving services for people with co-occurring support needs.

"It is difficult to understand who I need to see, or how to find them. My anxiety and panic disorders require me to see therapists in person, but they have almost all moved to online only now so finding one has become very difficult. Also finding one I can afford, that is covered by my insurance is very difficult. The type of disabilities I have are not 'bad enough' to warrant disability aid, so navigating life and working but struggling to function in society when I don't have the capacity and I cannot get any help is extremely difficult. It results in getting let go or forced to quit every year or two to float from one minimum wage job to another, never able to settle enough to earn my way to survive."

"Through the years of raising my son with autism, the knowledge and ability to translate that knowledge to me has made the difference between isolation and support. Poorly trained case managers resulted in lack of support both financially and socially. Lack of caregivers especially where my son grew up in Jefferson County, resulted in my loss of employment after he aged out of school. I was forced to quit my job to care full time for him which plunged us into poverty. When a behavioral specialist was finally made available, he was 23. She saved both our lives. Her funding was continually threatened by DDD. Early intervention would have prevented years of acting out which was not addressed either by DDD, the school system, or medical providers. We both suffered physical and mental harm by this glaring need that was never addressed."

"Mental health is an essential part of overall well-being, and the current system often leaves families without adequate resources. We need more accessible mental health services, including counseling, support groups, and preventive care, to truly address the mental health crisis."

"Through the years of raising my son with autism, the knowledge and ability to translate that knowledge to me has made the difference between isolation and support. Poorly trained case managers resulted in lack of support both financially and socially. Lack of caregivers especially where my son grew up in Jefferson County, resulted in my loss of employment after he aged out of school. I was forced to quit my job to care full time for him which plunged us into poverty. When a behavioral specialist was finally made available, he was 23. She saved both our lives. Her funding was continually threatened by DDD. Early intervention would have prevented years of acting out which was not addressed either by DDD, the school system, or medical providers. We both suffered physical and mental harm by this glaring need that was never addressed."

Introduction to Part Three

In the summer of 2024, the National Leadership Consortium conducted a comprehensive assessment of national policies, practices, and programs related to intellectual and developmental disabilities (IDD) and mental and behavioral health supports. This report provides an in-depth analysis of the current national landscape, highlighting key factors affecting the services available to people with co-occurring support needs. The study aimed to identify gaps in awareness, access, quality, diagnosis, and treatment by reviewing relevant national programs and initiatives, applying Burrow et al.'s (2021) five-domain framework as a guiding structure.

To inform this analysis, a systematic review of national literature was conducted, drawing from academic research, government reports, and policy papers. This was complemented by an evaluation of state-level best practices, focusing on programs and Medicaid waivers designed to improve service delivery for people with co-occurring IDD and mental health support needs. Additionally, insights were gathered from national experts through qualitative inquiry, exploring their perspectives on system gaps and opportunities. A comparative analysis was also performed, contrasting Washington State's policies and programs with those of the broader national landscape, further enriching the findings of this report.

Review of Relevant National Programs and Initiatives
The review of national literature and support models followed a systematic approach to identify key factors affecting services for people with intellectual and developmental disabilities (IDD) and co-occurring mental and behavioral health needs. A comprehensive search was conducted across academic databases, government reports, and policy papers from agencies like the U.S. Census Bureau. Key search terms included "IDD and mental health" and "co-occurring support needs," the review focused on identifying gaps in awareness, access, quality, diagnosis, and treatment. This review was guided by Burrow et al.'s (2021) framework of those five domains. Each domain served as a lens to categorize and evaluate policies, programs, and support models across different states and organizations.

In addition to academic literature, the review included an assessment of best practices from states recognized for their exemplary service delivery models. This involved cross-referencing state policies, Medicaid waivers, and specialized programs aimed at bridging the service gap for people with co-occurring support needs. The findings highlight trends, barriers, and successful interventions across the U.S. that address the mental health needs of people with IDD.

Feedback from National Experts

A qualitative inquiry was conducted to gather insights from experts in the field that have worked with the IDD and mental or behavioral health system nationally. A thematic analysis was performed to explore the perspectives of these professionals working in the field of co-occurring support needs, particularly focusing on people with intellectual and developmental disabilities (IDD) and mental health support needs.

Comparative Analysis

A comparative analysis was conducted by applying Burrow et al.'s (2021) framework, which categorizes key domains such as awareness, access, quality, diagnosis, and treatment for people with co-occurring IDD and mental health support needs. The analysis involved reviewing state and national policies, programs, and initiatives to identify gaps, solutions, and best practices. A thorough examination of literature, state-level initiatives, and Medicaid waivers was included to ensure a comprehensive understanding of the similarities and differences between Washington and the national landscape.

National Policy, Practice, and Literature Analysis

Review of National Literature and Support Models

In the United States, between 30% and 55% of people with IDD report having co-occurring mental and/or behavioral support needs (U.S. Census Bureau, 2022). Scholars have identified factors in services for people with co-occurring support needs that lead to gaps between systems of support (Burrow et al., 2021). Common causes of these gaps are misinterpreted or lack of understanding of how many people with IDD communicate, misinterpreted behaviors, lack of financial resources, lack of education among healthcare providers, access to services, and challenges to appropriate treatment (Burrow et al., 2021). These factors considerably diminish the quality of services received and the support to families and other caregivers. Scholars from the University of Massachusetts have developed a framework that includes the viewpoints of people with disabilities to comprehensively categorize and describe these and additional factors that impact quality mental health support. The framework (see Figure Forty-Five) consists of five domains: awareness (knowledge, public perception, and access to information), access (qualification and funding for, capacity to utilize, and ability to enter into), quality of care (how aligned services are with expectations and needs and how support promotes quality of life

outcomes), diagnosis (how level and type of need as well as appropriate services are determined), and treatment (interventions and services offered), each focusing on a specific aspect of the continuum of mental health care for people with IDD.

Figure Forty-Five Continuum of Mental Health Support
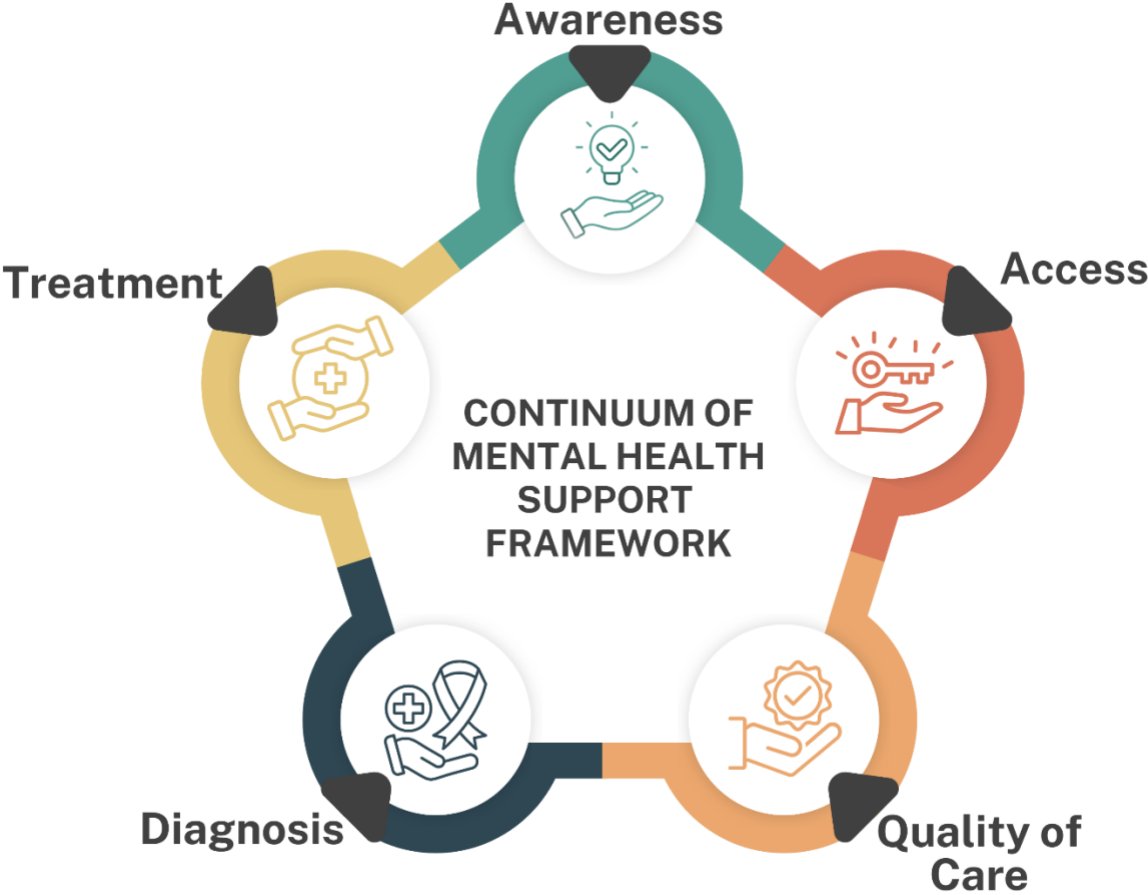
Each domain represents areas in which different organizations and states have worked to develop policies, initiatives, and programs to ensure a service continuum between IDD and mental health. This section outlines the specific strategies, programs, organizations, and policies that are currently working around the country toward closing the service gap for people with IDD and co-occurring mental health support needs by addressing these domains.

Awareness-Focused Efforts

This section describes a set of current policies, initiatives, and programs intended to increase the understanding and knowledge of the existence of possible mental health struggles, disorders, or diagnoses for people with disabilities. They include initiatives aimed at universalizing the understanding that people with disabilities are more likely than people without disabilities to have

a mental health diagnosis (Einfeld et al., 2011). Also, since mental health needs among people with disabilities may go unnoticed by self-advocates, family members, friends, allies, and service providers due to the overshadow phenomenon, for instance, this section illustrates educational strategies to overcome this issue.

Educational Support for Caregivers

The majority of people with disabilities and mental health needs do not seek or have access to mental health services, placing the responsibility of care on families and communities (Costello & Bouras, 2006). For instance, according to a 2021 needs assessment among Texas self-advocates, 61% reported that their families were their primary source of mental health assistance (Burrow et al., 2021). To be more prepared to recognize and care for comorbid mental health support needs in people with disabilities, families and caregivers can receive training and educational resources. Some examples of national initiatives to increase knowledge and awareness for caregivers and families are listed below.

Utah Family Voices (UFV) ([Utah Family Voices](#)) is a program dedicated to supporting families of children with special healthcare needs and disabilities. The initiative aims to empower families by providing information, resources, and training to enhance their advocacy skills. It emphasizes collaboration with families to improve access to healthcare, education, and community resources for their children. Through training sessions, workshops, and a strong network of family support, UFV seeks to elevate the voices of families in decision-making processes and policy development. The program offers direct support and assistance to families navigating the complex healthcare and education systems for their children with special needs. UFV conducts workshops and training sessions that educate families on effective advocacy strategies and the resources available to them. The program works with healthcare providers, schools, and community organizations to ensure families have a voice in matters affecting their children's services and supports. Families can access various resources through the UFV, including informational materials, toolkits, and contacts for local services tailored to their children's needs.

Family Support Program – The National Alliance on Mental Illness (NAMI) ([NAMI Family Support Program](#)) offers family support groups and education programs that provide caregivers with information on how to care for people with mental health support needs, including people with co-occurring IDD.

Educational Support for Staff

Providing adequate educational support to staff can contribute to a rise in workforce awareness regarding people with co-occurring support needs. There are several national programs that provide specialized training and preparation for the workforce in the field that are listed below.

Relias – IDD and Co-occurring Mental Health Training ([Relias IDD and Co-occurring Mental Health Training](#)) provides professional training programs for direct support staff and clinicians on

how to better care for people with IDD and co-occurring mental health support needs. It covers Trauma-Informed Care (TIC), communication strategies, and behavioral support. The Washington State Department of Social and Health Services already certifies this training program.

Trauma-informed care (TIC) is an approach that recognizes the widespread impact of trauma and emphasizes creating a safe, supportive environment to foster healing. It involves understanding the signs of trauma, integrating this knowledge into practices, and promoting resilience and recovery while avoiding re-traumatization ([Trauma-Informed Care Implementation Resource Center (chcs.org)](chcs.org)).

National Association of Dual Diagnosis (NADD) Direct Support Professional (DSP) Certification ([NADD-DSP Certification](#)), developed in association with the National Association of State Directors of Developmental Disabilities Services (NASDDDS), is a competency-based certification designed to validate the knowledge and skills of people who provide support to people with intellectual and developmental disabilities (IDD) and co-occurring mental health needs. This program emphasizes person-centered practices and effective communication strategies, ensuring that support professionals are equipped to meet the diverse needs of the people they serve. The certification process includes training, assessments, and ongoing professional development to maintain competency in the field. The certification focuses on developing specific competencies required to support people with IDD and mental health needs effectively. The program promotes a person-centered philosophy, emphasizing the importance of individualized support and respect for the autonomy of those receiving care. Candidates undergo assessments to demonstrate their knowledge and skills before obtaining certification, ensuring that they meet industry standards. NADD-DSP certification requires ongoing professional development to keep up with best practices and emerging trends in the field, ensuring continuous improvement in service delivery.

Educational Resources Hubs

The Link Center ([The Link Center](#)**)** The Link Center for People with Co-Occurring Intellectual and Developmental Disabilities and Mental Health Needs, established in 2022 by the Administration for Community Living (ACL), is a national initiative dedicated to improving the lives of people with intellectual and developmental disabilities (IDD) and mental health support needs. The Link Center is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the National Association of State Mental Health Program Directors (NASMHPD), the National Association for the Dually Diagnosed (NADD), the National Association of State Head Injury Administrators (NASHIA) among other university centers and self-advocate groups. Its mission is to enhance collaboration, share knowledge, and promote the development of best practices that ensure people with co-occurring support needs receive the comprehensive, integrated care they deserve. Through partnerships with service providers, policymakers, and advocacy groups, the Link Center works to bridge gaps in care and improve

access to services that support both mental health and IDD. By fostering an inclusive, coordinated approach to care, the center seeks to empower people and their support networks to achieve better outcomes and a higher quality of life.

The Link Center offers various programs to increase awareness and knowledge for caregivers, families, support staff, policymakers, and people with IDD. These programs are designed to equip stakeholders with the tools they need to navigate the intricate landscape of support services effectively. The center's focus on education, advocacy, and practical resources ensures that people with dual diagnoses receive the comprehensive care they require.

For caregivers and families, the Link Center provides specialized training programs and resources to help them recognize the signs of co-occurring mental health support needs in people with IDD. These programs emphasize the importance of early identification and intervention, equipping families with the knowledge to advocate for their loved ones within complex healthcare systems. By empowering families with the necessary tools and information, the center aims to reduce the stress and burden often placed on caregivers, creating a more informed and supportive network for people with IDD.

Support staff, such as direct care workers and community service providers, can benefit significantly from the Link Center's professional development initiatives. These programs focus on equipping staff with the skills to deliver trauma-informed and person-centered care. Training covers critical topics, including distinguishing between IDD-related behaviors and mental health symptoms, effective communication strategies, and crisis intervention techniques. By enhancing the competence and confidence of support staff, the center helps ensure that people with co-occurring support needs receive high-quality, respectful care that addresses their holistic needs.

Policymakers are another key audience for the Link Center's awareness efforts. Through advocacy campaigns, informative reports, and policy briefs, the center seeks to educate state and national leaders about the service gaps experienced by people with co-occurring mental health support needs. By providing compelling data and evidence-based recommendations, the Link Center aims to influence the development of policies that promote integrated care systems, enhance access to mental health services, and secure adequate funding for programs tailored to this population.

In addition to these initiatives, the Link Center directly engages people with IDD through self-advocacy programs. These initiatives are designed to help people better understand their mental health and wellness, empowering them to advocate for the services and support they need. By promoting self-determination and autonomy, the Link Center encourages people with IDD to take an active role in their care and well-being, ultimately fostering greater independence and an improved quality of life. Overall, the Link Center's multi-faceted approach to raising awareness among various stakeholder groups plays a vital role in building a more inclusive, informed, and

effective support system for people with co-occurring IDD and mental health support needs. Through collaboration and education, the center is working to create a society where people with dual diagnoses can access the resources and support necessary to thrive.

The NADD ([The NADD](#)) The NADD serves as another vital educational hub for raising awareness and providing resources to family members, caregivers, and people with intellectual and developmental disabilities who also have mental health needs. NADD offers an array of training programs, webinars, and certification courses designed to equip families and caregivers with the tools to better understand and manage the complex needs of people with co-occurring diagnoses. These educational resources emphasize critical areas such as recognizing mental health symptoms in people with IDD, effective communication strategies, and the importance of trauma-informed care. By educating caregivers, NADD empowers them to advocate more effectively for their loved ones, enhancing their ability to navigate healthcare systems and mental health services.

For people with IDD, NADD provides self-advocacy tools and training that encourage autonomy and self-determination. Through their programs, people are equipped to better understand their own mental health needs and take an active role in their services. NADD's efforts not only help reduce stigma and increase mental health awareness but also foster a sense of empowerment for people with IDD, allowing them to advocate for appropriate care and supports tailored to their unique challenges. This holistic approach ensures that both people with IDD and their caregivers are better prepared to engage with the mental health system and receive the comprehensive care they deserve

National Center for START Services ([National Center for START Services](#)) The National Center for START Services, housed at the University of New Hampshire's Institute on Disability (IOD), is dedicated to improving the lives of people with intellectual and developmental disabilities (IDD) and co-occurring mental health needs through research, training, and service innovations. START (Systemic, Therapeutic, Assessment, Resources, and Treatment) is a comprehensive program designed to support people with IDD and mental health diagnoses by promoting evidence-based practices and systemic collaboration. The center offers a range of services, including specialized training for professionals, crisis prevention and intervention, and the development of community-based support models. Through partnerships with service providers, policymakers, and families, the National Center for START Services works to increase access to quality mental health services for people with co-occurring support needs, while also enhancing overall well-being and community inclusion. The START model emphasizes person-centered care, family involvement, and cross-systems collaboration, making it a leading resource for stakeholders seeking to improve outcomes for this population. By providing training and consultation services, the center helps professionals and caregivers better understand the unique challenges of people with co-occurring

support needs, ensuring that interventions are both individualized and effective. Additionally, the National Center for START Services plays a critical role in advancing research and policy development, fostering a more inclusive and supportive system of care for people with IDD and mental health support needs.

Programs that Improve Access to Services

People with co-occurring support needs face challenges accessing mental health services. Programs that provide financial assistance to people with disabilities increase the number and quality of mental health care providers and promote overall well-being improve access to mental health care

Financial Relief

Programs like loan repayment plans and state tax waivers offer families essential financial relief, helping to reduce the economic barriers that often hinder access to mental healthcare services (Rural Health Information Hub, 2018; Jackson et al., 2015). For instance, the Health Resources & Services Administration (HRSA) Loan Repayment Program offers incentives to mental health professionals who commit to working in underserved communities, making care more affordable and accessible for people with co-occurring needs. These programs help bridge the gap between financial limitations and necessary mental health support, ensuring families can access the care their loved ones need.

State Medicaid Agencies Incentives

State Medicaid agencies can significantly improve access to mental health services for people with disabilities by establishing clear performance measures and payment incentives in contracts with Managed Care Organizations (MCOs) and Accountable Care Organizations (ACOs). These contracts should specify service provider requirements to ensure that people with disabilities and mental health support needs receive personalized care plans tailored to their unique service needs. For example, California's Department of Health Care Services has created a Medi-Cal Managed Care Program that requires MCOs to implement strategies for improving care coordination and access to behavioral health services. This program emphasizes the development of individualized care plans that address the comprehensive needs of beneficiaries with mental health support needs.

In New York, the Health Home Program is designed to enhance care coordination for people with complex health diagnoses, including those with co-occurring mental health and substance use disorders. The program mandates that care management organizations create individualized care plans to integrate physical and mental health services to improve overall health outcomes. Minnesota has implemented a Mental Health Integrated Care initiative through its Minnesota Department of Human Services, which incentivizes MCOs to provide holistic care. This initiative

requires that contracts include provisions for personalized care plans, ensuring access to qualified mental health professionals and recovery support services for people with disabilities (American Association on Intellectual and Developmental Disabilities, 2013; Beasley & duPree, 2003; Pinals et al., 2017).

Recruitment of Mental Health Care Professionals

A major challenge in providing mental health care to people with disabilities is the shortage of skilled professionals, particularly in rural areas. To address this, community-based programs can offer clinical rotations and training opportunities to grow the workforce. For example, the National Health Service Corps (NHSC) Loan Repayment Program encourages mental health professionals to work in underserved areas by offering loan repayment in exchange for a service commitment. Programs like this help increase the availability of skilled providers, improving access to quality care for people with co-occurring support needs (Rural Health Information Hub, 2018).

Community Living Policies

Social isolation can lead to negative health outcomes like depression, especially for people with disabilities. Community living policies that promote accessible housing, walkability, and neighborhood safety can foster social inclusion and improve overall well-being. The Olmstead Plan is an example of a policy designed to help people with disabilities live in integrated community settings, supporting their social integration and access to resources. These policies help relieve the strain on family caregivers and public service systems by building broad social networks and community support systems (Jackson et al., 2015).

Programs Designed to Improve Quality of Care

Quality of care encompasses the condition of comprehensive systems, methodologies, and attitudes that influence the services provided to people with disabilities who are dealing with mental health issues, from diagnosis through treatment. People with disabilities often require support from multiple providers due to their complex needs and treatment plans. However, the fragmentation of these services, where providers fail to communicate effectively about treatment, can hinder progress toward treatment objectives and compromise the quality of care received.

Service Coordination

Service coordination is critical in helping people plan, organize, identify, access, and monitor the services and supports they need to achieve an optimal quality of life and full participation in their communities. When executed effectively, service coordination is person-centered, comprehensive, free of conflicts of interest, and adept at navigating multiple complex systems (Einfeld et al., 2011). It should operate independently of service delivery to ensure that the service coordinator remains unbiased and does not have competing interests related to the provision or payment for direct services. Access to service coordination must be available upon request for all

people with disabilities who require assistance in accessing a variety of services and supports (Texas Council for Developmental Disabilities, 2016c).A relevant example of an initiative to improve service coordination is the partnership between The Arc and United Health Foundation. The partnership intends to expand access to quality mental health care services, improve coordination between disability and health systems, and train providers and caregivers to recognize mental health needs in people with IDD (The Arc, 2024).

Integrated Care

It is essential to address the needs of people with disabilities in a holistic manner, integrating services across various domains (Texas Council for Developmental Disabilities, 2014). Providing integrated care for people with disabilities is more responsive to their often complex requirements and enhances their overall quality of life (Einfeld et al., 2011). Integrated care encompasses a wide range of services, including primary care, specialized mental health services, employment assistance, educational resources, housing support, habilitative services, behavioral assistance, pharmacological treatment, environmental modifications, financial support, and social services (National Health Service, 1999; Pinals et al., 2017). Research has shown that integrated care improves both the effectiveness and efficiency of healthcare delivery (Jansen et al., 2006), which can lead to reduced costs, better identification of mental health needs, and improved access to mental health services (Ervin et al., 2014; American Association on Intellectual and Developmental Disabilities, 2013). Developing integrated care involves extending appointment times, providing spacious examination rooms, and employing specialized equipment (Ervin et al., 2014).

Multi-Disciplinary Training for Professionals

Multi-disciplinary training involves education in various treatment areas that, while distinct, collectively influence an individual's overall health. To support people with the most complex needs, it is crucial to employ highly skilled staff. Training should be frequent and consistent, focusing on relevant issues that affect people's support and assistance needs, such as fostering attachment and positive relationships, addressing fears, and alleviating depression (Moseley, 2004; Ahlstrom et al., 2020).

Training opportunities exist across various settings and for different healthcare professionals. For instance, board-certified behavior analyst training and a competency-based workforce development program created by The NADD in collaboration with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) can help enhance the workforce available to support people with co-occurring needs. Specialized programs in university systems, such as Leadership Education in Neurodevelopmental and Related Disabilities (LEND), prepare trainees from diverse professional backgrounds for leadership roles that serve people with disabilities (Maternal and Child Health Bureau, n.d.). Additionally, university-based programs like the University Centers for Excellence in Developmental Disabilities (UCEDDs) provide

interdisciplinary training for students and professionals aiming to assist people with disabilities across all age groups and their families (Pinals et al., 2017). Research by Winters and Shelow (2016) suggests that establishing a Professional Learning Community (PLC) for collaborative learning on intellectual and developmental disabilities (IDD) and co-occurring mental health support needs has effectively better prepared medical staff to support people with disabilities.

Person-Centered Care

Person-centered care emphasizes an approach to treatment that focuses on people's strengths, capabilities, and potential contributions to the community rather than their limitations (Pinals et al., 2017). People with disabilities who have control over their lives are more likely to engage actively in community activities, achieve greater independence, and enjoy a higher quality of life, including securing higher-paying employment. Behavioral interventions should prioritize person-centered approaches before considering pharmacological treatments for addressing symptoms of IDD and/or mental health challenges (Pinals et al., 2017). The focus should be on what matters to people with disabilities and mental health support needs, rather than solely on what may be deemed important for them (Moseley, 2004). Consequently, any proposed treatments that are primarily intended for the convenience of caregivers — such as medical procedures that may hinder normal growth and development — should be rejected (American Association on Intellectual and Developmental Disabilities, 2013). An example of services delivery under this approach is the National Center for START Services. This center provides technical assistance, training, evaluation, and certification to START programs and resource centers, serving the mental health needs of thousands of people with intellectual disabilities (START Model, 2022).

Practitioners' Cultural Competence

When building a workforce, it is essential to recruit people who reflect the communities they serve. Furthermore, it is vital to ensure that employees receive education in cultural awareness, knowledge, and skills, along with training to promote cultural sensitivity (National Health Service, 1999; American Association on Intellectual and Developmental Disabilities, 2013; National Association of State Mental Health Program Directors, 2004).For instance, the Cultural Competence Plan Requirements (CCPR) in California exemplify a robust practice for fostering equitable, inclusive, and culturally responsive care within health and human services. Mandated by the Department of Health Care Services (DHCS), CCPR requires agencies to develop, implement, and regularly update comprehensive plans that address the cultural and linguistic needs of their diverse populations. The initiative is guided by eight critical criteria: service delivery in preferred languages, community outreach and engagement, workforce development through cultural competence training, language assistance services, stakeholder feedback integration, monitoring and evaluation of health disparities, maintaining a diverse workforce, and the adoption of policies that promote cultural and linguistic competency (California Department of Health Care Services, 2010). These efforts are part of a broader strategy by DHCS to reduce behavioral health

disparities, particularly among historically marginalized populations (California Department of Health Care Services, n.d.). By embedding these principles into organizational practices, California works toward achieving more equitable access to care and improving the quality of services for all communities across the state.

Programs that Support Comprehensive Diagnosis

Diagnosis encompasses the various methods, tools, and strategies employed to accurately identify mental health needs that coexist with disabilities. An accurate and timely diagnosis is essential for determining and evaluating potential treatment options, as it directs people toward appropriate resources for managing co-occurring conditions. The processes and tools used for assessment play a vital role in facilitating effective treatment. However, several challenges hinder accurate diagnosis, including the inability of structured assessment tools to be generalized and the lack of instruments specifically tailored for people with disabilities.

Multi-Dimensional Assessment Process

Effective assessment to identify co-occurring support needs and recommend treatment involves multiple factors. The quality of assessment is enhanced when conducted by a multidisciplinary team, as it can address the physical, psychiatric, psychological, and social functioning of people with disabilities. Additionally, knowledge of factors related to co-morbidity and personal situations, such as family dynamics, housing, financial status, and occupational circumstances, contribute valuable insights for accurate diagnosis and treatment.

Colorado's implementation of the Pre-Admission Screening and Resident Review (PASRR) program exemplifies a comprehensive, multi-dimensional assessment effort for people with disabilities who may have co-occurring needs. As a federal mandate, PASRR requires that people seeking admission to nursing facilities undergo thorough assessments conducted by multidisciplinary teams. The Colorado Department of Health Care Policy and Financing (HCPF) administers this program by evaluating physical health, psychiatric conditions, psychological needs, and social functioning, providing a holistic understanding of each person's circumstances (Colorado Department of Health Care Policy and Financing, n.d.). For instance, through the PASRR program, a person with both intellectual disabilities and mental health support needs is assessed not only for their medical needs but also for factors such as family dynamics, housing stability, financial status, and employment opportunities. By integrating these elements into the assessment process, Colorado develops tailored treatment plans that reflect the Biopsychosocial Model (a model that considers the biological, social, and psychological factors that impact different parts of a person's life, including their mental health) (Putnam, 2009). This exemplary implementation of the federal mandate enhances the quality of care and life for people with disabilities. Ohio's Department of Developmental Disabilities is also recognized for its effective implementation of multi-dimensional assessment practices like PASRR, showcasing the

importance of addressing the diverse needs of people in the system (*Ohio Department of Developmental Disabilities*, n.d.).

Targeted Assessment Tools

Diagnosing mental health support needs in people with disabilities can be complex, but various assessment tools are specifically designed for identifying co-occurring support needs. Literature consistently recommends the use of a biopsychosocial assessment model, which explores the interplay between biological, psychological, and social factors (Putnam, 2009). (Putnam, 2009). These assessments include:

- Impact of Event Scale–Intellectual Disabilities (IES-IDs) (Wigham & Emerson, 2015)
- Developmental Behavioral Checklist (Parent/Caregiver or Teacher)
- Emotional Problems Scales (Self-Report and Behavior Rating Scales)
- Reis Scales for Children's Dual Diagnoses
- Devereux Scales of Mental Disorder; Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD; Putnam, 2009)
- Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD; Zeilinger et al., 2013)

Moreover, given that people with disabilities often experience higher rates of traumatic events, screening for Post-Traumatic Stress Disorder (PTSD) is crucial for implementing targeted treatments and improving behavior (Bedard, 2013; Pinals et al., 2017; National Association of State Mental Health Program Directors, 2017b; Texas Health & Human Services, n.d.).Texas is an example of a U.S. state that addresses the complexities of diagnosing mental health support needs in people with disabilities, particularly those with co-occurring support needs. The Texas Health and Human Services (HHS) provides guidance and resources for assessing and treating people with intellectual and developmental disabilities (IDD) who have mental health support needs. They utilize various specialized assessment tools, such as the Developmental Behavioral Checklist and the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD), to identify co-occurring diagnoses. Additionally, Texas emphasizes the importance of screening for Post-Traumatic Stress Disorder (PTSD), acknowledging the high incidence of trauma in this population (Texas Health & Human Services, n.d.). These tools, aligned with the biopsychosocial assessment model, ensure a comprehensive evaluation of biological, psychological, and social factors affecting people with disabilities (Putnam, 2009).

Strategies that Support Comprehensive Treatment

Treatment encompasses both general strategies and specific methods or protocols. Options for people with disabilities and mental health conditions range from behavioral interventions and pharmacological solutions to crisis services and psychotherapy. However, many services fall short due to a lack of understanding regarding the treatment of co-occurring diagnoses and

trauma-informed care for this population. While general frameworks exist for addressing mental health issues, they are often not specifically adapted for people with disabilities. For instance, a Texas survey identified a gap in access to evidence-based practices in mental health care within the IDD system (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Telehealth

Telehealth involves delivering patient care, education, and health administration services through telecommunications such as videoconferencing, the internet, and wireless communications. Patients receiving a hybrid model of telepsychiatry along with in-person visits have greater access to care than those who only receive in-person services (Genoa Healthcare, 2019). Telehealth represents a promising approach to expanding access to mental health care in underserved areas (Rural Health Information Hub, 2018). California is a leading example of effectively utilizing telehealth to enhance access to mental health care, particularly in underserved areas. The California Department of Health Care Services has implemented various telehealth initiatives to deliver psychiatric services through videoconferencing, the internet, and mobile applications. For instance, during the COVID-19 pandemic, California expanded telehealth services, enabling mental health providers to offer care remotely while ensuring continuity of services for people in rural and low-income communities. Patients receiving a hybrid model of telepsychiatry — combining virtual visits with in-person appointments — experience increased accessibility and flexibility compared to those relying solely on traditional in-person services (Genoa Healthcare, 2019). This innovative approach allows California to effectively address the mental health needs of its population, demonstrating the potential of telehealth to bridge gaps in care and improve health outcomes in underserved regions (Rural Health Information Hub, 2018).

Appropriate Use of Medication

Psychotropic medications must be utilized within a multidisciplinary framework and not in isolation from other therapies (Putnam, 2009). New York is a notable example of a state that emphasizes the appropriate use of medication within a system of interventions to manage mental health support needs by combining pharmacological treatments with psychotherapy and other therapeutic interventions (New York State Office of Mental Health, n.d.). An exemplary initiative is the Single Point of Access (SPOA) program in Erie County, which streamlines access to mental health services and supports effective medication management. The SPOA program ensures that people receive appropriate psychiatric evaluations to determine the suitability of psychotropic medications and facilitates ongoing support through follow-up assessments (Erie County Department of Mental Health, 2022). By incorporating a multidisciplinary team approach, the SPOA program encourages collaboration among psychiatrists, primary care providers, therapists, and other healthcare professionals, optimizing medication management for diagnoses such as depression, anxiety, and other mental health diagnoses while addressing co-occurring physical

health issues (Putnam, 2009). This integrated care model not only enhances treatment effectiveness but also sets a standard for effective mental health care that prioritizes holistic treatment and improved outcomes for people.

Short-term mental health diagnoses can typically be managed through a combination of medications prescribed by primary care physicians and psychotherapy provided by specialized services (National Health Service, 1999). Pharmacological treatments are particularly beneficial for those dealing with insomnia, depression, suicidal thoughts, and panic attacks (Bedard, 2013). A psychiatric evaluation can determine medication suitability and follow-up assessments can track the individual's response to various drug treatments (Utah Parent Center, 2013).

The Restorative Integral Support Model

This model is designed for social service agencies aiding people facing multiple challenges and those with histories of adverse childhood experiences. This model recognizes the impact of early-life adversity on development and promotes resilience and recovery. The core principle of the RIS model is to cultivate a recovery-oriented culture that fosters social connections (Marcal & Trifoso, 2017). For instance, the Restorative Integral Support model is effectively implemented in Florida through the work of the Children's Home Society of Florida (CHS). This organization utilizes the model to provide comprehensive services to children and families facing multiple challenges, including those with histories of adverse experiences. By recognizing the profound impact of early-life adversity on development, CHS aims to promote resilience and recovery among its clients. The core principle of the RIS model at CHS is to cultivate a recovery-oriented culture that fosters social connections, thereby enhancing the support networks available to people (Marcal & Trifoso, 2017). For instance, CHS offers programs that integrate mental health services, family support, and community resources, helping children and their families build meaningful relationships and cope with the effects of trauma. This holistic approach not only addresses immediate needs but also lays the foundation for long term well-being and resilience.

Crisis Behavior Intervention Services

Crisis prevention planning — creating strategies to anticipate, avert, and prepare for mental health crises — supports people and their caregivers in managing difficult times (Beasley & Kroll, 1999). The five goals of the crisis prevention planning process are:

- Understanding communication of needs through maladaptive behaviors
- Developing or enhancing coping strategies for people and their family caregivers
- Preventing the system from entering a crisis
- Defining roles and responsibilities for specific professionals and service providers
- Simplifying access to services

Crisis intervention serves as a short-term measure for stabilizing mental health needs. Local authorities deploy crisis intervention teams to provide support for people with disabilities

experiencing mental health crises. Services such as crisis respite (short-term emergency residential treatment), intensive in-home support, and other crisis intervention resources must also be readily available. Crisis teams must be trained in both Trauma-Informed Care (TIC) and person-centered practices (Hogg Foundation for Mental Health, 2015). The START program has demonstrated improvements in mental health symptoms, reductions in hospitalizations and emergency room visits, and enhanced caregiver satisfaction with service providers after implementing crisis intervention services (Kalb et al., 2019).

Key Informant Feedback

Drawing insights from experts with extensive experience across various state systems, including Medicaid waiver programs, mental health services, and IDD services, the analysis of key informant feedback identifies key themes and recommendations for improving services and support systems at both state and national levels. Nine experts in the field were invited to provide their understanding of the complexities within the current service landscape, having contributed to multiple initiatives across regions such as Pennsylvania, Ohio, Tennessee, and 25 other states. The analysis involved a systematic approach to data collection, where insights were gathered through interviews and written responses addressing service delivery challenges, systemic barriers, and recommendations for improvement (see Supplemental Materials for data analysis and collection tools). Participants were encouraged to share their experiences with specific state systems, highlighting the unique nuances and variations in service delivery that exist. This collaborative process enabled the identification of recurring themes related to the support needs of people with dual diagnoses, emphasizing the importance of trauma-informed care, community engagement, and the integration of behavioral health services. A thematic coding approach was utilized to analyze the data, synthesizing key findings that reflect the current landscape of services for people with co-occurring support needs. The resulting themes reveal critical areas for development and exemplary practices that can inform future initiatives. Actionable recommendations are presented based on the collective insights gathered, providing a roadmap for stakeholders seeking to enhance care and support for this vulnerable population.

This thematic analysis serves as a valuable resource for understanding the intricacies of service delivery for people with co-occurring support needs. By leveraging the expertise of professionals from various regions, the analysis highlights essential areas for growth and offers concrete strategies to improve access to services, thereby fostering better health, well-being, and quality of life for people facing these challenges.

Access to Services for People with Co-Occurring Needs from Historically Marginalized or Underserved Groups

The responses from national experts reveal several recurring themes regarding access to services for people with dual diagnoses from historically marginalized and underserved groups, including BIPOC and rural communities. Several recurring themes emerged from the responses, including: barriers to access related to terminology and provider discomfort and preparedness, service limitations related to quality and capacity and geographic disparities, marginalization due to cultural and language gaps and racial and ethnic disparities (see Figure Forty-Six). Addressing these issues requires a multifaceted approach that involves better training for providers, culturally competent care, and expanding service capacity in both urban and rural areas.

Terminology as a Barrier

One key issue raised was the use of the term "dual diagnosis," which some experts noted could act as a barrier to accessing services. One respondent pointed out, *"I think that using the term 'dual diagnosis' has been a barrier... access to mental health services and treatment for people with IDD has been very spotty."* This comment highlights the confusion and lack of clarity around the term, which may prevent effective service provision and accurate identification of needs. The challenge of defining and addressing the needs of people with co-occurring IDD and mental health support needs can lead to limited availability of specialized services.

Provider Discomfort and Preparedness

Some experts pointed to provider discomfort and lack of preparedness as significant barriers to access. Clinicians, particularly those on the mental health side, often feel ill-equipped to manage the complexities of dual diagnoses, resulting in denial of care. One key informant explained: *"Providers on the mental health side tend to deny care because most clinicians are not trained in IDD/MI and are not comfortable or confident with the patient populations."* This lack of confidence extends beyond mental health providers to medical offices, as *"some medical offices...do not feel prepared to accept individuals with MI/IDD into their practices because of diagnostic overshadowing, communication challenges, [and] cognitive deficits."*

The fear of responsibility for coordinating care across multiple systems, particularly for housing and behavioral interventions, further exacerbates this issue. As one expert noted, *"They also fear that they will be responsible to identify housing, programming, and behavioral interventions for ID and are not prepared for that."*

Figure Forty-Six Thematic Map of Barriers to Service Access for People with Co-Occurring Support Needs from Historically Marginalized or Underserved Groups From Key Informant Interviews
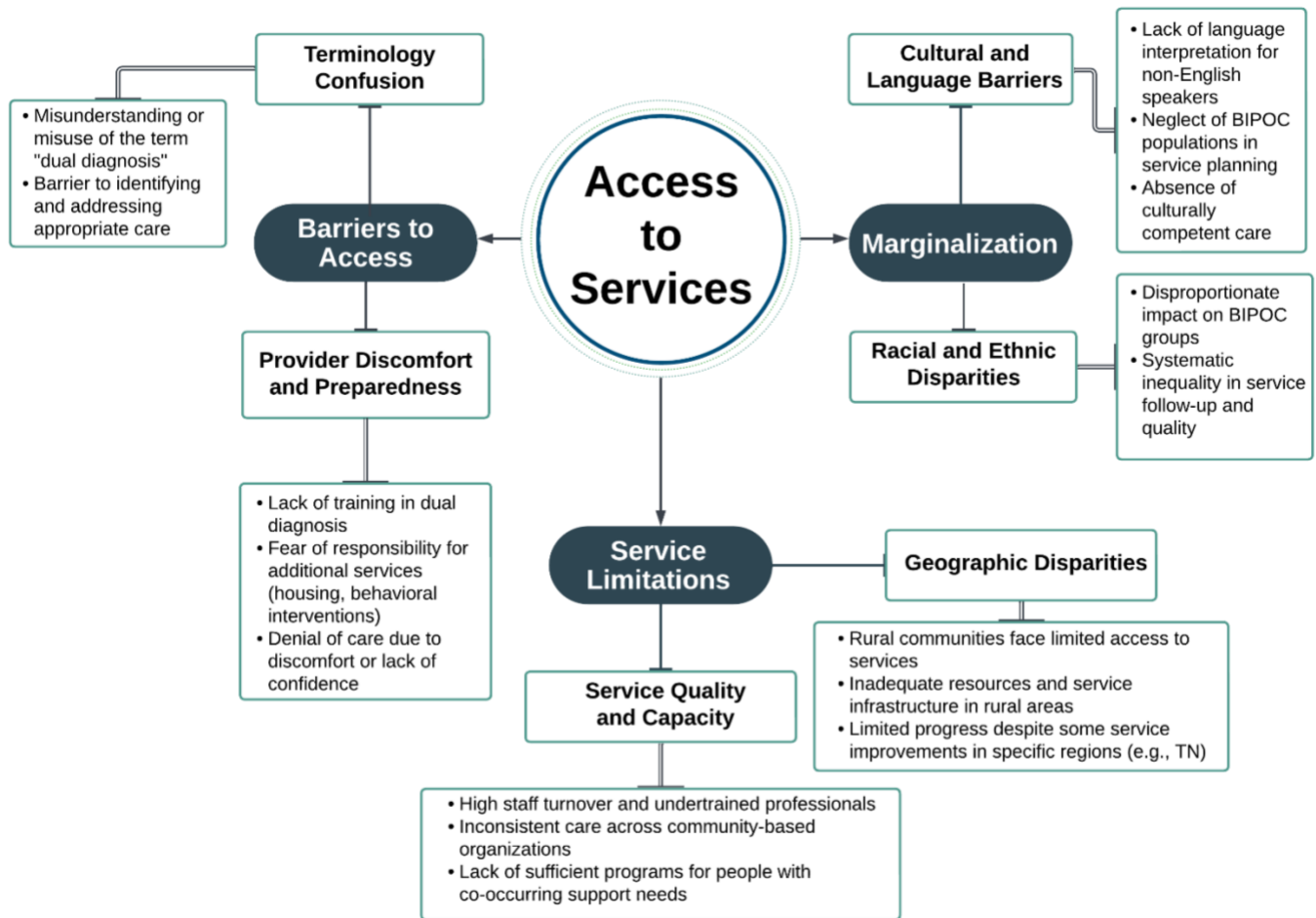
Service Quality and Capacity

Another theme was the poor quality and limited capacity of services, especially within community-based organizations. One expert shared, *"The barrier is the quality of those services provided. Often folks are referred to community-based organizations that have high staff turnover and undertrained staff."* This issue results in inconsistent care and insufficient expertise to address complex needs. Additionally, another expert described how *"the accessibilities of services is limited, as there is a lack of programs that can provide adequate treatment."* While services may exist, they are not always equipped to offer the appropriate support needed.

Geographic Disparities

Additionally, geographic location plays a major role in determining access to services, especially for rural communities. While progress has been made in some areas, significant gaps remain. As one expert from Tennessee remarked, *"Access to services in Tennessee has grown, but still falls well short of what is needed to support people with IDD and co-occurring mental health*

disorders." The disparities are more pronounced in rural areas, where resources are scarcer, and service networks less developed.

Cultural and Language Gaps & Racial and Ethnic Disparities

Finally, cultural and language barriers disproportionately affect historically marginalized communities, particularly BIPOC and non-English speakers. One expert highlighted this gap: *"Race and ethnic minority groups suffer the most, due to treatment lacking interpretation for non-English groups [and] lack of follow-up treatment."* This underscores the systemic neglect of people whose primary language is other than English, leading to incomplete or inappropriate care and poor health outcomes. The lack of culturally competent care further exacerbates the barriers these populations face in accessing appropriate services.

Barriers to Initiating or Implementing Programs to Increase Access to Services for People with Co-Occurring Support Needs

Experts provided valuable insights helping identify key barriers to initiating or implementing programs to increase access to services for people with dual diagnoses. Several themes emerged, including: structural barriers related to the medical model, financial and resource constraints, lack of consensus on treatment approaches, and logistical challenges (see Figure Forty-Seven).

Structural Barriers (Medical Model)

A recurring theme is the application of the medical model to IDD as a disorder rather than a disability. One expert stated, *"The medical model applied to IDD as a 'disorder or condition' rather than a disability has created barriers and motivation to treat mental health conditions in the population."* This conceptualization of IDD as a medical condition creates systemic obstacles to effectively addressing the mental health needs of this population. The rigid structure of the medical model fails to capture the holistic needs of people with co-occurring support needs.

Financial and Resource Constraints

Another prominent theme relates to financial limitations and resource shortages, particularly concerning staff pay and reimbursement rates. One respondent noted, *"The biggest barrier is reimbursement and pay of staff."* This issue reflects the chronic underfunding of programs, which undermines their ability to attract and retain qualified professionals. Another expert expanded on this by mentioning the need for *"funding, Medicaid/Medicare, need for additional accommodations,"* such as longer appointment times, specialized therapies, and increased staffing levels. The cost burden of these additional accommodations often exceeds available funding, creating further barriers to implementing comprehensive services.

Figure Forty-Seven Thematic Map of Barriers to Initiating or Implementing Programs to Increase Access to Services for People with Co-Occurring Support Needs Given in Key Informant Interviews
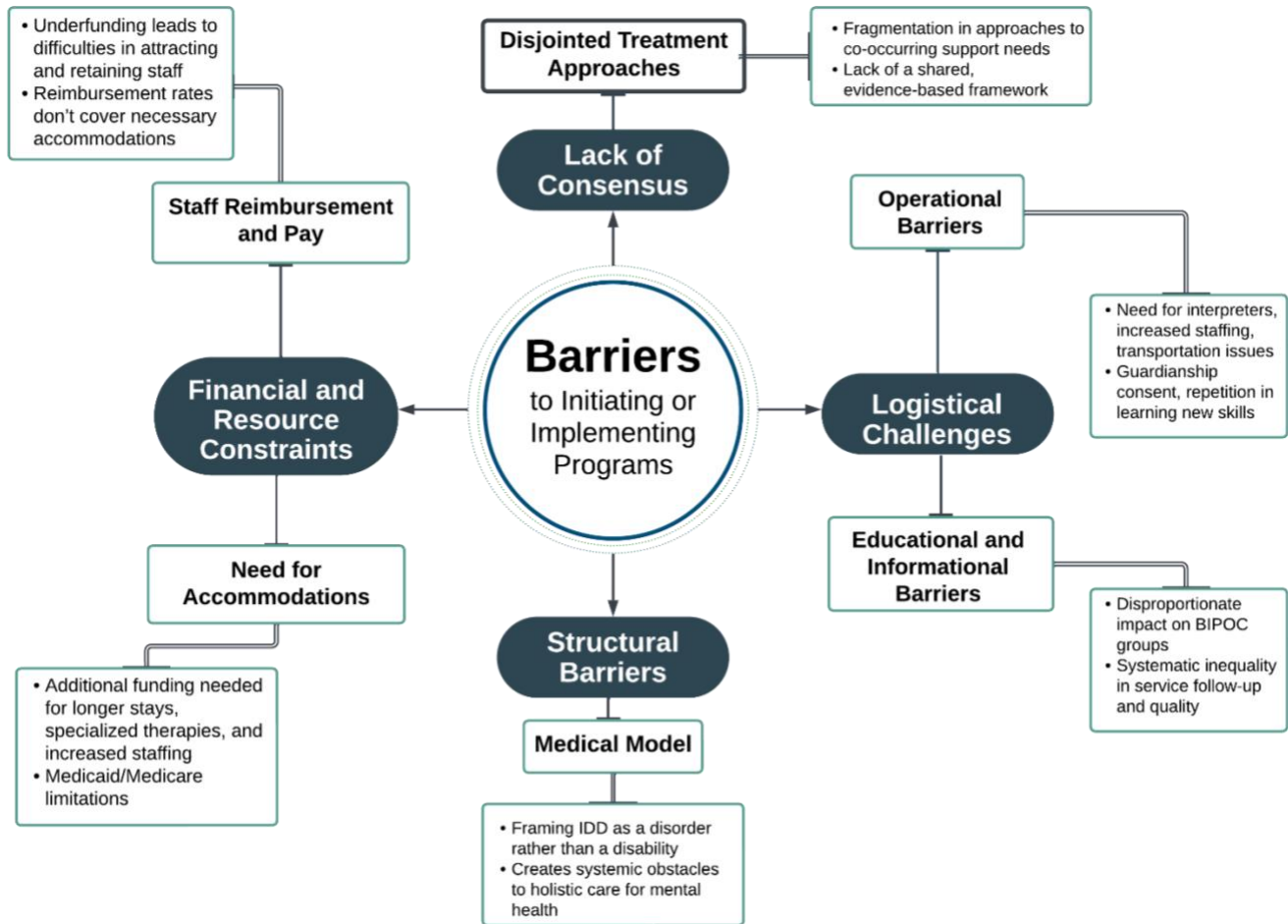
Lack of Consensus and Unified Vision

A critical issue raised by multiple experts was the lack of a unified vision and consensus on how to address the mental health needs of people with co-occurring support needs. One expert expressed this issue, noting, *"The lack of a consensual vision and unified effort to attain the goal. Too many people continue to apply ineffective approaches to people with mental health conditions."* This highlights the fragmentation in approaches, with many providers using outdated or ineffective methods due to misunderstandings about the individualized needs of people with dual diagnoses. The absence of a collaborative, evidence-based framework hampers the development of successful programs.

Logistical and Operational Challenges

Experts also emphasized the logistical and operational challenges that arise when implementing programs for people with co-occurring support needs. One expert mentioned the broad range of obstacles, including *"the need for interpreters, increased staffing, transportation issues, guardian*

consent, and repetition in learning new skills." These operational barriers complicate the effective delivery of services and make it difficult to maintain continuity of care. The lack of plain language information about available services, as well as a lack of education about the need and benefits of these services, further complicates program initiation.

Factors Contributing to the Success of Programs for People with Co-Occurring Support Needs

Invited experts provided insights on what has contributed to the success of programs designed to increase access to services for people with IDD and mental health disorders. Their responses highlight several key factors, including: cross-system collaboration, staff training and support, trauma-informed care, data-driven decision-making, and incorporating feedback from those with lived experience (see Figure Forty-Eight).

Cross-System Collaboration

A prominent theme in the responses is the importance of collaboration across different systems. One expert noted that successful programs are built on *"cross systems collaboration, inclusive and strength-based practices, and clarity regarding roles and responsibilities."* By engaging multiple stakeholders, including mental health services, social services, and disability support providers, these programs ensure a comprehensive approach to care. Collaboration enhances communication and ensures that various needs are met more effectively.

Another expert echoed the value of collaboration, highlighting the importance of partnerships with academic institutions: *"Linking with academic institutions so that learners from every discipline have exposure to people with DD … leads to recruitment and retention."* This strategy enhances workforce development by exposing future professionals to the population early in their careers.

Staff Training and Support

Providing adequate staff training and support emerged as another key factor. One expert mentioned, *"Adequate training of staff, equitable pay, [and] access to supervisor/support"* as vital to program success. Ensuring that staff members are well-trained and fairly compensated leads to higher quality services and improves staff retention. This support structure also allows staff to feel more confident and capable in their roles, which ultimately benefits the people with co-occurring support needs receiving care.

Figure Forty-Eight Thematic Map of Factors Contributing to the Success of Programs for People with Co-Occurring Support Needs Given in Key Informant Interviews
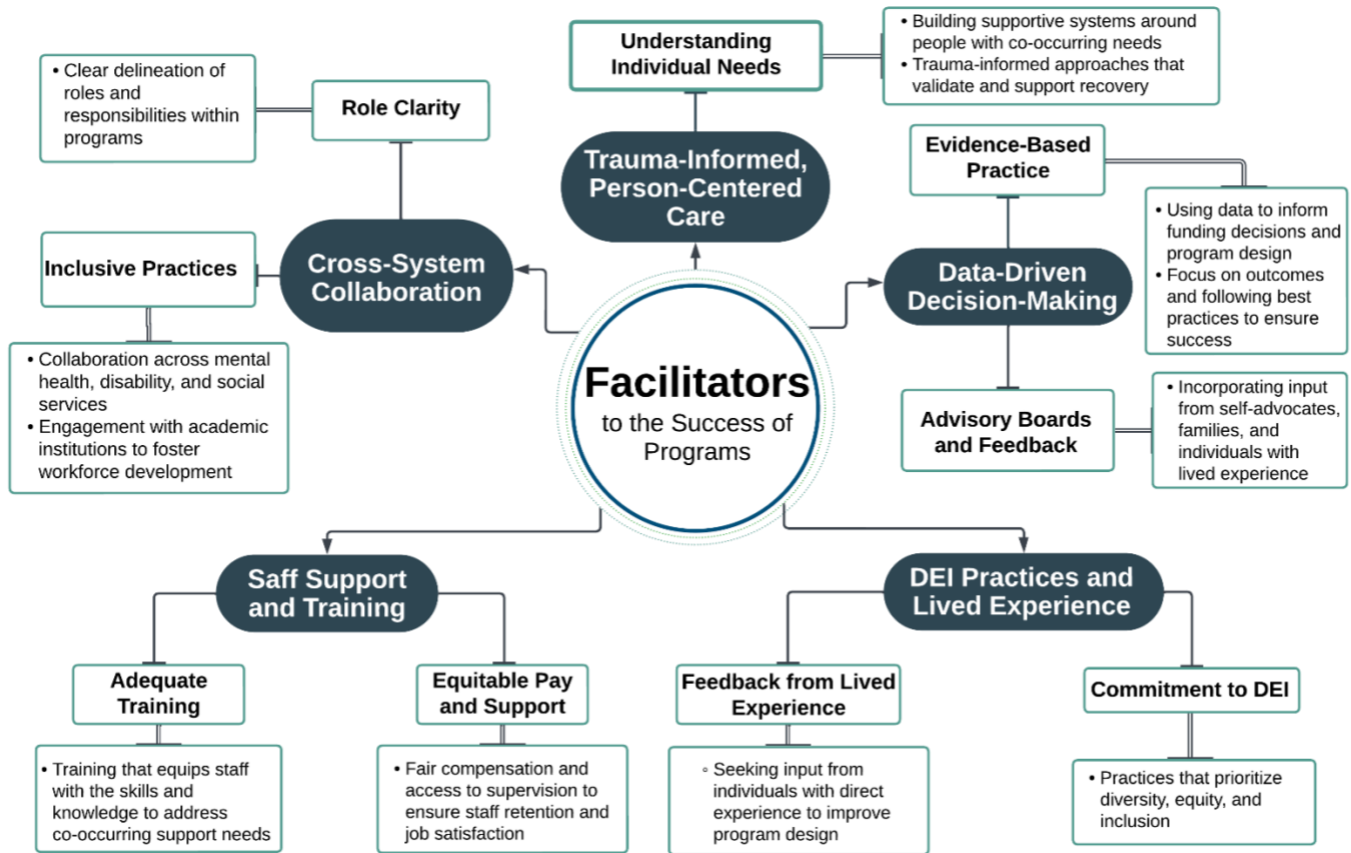
Trauma-Informed and Person-Centered Care

The need for trauma-informed and person-centered approaches was emphasized by multiple experts. A participant from Tennessee mentioned the implementation of the Systemic, Therapeutic, Assessment, Resources, and Treatment (START) model from the University of New Hampshire, which aims to create a supportive system around everyone. They highlighted that *"people are more successful when they have people around them who seek to understand their experience"* and avoid actions that hinder learning. A trauma-informed approach, including the use of counter-intuitive strategies such as validation, was described as essential in addressing trauma-based responses.

Data-Driven Decision-Making and Best Practices

Another recurring theme is the focus on data and evidence-based practices. One expert suggested forming advisory boards or focus groups, including self-advocates and parents, to inform program plans and decisions. Additionally, they recommended focusing *"on data and outcomes when dealing with funders"* and following best practices to design programs, stating that *"you have to follow the science to justify your education, programming, and employment."*

This approach ensures that programs are not only effective but also able to secure the necessary funding and support from stakeholders.

Incorporating Feedback and DEI Practices

Experts identified the feedback from those with lived experience, as well as a commitment to diversity, equity, and inclusion (DEI) practices as a critical facilitator to beneficial services. One expert mentioned that successful programs seek *"feedback from those with lived experience"* and focus on *"seeking to understand versus judgment."* Incorporating perspectives from people who have firsthand experience with dual diagnoses ensures that programs are responsive to the actual needs of the population they serve.

Best Practices to Improve Access for Intersectional Populations

Experts provided insights on best practices for improving access to services for intersectional populations—specifically BIPOC, LGBTQI+, and rural communities—with dual diagnoses. The responses highlight key strategies, including: community inclusion, embedding services, workforce diversity, peer support, DEI training, and feedback integration (see Figure Forty-Nine).

Community Inclusion and Participation

A recurring theme is the importance of including the perspectives and voices of intersectional populations in service development and implementation. One expert emphasized that it is *"important to include the perspective and voices of these groups in service development and implementation planning to ensure accessibility and meaningful care."* This inclusion ensures that services are designed with the needs of marginalized communities in mind, leading to more tailored and effective care.

Embedding Behavioral Health in Primary Care

Experts also highlighted the value of integrating behavioral health services within primary care settings. One respondent suggested *"embedding behavioral health services within primary care, including staff in-services around working with 'special populations.'"* This approach brings mental health services closer to patients, making it easier for people in rural areas and underserved groups to access care without needing to navigate multiple systems.

Workforce Diversity and Peer Strategies

Increasing workforce diversity is another key recommendation. One expert pointed out that having *"more practitioners from these populations would help significantly,"* as trust plays a critical role in mental health care. People tend to trust practitioners who share similar backgrounds or experiences. Expanding the use of peer support strategies was also mentioned as an effective way to build trust and improve service accessibility, especially for marginalized communities.

Figure Forty-Nine Thematic Map of Best Practices to Improve Access for Intersectional Populations with Co-Occurring Support Needs Given in Key Informant Interviews

DEI Training and Policy Accountability

Another crucial element is mandatory DEI training for service providers, coupled with policy changes to improve access and accountability. One expert advocated for *"mandatory DEI training & consideration of policy changes needed to increase access to appropriate treatment and accountability at all levels of service delivery."* These initiatives help to dismantle biases within service systems and ensure equitable access for all populations.

Feedback and Advisory Groups

Gathering feedback from intersectional populations and forming advisory groups are key best practices. One expert recommended that programs should *"obtain feedback from these populations and establish advisory groups to address needs/gaps/planning."* This participatory approach ensures that services are continually improved based on the lived experiences of the communities they aim to serve.

Research and Resources

Accessing research and resources from specialized organizations was also suggested as a best practice. One respondent mentioned checking out the websites of state departments like the Ohio Department of Developmental Disabilities and the Ohio Center of Autism and Low Incidence (OCALI) for insights and resources. This approach helps organizations remain informed about innovative practices and policies that benefit intersectional populations.

Practices or Strategies for Supporting Health, Well-being, and Quality of Life for People with Co-occurring Support Needs

Respondents discussed some of the most useful practices or strategies that service providers or state departments have implemented to support people with co-occurring support needs, specifically focusing on health, well-being, and quality of life. The responses emphasize approaches like positive psychology, trauma-informed care, and community participation are as key strategies for promoting both mental and physical well-being. Initiatives like individualized exercise programs and comprehensive assessments were also identified as practical approaches that contribute to a higher quality of life for people with IDD and mental health support needs. These themes emphasize a holistic, person-centered approach to care that seeks to address the whole person, rather than focusing solely on their diagnoses.

Positive Psychology

One respondent noted the effectiveness of *positive psychology* as a framework for promoting well-being, specifically highlighting the work of Dan Tomasulo. This approach focuses on the strengths and resilience of people, rather than their deficits, contributing to their overall sense of well-being. Positive psychology supports the mental health of people by fostering optimism, gratitude, and mindfulness, which can have a profound effect on their quality of life. *"Positive psychology, the work of Dan Tomasulo"* was highlighted as a useful strategy for enhancing the mental and emotional well-being of people with co-occurring support needs.

Community Participation and Involvement

Another theme is the importance of *community participation* and involving people in all aspects of their care. This strategy creates a sense of *"buy-in"* from the people themselves, fostering a collaborative approach that empowers them to take an active role in maintaining their own health and wellbeing. This engagement helps build stronger support networks and fosters independence. *"Community participation is important. Involving the individual in all aspects of care creates buy-in as well."* Active involvement can lead to better health outcomes.

Trauma-informed Care and START Practices

Several experts pointed to the value of *trauma-informed care*, including the use of the START model. Trauma-informed approaches, like Dialectical Behavior Therapy (DBT) and the Skill System, emphasize understanding the person's day-to-day experiences and emotional well-being

rather than focusing solely on their diagnosis. These approaches are crucial in addressing the root causes of challenges and helping people manage trauma in a healthy, productive way. *"START practices are quite helpful and promote understanding and appropriate treatment." "Trauma-based approaches like DBT (Linehan, 1993) and Skill System (Brown, 2016) are helpful in providing appropriate intervention services."*

Individualized Exercise and Wellness Programs

Experts also highlighted successful initiatives from community-based organizations like the *YMCA and YWCA*, which have created tailored exercise programs for people with IDD. These programs focus on individual needs and allow participants to attend 1-5 days per week, helping them maintain physical health while also fostering community engagement. *"YMCA and YWCAs in our region designed a daily/weekly schedule for persons with IDD … Each person had their own exercise program [individualized] and attended 2-5 days/weekly."*

Comprehensive and Person-Centered Assessments

A key best practice identified is the use of *comprehensive, person-centered assessments* to evaluate the biopsychosocial factors that contribute to the challenges faced by people with co-occurring support needs. These assessments provide a holistic view of the person, allowing for a more accurate identification of treatment needs and gaps in care. This approach supports the *"whole person"* and leads to better coordination of transdisciplinary treatments that address various aspects of a person's life. *"Comprehensive assessments that are person-centered; identifying biopsychosocial factors contributing to or at the root of challenges/barriers."*

Necessary Changes for State Systems to Improve Services for People with Co-Occurring Support Needs

Experts claimed that to improve services for people with co-occurring support needs, state systems must enhance support structures, attract and retain qualified professionals, and promote a deeper understanding of trauma's impact on behavior. Additionally, supplementing mental health clinics and funding evidence-based programs while ensuring accountability are crucial steps. These insights reflect the need for a comprehensive approach that addresses the diverse needs of people with IDD and mental health support needs, fostering a system that prioritizes their well-being and inclusion.

Enhanced Support Systems for IDD and Education

A recurring theme in the responses is the necessity for state systems to provide improved support for people with IDD, especially during their youth. This includes promoting inclusion and engagement in educational settings to mitigate trauma and enhance emotional wellbeing. Efforts must be made to reach isolated populations and implement job coaching and other strategies to empower people to achieve their full potential. *"People with IDD need to be better supported by*

the IDD system and education system as youth. More inclusion and engagement are needed to reduce trauma and increase emotional well-being."

Attracting and Retaining Professionals To address staffing shortages and enhance service delivery, states must focus on attracting and retaining qualified professionals. This can be achieved through improved reimbursement structures, enhanced pay, and ongoing education and training opportunities. An expert said that *"States need to entice professionals through reimbursement, enhanced pay, and education."* Such measures can help create a motivated workforce committed to providing high-quality care.

Understanding Trauma and Behavior

An essential change highlighted is the need for a better understanding of the relationship between trauma and behavior. Practitioners must recognize that what is often labeled as *"bad behavior"* may be rooted in trauma experiences. Training programs should emphasize this perspective, ensuring that mental health, counseling, and behavioral services prioritize helping people rather than merely meeting provider expectations. *"Improvement in understanding of the impact of trauma on what is often labeled 'bad behavior.' All practitioners need to adopt this view."*

Enhancing Mental Health Clinical Services

Suggestions include supplementing public mental health clinics that accept Medicaid and Medicare, allowing for longer appointment times and more frequent visits. The establishment of managed care organizations specifically for IDD can facilitate education for prescribers, provide trained care coordinators, and increase public awareness to keep people healthy and stable within their families. *"Supplement public mental health clinics who take Medicaid and Medicare so they can lengthen appointments and see people more often."*

Funding and Accountability for Evidence-Based Programs

A multi-faceted approach is necessary to address systemic gaps in services for people with co-occurring support needs. Funding should be directed toward evidence-based programs, with a focus on holding organizations and service providers accountable for delivering high-quality services. Additionally, educating service providers at all levels and mandating that higher education programs incorporate relevant training is essential. *"Fund evidence-based programs and address [not just identify] systemic gaps with a multi-prong approach."*

Policy and Rule Recommendations for Addressing Challenges Faced by People with Co-Occurring Support Needs

The experts provided several key policy recommendations aimed at improving the lives of people with co-occurring support needs. Overhauling the CMS waiver system, simplifying cross-systems funding, and allowing for greater risk-tolerance are critical areas for reform. Additionally, ensuring access to preventive medical care and creating an advisory group to hold policymakers

accountable are essential steps toward providing equitable and effective care. These policy adjustments aim to address both the structural barriers and systemic challenges faced by people with co-occurring support needs, fostering an environment where they can achieve greater autonomy, well-being, and quality of life.

CMS Waiver Methods and System Overhaul

Experts recommend a comprehensive review and *overhaul of the CMS waiver methods*. This is necessary to ensure that the funding structures and support services are better aligned with the needs of people with co-occurring support needs. Current waiver systems can be confusing for both service providers and beneficiaries, often leading to inadequate or misaligned supports. Improving the system through better education and training for both mental health and IDD professionals is seen as key to resolving these issues. *"The CMS waiver methods need a complete review and overhaul along with education and training for mental health practitioners and IDD professionals."*

Cross-Systems Funding and Parsimonious Systems

Cross-systems funding is another critical area where reforms are needed. The fragmented nature of current systems often leaves staff unsure about where to find and how to access the necessary supports, including insurance and other services. Simplifying the system to create a more parsimonious approach would help alleviate confusion and ensure that people receive appropriate care. *"Cross systems funding always seems to be an issue. It's been my experience that the staff supporting individuals with dual diagnosis needs are confused regarding where to get adequate supports."*

Risk-Tolerance and Individual Freedom

Another important recommendation is to adjust policies to allow for *greater risk-tolerance* for people with co-occurring support needs. The current focus on safety can limit the freedom of people to take calculated risks, which are essential for personal growth and skill development. Allowing for more choices that have potential risk can lead to both positive and negative experiences, but the long-term benefits — such as independence and new skills — are seen as worth the trade-offs. *"Another important policy adjustment is the creation of greater risk-tolerance. People can only be free if they can take some calculated risks. Focusing entirely on safety limits their ability to do that."*

Preventive Medical and Psychiatric Care

The need for *preventive medical care* is also highlighted as a key policy area. Providing frequent, early preventive care (more often than for the general population) and ensuring access to the highest levels of psychiatric and medical care can help keep people with co-occurring support needs healthy and stable, reducing the risk of crises and hospitalizations. *"Provision of preventive*

medical care that is early and often (versus the general population) and provide the highest level of psychiatric and medical care to keep people healthy, stable, and safe."

Accountability and Policy Reform

One expert suggests forming an advisory group that identifies policies and laws that perpetuate the marginalization of people with co-occurring support needs. The advisory group would focus on holding policymakers accountable for making the necessary changes to ensure equitable treatment and to remove barriers that deny access to appropriate services. *"Create an advisory group that identifies policies/laws put in place that maintain marginalization of this population and lead to denied access to appropriate treatment & hold policy-makers accountable."*

Exemplary National Programs for People with Co-Occurring Support Needs

The responses highlight several exemplary programs that provide outstanding support for people with co-occurring support needs. The START model stands out for its evidence-based, person-centered approach to crisis prevention, while Ohio's statewide resources are noted for their innovative use of telepsychiatry and comprehensive, county-wide services. Experts emphasize that following programs and initiatives that prioritize research and systemic change, while promoting culturally responsive practices are essential to expanding the reach of these services. These programs serve as models for addressing the complex needs of people with co-occurring support needs and improving both access and outcomes.

START Model for Crisis Prevention and Interventions

The *Systemic, Therapeutic, Assessment, Resources, and Treatment (START)* model was consistently identified as exemplary by several experts due to its national reach, evidence-based methods, and focus on cross-systems crisis prevention and intervention. START promotes a deeper understanding of the person being supported, encouraging a balanced focus on both safety and personal growth. Data reporting and evaluation are key aspects of its quality approach, ensuring that outcomes are continuously assessed and improved. *"The START model for cross-systems crisis prevention and intervention. What makes it exemplary is its national reach and evidence-informed methods. Data reporting and evaluation is key to a quality approach." "The START approach is great for one reason. It promotes greater understanding of the person you're working with."*

Ohio's Statewide Resources

Ohio's statewide resources for mental illness and intellectual disabilities (MI/ID) are cited as exemplary due to their accessibility across all 88 counties and their ability to reduce emergency department visits and hospitalizations. These resources include the Center of Excellence in MI/ID, which provides educational programs, second-opinion psychiatric assessments, and local county teams, as well as Ohio's Telepsychiatry Program, offering virtual psychiatric care, counseling, and case management. These services are recognized for their innovative approach to expanding

access to psychiatric care and their measurable impact on health outcomes. *"Ohio has two statewide resources available to all 88 counties: the Center of Excellence in MI/ID and Ohio's Telepsychiatry Program. We have lowered emergency department visits and hospitalizations by 84-96%."*

Person-Centered and Evidence-Based Approaches

Another key theme is the use of *person-centered, evidence-based interventions*. Programs like the National Center for START Services and The Arc are noted for their dedication to advancing research and focusing on the person. These programs emphasize systemic interventions that not only support the person but also address broader systemic challenges, helping to ensure that services are effective and accessible to all. *"National Center for START Services — evidence-based, advancing research, person-focused and systemic intervention." "The Arc; NADD."*

Culturally Responsive and Comprehensive Approaches

The experts also emphasized the importance of *culturally responsive practices* in exemplary programs. By ensuring that services are tailored to the unique needs of diverse populations, including BIPOC and rural communities, these programs expand their reach and improve access to care. Comprehensive assessments and services that take into account the whole person, rather than just their diagnosis, are also cited as key to the success of these programs.

Changes in the Disability and Mental/Behavioral Health System Over the Last Five Years

According to the experts consulted, the last five years have seen meaningful changes in the disability and mental/behavioral health systems, including adoption of humanistic and positive approaches, improvements in telehealth access, and increased awareness of IDD. However, the decrease in psychiatric hospitalization availability for people with IDD and the challenges of diagnostic overshadowing pose significant obstacles. Additionally, while there is growing recognition of mental health support needs at the governmental level, efforts to address systemic gaps are progressing slowly. These insights underscore the need for continued advocacy and reform to enhance the quality of services for people with co-occurring support needs.

Humanistic and Positive Approaches

One of the most significant changes noted is the inclusion of *humanistic and positive approaches* in mental health treatment. This includes the adoption of *Positive Psychology* and *Positive Cognitive Behavioral Therapy (CBT)*, which focus on strengths and well-being rather than challenges. An expert noted that the *"inclusion of more humanistic and positive approaches such as Positive Psychology and Positive CBT" would be helpful.* This shift reflects a growing recognition of the importance of a holistic approach to mental health and the value of fostering positive experiences.

Expansion of Telehealth Services

The responses indicate that *telehealth services* have significantly improved access to care for people across various demographics. According to a respondent, *"Overall telehealth services have improved access for everyone."* The COVID-19 pandemic accelerated the adoption of telehealth, which has proven to be a valuable tool for delivering mental health and disability services, particularly for those in remote or underserved areas.

Decreased Availability of Psychiatric Hospitalizations for IDD

A troubling trend observed is the decreased availability of *psychiatric hospitalizations* for people with IDD in certain regions. This decline has been attributed to *diagnostic overshadowing*, where symptoms are attributed solely to the IDD diagnosis, leading to insufficient mental health treatment. An interviewee said, *"Psychiatric hospitalizations have become less available for people with IDD in some parts of the country. Diagnostic overshadowing, 'it's all because of the ID,' is a major reason for that."* This phenomenon poses a challenge for people needing comprehensive care, as their complex needs may be overlooked.

Increased Awareness and Advocacy for IDD

There has been a notable increase in awareness regarding mental health issues among people with IDD. Organizations like the *American Psychiatric Association* have established an IDD caucus, and the *American Association of Child/Adolescent Psychiatrists* has focused on IDD in their sessions. This growing recognition is vital for advancing research, practice, and policy changes to support people with dual diagnoses effectively. *"Increased awareness of MI/IDD by the American Psychiatric Association. We now have a national IDD caucus, and the American Association of Child/Adolescent Psychiatrists has an IDD focus for several sessions each year."*

Evolving Government Funding and Systemic Gaps

The responses also highlight a larger focus on mental health support needs in government funding. Although there has been progress in identifying gaps in the mental health and disability systems, there is still slow movement in addressing these gaps. "Larger focus on mental health in general in government/funding sources; more groups identifying gaps in systems; still slow progress in addressing those gaps and failure to identify the root of the barriers." Experts stressed the need for continued efforts to understand and tackle the root causes.

Comparative Analysis

Figure Fifty shows a comparative analysis between Washington State and the national landscape. The analysis follows Burrow et al.'s (2021) framework to break down each domain, highlight the key issues, barriers, proposed solutions, stakeholders, and expected outcomes, and compare the gaps between Washington and the national landscape.

Figure Fifty Comparative Analysis Between Washington State and the National Landscape

	Key Issues Identified	Barriers	Solutions Proposed	Stakeholders Involved	Outcomes Expected	Interventions	
						Washington	National
AWARENESS	Lack of awareness of mental health needs in people with IDD	Stakeholders (e.g., parents, caregivers) are not equipped with resources or knowledge	Educating stakeholders on the differences between IDD and mental health needs. Normalizing mental health services and reducing stigma	Parents, caregivers, professionals, policymakers	Increased knowledge, reduced stigma, better recognition and treatment of co-occurring needs	Educational and community support programs, Community engagement and empowerment	Educational resources hubs, Educational support for staff, Educational support for caregivers
ACCESS	Limited access to mental health services for people with IDD	Systemic (e.g., waitlists) and pragmatic barriers (e.g., lack of technology, scarcity of providers)	Stronger community living policies, Medicaid incentives, recruit qualified providers, expand training	State agencies, Medicaid, healthcare providers, mental health professionals	Improved service availability, reduced financial barriers, and increased access to qualified providers	The Individual and Family Services waiver and the Community First Choice (CFC) waiver (WAC 388-106-0270, n.d.)	Financial relief, State Medicaid agency incentives, Recruitment of mental healthcare professionals
QUALITY OF CARE	Poor quality of services due to fragmented services and lack of person-centered services	Providers with biases or poor understanding of IDD and mental health needs	Integrated service coordination, person-centered services, educating providers on IDD and mental health intersectionality	Healthcare providers, organizational leaders, support staff	Enhanced quality of services, increased autonomy for people, and more effective treatments	Washington's move toward Fully Integrated Managed Care (FIMC) in 2016	Service coordination, Integrated care, Multi-disciplinary training, Person-centered services, Practitioners' cultural competence

Figure Fifty (Cont.) Comparative Analysis Between Washington State and the National Landscape

	Key Issues Identified	Barriers	Solutions Proposed	Stakeholders Involved	Outcomes Expected	Interventions	
						Washington	National
DIAGNOSIS	Inaccurate or absent diagnoses due to a lack of suitable diagnostic tools for people with IDD	Tools not sensitive to race, ethnicity, or disability, lack of multidisciplinary teams	Development of diagnostic tools for the IDD population, multidisciplinary assessment, and better education on culturally sensitive approaches	Diagnostic teams, healthcare providers, researchers	More accurate diagnoses, improved treatment plans, reduced misdiagnosis	Data from service recipients in WA suggest that diagnostic-related initiatives are limited to institutions due to overshadowing and infrastructural failures in the system	Targeted assessment Tools
TREATMENT	Misunderstanding of behavior leads to inappropriate placements and ineffective treatments	Misinterpretation of trauma and disability-related behavior, inappropriate crisis interventions	Trauma-informed services, specialized crisis units, proper medication management, and therapeutic methods	Mental health professionals, trauma experts, crisis intervention teams	Reduced overmedication, better therapeutic outcomes, fewer inappropriate placements, and improved wellbeing of people	Expansion of telehealth services post COVID-19 pandemic and CCSS that provide short-term residential services for people in crisis, Washington services recipients say institutionalization is used as part of treatment initiatives	Telehealth, Appropriate use of medication, The Restorative Integral Support model, Crisis behavior intervention services

Conclusion

While Washington State has made significant strides in addressing the mental health needs of people with IDD, gaps remain when compared to the national landscape. The state has pioneered several promising initiatives, such as the implementation of Fully Integrated Managed Care (FIMC) and the expansion of crisis stabilization services. However, systemic barriers, such as fragmented services, limited access to knowledgeable and specialized providers, and a lack of culturally sensitive diagnostic tools, continue to hinder progress. Moving forward, Washington can benefit from adopting national best practices suggested by research and national experts in this study that emphasize integrated services, trauma-informed approaches, and the development of tailored diagnostic tools. By fostering collaboration among key stakeholders and expanding initiatives that prioritize person-centered care, Washington can further align with national trends and continue improving the quality of services and wellbeing of people with co-occurring intellectual and developmental disabilities and mental health support needs.

PART FOUR PUTTING IT ALL TOGETHER & RECOMMENDATIONS

This section synthesizes findings from each part of the report to outline actionable recommendations that may improve the Washington Disability, Mental Health, and Behavioral Health service systems.

"Anxiety makes it very hard to deal with scheduling and waiting. Not knowing what resources are available makes it difficult to know what/where you can get help/resources."

"Everything is in silos. IDD knows nothing about psychiatry, and psychiatry knows nothing about IDD or even disability. Both are still operating within a medical model instead of planning 'supports' and taking guidance from individuals."

"Having to quit my full-time job to take my child to all the therapies. We receive Molina insurance, but the cost of gas is expensive, and we drive for an hour. At times we only get 30 min therapy sessions."

"The largest barrier is the lack of providers willing to work with this specific demographic overall. It gets even harder when you have someone who has IDD that also has them communicate in ways that are socially inappropriate. In my experience providers are willing to take on new clients, quote a wait of 6 months, but then they hear that the client is moving from one of the state hospital programs, and the wait suddenly increases. Finding people to work in the home for daily living supports is difficult, and many of those hired are working for multiple agencies in the area. The wage is not competitive for the type of care expertise that is needed, and more and more those who require support with daily living in supported living homes are people who cannot live with their families, and have been with people who exhibit some sort of maladaptive behavior, meaning that there needs to be more staff in the house, but hours assigned are too low to have the house properly staffed, even with case managers who are good about getting the supports needed into the home."

Introduction to Part Four

The state of Washington has a significant opportunity to improve the quality of supports and services available to people with co-occurring intellectual and developmental disabilities (IDD) and mental and/or behavioral support needs. This part of the report provides a brief overview of the findings from parts one through three of the report and the resulting recommendations to improve the state of services for people with IDD and mental health/behavioral support needs, particularly for traditionally underserved communities. To generate the recommendations in this section, ideas provided by people with disabilities and family members from the focus group, interviews, and survey, as well as from key informants from other states, were prioritized. Findings from the policy analysis, secondary data analysis, and other state models and approaches analysis were also helpful in developing actionable recommendations.

Putting it All Together: Overview of Washington Policies, Impact, & Need

Washington Models, Practices, and Policies Overview

Washington's policies addressing the needs of people with IDD and co-occurring mental or behavioral health support needs have shown varying degrees of effectiveness. Initiatives like expansions to the Home and Community-Based Services (HCBS) waivers and the Fully Integrated Managed Care (FIMC) model have made notable strides in transitioning people with co-occurring needs from institutional care to community-based services, promoting person-centered care and offering more comprehensive health coverage. HCBS waivers have allowed thousands of Washingtonians with IDD to receive individualized services in their homes, significantly improving quality of life and reducing reliance on restrictive settings. Similarly, the FIMC model has improved care coordination by integrating physical, behavioral, and developmental services under a single managed care system, reducing fragmentation and helping streamline access to holistic care.

Washington has also implemented several workforce development initiatives, such as offering training programs for providers working with people with co-occurring support needs and creating incentives for professionals to work in underserved areas. For example, the state's Behavioral Health Integration Training Initiative provides training to behavioral health providers on best practices for working with people with IDD. However, these efforts are still in their early stages, and more investment will be necessary to fully address the workforce gaps affecting service delivery across the state (Developmental Disabilities Administration, 2022).

These policies still face critical challenges that limit their effectiveness. A major gap lies in the availability and timeliness of services, as long waiting lists for HCBS waivers, like the Individual and Family Services waiver, remain a persistent issue. This is particularly problematic in rural areas, where regional disparities in service availability exacerbate inequities. While FIMC has

improved care coordination, the shortage of behavioral health providers trained to work with people with IDD also continues to hinder the quality of services. Crisis intervention programs such as Community Crisis Stabilization Services (CCSS) and Mobile Crisis Response Teams have improved emergency response, but their limited availability in rural regions leaves many without adequate support during critical moments. Additionally, while telehealth has expanded the availability and conveniences of services, digital equity issues, such as limited access to broadband and technology, prevent many people from fully benefiting from these services. Finally, all of these issues compound in a continued reliance on, and even support for, the expansion of institutional services for people with co-occurring IDD and mental and behavioral health support needs. Institutional supports, while intended to be temporary for many people, instead keep people segregated and excluded from their communities, loved ones, and opportunities to live fulfilling and meaningful lives. While Washington's policies have made commendable progress in improving access to critical services for people with co-occurring support needs, significant gaps in service accessibility, regional equity, workforce capacity, and reliance on institutional care still need to be addressed to improve the overall effectiveness of these programs.

Secondary Data Overview

Findings from 2022 Washington National Core Indicators data show that there are a considerable number of people with IDD with co-occurring mental and behavioral health support needs who are highly satisfied with the respect that direct support staff show them, the availability of services in their preferred language, and the amount of technology and/or transportation support that they receive. Further, when the experiences of only people with co-occurring IDD and mental and behavioral health support needs were considered, the data revealed that this subsample was even more satisfied with the quality of direct support staff respect and communication. These results are not consistent with the findings from the data collected specifically for this study (outlined below); however, inconsistencies may be due to differences in respondents, timing of data collection, or other unknown and uncontrollable factors.

Analysis of the NCI data also showed that many people who reported having mental and behavioral health support needs did not have needed behavioral supports and plans in place. Further, a substantial proportion of the subsample with co-occurring support needs required more intensive and/or consistent interventions and services, particularly people who tended to be harmful to themselves or others. While the data did not specifically reveal that people felt consistently underserved or that professionals were ill-equipped and undertrained to support them, findings from the data collected for this study as well as results of the policy and practice analysis outlined above indicate that there are likely challenges in providing needed services to many of the people in this sample with the highest mental and behavioral support needs.

Focus Group, Interview, and Survey Overview

Results from the focus group, interviews, and online survey conducted with Washingtonians with co-occurring IDD support needs and their families demonstrate the need to build infrastructure and support to make coordinated supports available, accessible, and responsive for people with disabilities across the state, particularly for traditionally underserved communities. In total, the perspectives of 426 people with lived experience revealed that while there are many facilitators helpful to increasing knowledge about, access to, and effectiveness of coordinated IDD and mental and behavioral health services, there are several barriers that leave many people with co-occurring support needs under-supported, inappropriately supported, or confined to institutions.

Commonly named factors that got in the way of quality IDD and mental and behavioral health services included ongoing discrimination in the form of ableism, racism, or lack of cultural respect from disability service professionals, mental and behavioral health professionals, and community members as well as language inclusivity and stigma toward public service users. Many people also noted that receiving needed supports was a challenge due to strict qualifications, service denials, difficulty navigating service systems, lack of support or needed knowledge from professionals, including case managers, service unavailability or inability to support people with higher support needs. Similarly, several respondents shared that disconnections between service systems and limited responsiveness and service options leave many caregivers feeling isolated, overworked, and burnt out. Other barriers included financial and geographical challenges to accessing services, particularly for people from underserved and rural communities, as well as lingering disruptions from the COVID-19 pandemic that perpetuate isolation.

Respondents also noted several factors that helped them access and benefit from needed services. When resources, such as funding, payment for family caregiving, information about services, and referrals were available, respondents noted that accessing services was much less challenging. Support, availability, and proximity of providers, having a strong and coordinated support system of case managers, providers, and respite services, and family-to-family support, insider knowledge, and advocacy were crucial in accessing and utilizing quality services.

National Models and Key Informant Expertise Overview

Results from an investigation of national and state models (outside of Washington) and interviews with key informants who are experts in systems of support for people with co-occurring IDD and mental and behavioral health support needs showed that many of the challenges noted in Washington are pervasive across the rest of the United States. At the same time, there are many evidence-based systems, strategies, and practices that can inform the priorities of Washington policies, initiatives, and advocacy. The review of national models and perspectives of key informants revealed that trauma-informed and person-centered approaches to services, adoption

of evidence-based and informed decision-making that includes people with lived experience, commitment to culturally competent and inclusive practices, fostering a diverse and representative workforce, including people from traditionally marginalized communities in collaboration, increased investment in professional training and development, and cross-system collaboration between IDD and mental and behavioral-health systems were all necessary to adopting effective practices in supporting people with co-occurring needs. As is true in Washington, many of the national and state-specific programs, interventions, models, and practices adopted to support people with IDD and mental and behavioral health support needs are relatively new and are being built, tested, and continuously improved.

Comparative Analysis Overview

Results of the analysis of Washington compared with other state and national practices and models also showed that the state is not alone in its challenges in providing accessible, quality services to people with co-occurring support needs, particularly people from traditionally underserved communities. Using a framework focused on the five domains of awareness, access, quality of care, diagnosis, and treatment (Burrows et al., 2021) to examine Washington's approaches in the context of the effective practices outlined by the key informants and national scoping assessment, the results show opportunities for improvement in the following areas:

- **Awareness**: Washington has education, community support, and outreach programs. Opportunities to expand these efforts and utilize effective models and programs include creating resource hubs, increasing evidence-based training for professionals, and providing educational opportunities for people with co-occurring support needs and families
- **Access**: Washington has created several waiver options so that people with co-occurring support needs can access needed community services. Opportunities to expand these efforts and utilize effective models and programs include offering additional financial relief to families and providers, recruiting a diverse workforce of qualified mental and behavioral healthcare professionals, and creating incentives to increase service access
- **Quality of Care**: Washington has adopted the FIMC model that supports the integration and increased quality of IDD and mental and behavioral health services. Opportunities to expand these efforts and utilize effective models and programs include enhancing service coordinator skills and resources, providing multidisciplinary training, and increasing the person-centered and culturally competent practices of practitioners
- **Diagnosis**: Washington has diagnostic initiatives that are limited to and tend to promote institutionalization. Opportunities to utilize effective models and programs include reviewing and adopting more effective targeted assessment tools.
- **Treatment**: Washington has expanded telehealth services and community crisis supports. At the same time, it continues to rely on institutional services and treatment initiatives over community options for people with the highest support needs. Opportunities to expand promising efforts and utilize effective models include enhancing telehealth support, examining reliance on medication, and improving crisis behavioral intervention services.

Recommendations

Addressing the disparities in services for people with intellectual and developmental disabilities (IDD) who also require mental or behavioral health services is critical, particularly for BIPOC, rural, and other historically underserved communities. These populations often face unique challenges that can exacerbate difficulties in accessing comprehensive support. By addressing the identified systemic barriers and providing opportunities for improvement, Washington can enhance the effectiveness of interventions aimed at bridging this gap. This includes recognizing how systemic inequities affect service delivery and the importance of culturally responsive care that acknowledges the diverse backgrounds and experiences of these communities.

Based on the findings outlined in parts one, two, and three of this report, recommendations to improve access, availability, and quality of services for people with co-occurring IDD and mental and behavioral health support needs have been organized into six categories:

- Recommendations to enhance service integration
- Recommendations to build workforce capacity
- Recommendations to increase service access and availability
- Recommendations to improve the quality of services and supports
- Recommendations to reduce reliance on institutional models of support
- Recommendations to gain systems support for change

Recommendations to decrease the gap in service availability, quality, and responsiveness for people from underserved communities are embedded within each of the areas of recommendation above to increase equity for BIPOC, rural, and underserved communities. A table at the end of each section is included to summarize the recommendations provided.

Recommendations to Enhance Service Integration

Throughout the study, the Consortium consistently heard that a disconnected service system, particularly across intellectual and developmental services and mental and behavioral support services, was a critical barrier to accessing needed support. These findings are common across states and have led to the creation of several models and national organizations dedicated to bridging that gap. Recommendations to enhance service integration include strategies at the level of people with disabilities and families, service professionals, and systems.

Create dedicated navigator positions for navigating both the IDD and mental/ behavioral health systems and increase education of options across systems for service coordinators
To address the challenges that people have accessing needed services, many focus group, interview, and survey participants mentioned gaps in support coordinator knowledge or capacity to guide them through multiple service systems. Dedicated navigators who have expertise in service options, what is needed for service approval, options when people are in crisis, and

appropriate supports for people with multiple diagnoses could help people explore and select the services they need (Budde et al., 2022). Alternatively, increasing the knowledge, resources, and information that service coordinators have about IDD services, as well as mental and behavioral health supports, would ensure that people with co-occurring support needs can gain essential information about service options. Interviewees who felt their support coordinators had needed knowledge about both systems named them as essential facilitators in accessing quality supports. Increasing training and education opportunities, as well as accessible and readily available resources with up-to-date information can help support coordinators become more effective. However, due to high caseloads and job demands, many support coordinators would likely struggle to take on additional responsibilities or fully participate in training opportunities. Providing more training and education without decreasing support coordinator workloads would reduce the impact of the training.

Encourage service users to invite qualified mental health support professionals in person-centered planning processes
Although there is a shortage of qualified mental and behavioral health professionals who understand how to support people with IDD, those who do have access to such professionals should consider including them in their person-centered planning meetings to ensure that needed supports (beyond behavior plans) are incorporated into daily service expectations, goals, and plans. Qualified mental and behavioral health professionals may support people include crisis planning, preventative goals, and direct service approaches to help people access needed interventions while reducing the risk of hospitalization or institutionalization. This could be particularly beneficial for people from underserved communities who are three times more likely to be institutionalized or 2.6 times more likely to fear institutionalization due to mental or behavioral health needs not being met by community-based supports.

Increase coordination and integration across offices, systems, and professionals who may be involved in the services of people with IDD and mental and behavioral health support needs
Washington has an opportunity to invest in coordinated resources and cross-agency efforts, including improved and relevant mental health assessments, targeted therapeutic interventions, bundled payments for integrated care models, and incentives for collaboration between IDD and mental and behavioral health service providers. President Biden's policy package to address the national mental health crisis outlines relevant strategies (Bagalman, 2022), including adopting the *Support Americans by Creating Healthy Environments* policy strategy to align structural support and integrate promotion and prevention programs in community-based settings from early childhood to young adulthood. Proactive approaches could allow service systems to reach more people at key points, such as childhood and young adulthood, when onset of mental and behavioral health needs is common.

Future federal support may be available to support these efforts. The Department of Health and Human Services has launched the development of this strategy by funding research projects and programs intended to expand the evidence base for effective promotion and prevention programs operating across diverse settings and translating the evidence into practice. In 2022, the National Institute of Health also announced a research funding opportunity aimed at exploring innovative approaches to identify, understand, and develop strategies to overcome barriers in adopting, adapting, integrating, scaling up, and sustaining evidence-based preventive interventions to support the mental, emotional, and behavioral health of children in school settings (Bagalman, 2022). Figure Fifty-One summarizes policy issues related to service integration, evidence-based recommendations for models, initiatives, and policies, and implementation examples.

Figure Fifty-One Issues and Recommendations for Service Integration

Policy Issue	Recommendation	What it Looks Like	Implementation
Traditional healthcare systems often treat IDD and mental/behavioral health as separate entities, leading to fragmented care	Development of Integrated Care Models (Williams & Ervin, 2016; Whitehead et al., 2021)	Create interdisciplinary teams or navigator positions or increase the capacity of support coordination to aid in comprehensive service plans	Create integrated support positions and models that address both IDD and mental/behavioral health concurrently can improve outcomes
IDD and mental health supports are not developed in a coordinated manner	Shared Care Planning (Mann et al., 2021)	Service and person-centered plans should be developed collaboratively between IDD and mental/behavioral health professionals to ensure people receive holistic support	Establish regular coordination between IDD and mental/behavioral health providers to monitor progress, adjust interventions, and address emerging needs
Fragmented funding can be a barrier to integrated care	Integrated Funding Streams (Friedman et al., 2015; Williams & Ervin, 2016)	Explore ways to integrate funding streams for IDD and mental/behavioral health services, allowing for more flexible and comprehensive options	Include bundled payments for integrated care models or grants that incentivize collaboration between service providers

Recommendations to Build Workforce Capacity

Increase training and education for Direct Support Professionals, Frontline leaders, and provider organization employees about recognizing, respecting, and supporting people with co-occurring IDD and mental and behavioral service needs

While some training exists, many participants noted that more in-depth or relevant training would be helpful. It is crucial to introduce policies that require regular training in de-escalation

techniques and trauma-informed care, fostering a safer and more compassionate response to behavioral incidents (Rich et al., 2021). Ideally, training aids people recognize the signs of a mental or behavioral health support need or crisis and determine how to respond In ways that are respectful, peaceful, non-aversive, and avoid (when possible) hospitalization. Targeted training could be especially beneficial for professionals working with people who have higher support needs or who are more at risk for self or other harm. Because an estimated 1/3 of people with disabilities have experienced abuse (Fang, et al., 2022), training that is based in trauma-informed supports is critical. Further, training must include cultural competence and provide disability sector professionals with tools to navigate different interpretations and traditions related to mental and behavioral health supports.

Increase training and education for medical, mental health, and behavioral professionals about co-occurring support needs

In the same way that disability sector professionals need more training, medical and mental and behavioral health professionals also require targeted education to ensure they have the skills and knowledge needed to recognize and support people with co-occurring support needs. Training, based in trauma-informed practices, should help professionals recognize

- How mental and behavioral health support needs may present differently for people with IDD
- Current or previous instances of abuse and neglect that may be impacting a person's mental health
- The impact that environment and services can have on mental and behavioral health
- The interplay of identity, culture, and approach to mental and behavioral health for people with intersecting identities and/or from underserved communities
- Opportunities for support that do not rely solely on medication, hospitalization, or institutionalization.

The training should also incorporate strategies to help people recognize and prevent crises when possible and build skills to navigate their mental and behavioral health support needs.

Provide resources to agencies that support people with disabilities to increase frontline leadership retention via certification and pay increases for DSPs who specialize in supporting people with mental and behavioral health supports

Across the U.S., there is a push toward certification, recognition, and professionalization of the Direct Support Professional and Frontline Leadership roles from many local, state, and national organizations. For instance, due to efforts of the National Alliance for Direct Support Professionals, there are federal initiatives to recognize the Direct Support Professional role as a Standardized Occupational Classification. Many states are using certification and training as a way to structure wage increases and incentives for DSPs and frontline leaders. This approach may be useful if it is paired with enhanced training opportunities as a way to ensure the acquisition and

retention of skills learned. Further, certification and recognition programs have shown to be effective in increasing retention and engagement, which, in turn, reduces the high cost of turnover and the revolving door of professionals in people with disabilities lives. Figure Fifty-Two summarizes policy issues related to workforce capacity, evidence-based recommendations for policies, models or initiatives, and implementation examples.

Figure Fifty-Two Issues and Recommendations for Building Workforce Capacity

Policy Issue	Recommendation	What it Looks Like	Implementation
There is a lack of staff trained to address both IDD and mental/behavioral health needs	Cross-Training of Staff (Greenwald et al., 2024; Kelley et al., 2024)	Cross-training initiatives to equip support staff, mental health professionals, and direct support workers with the skills needed to recognize and manage the unique needs of people with co-occurring conditions	Focus training on understanding the interaction between IDD and mental health, effective communication strategies, and behavior management techniques
Staff supporting people with co-occurring support needs need to receive specialized training	Specialized Certification Programs (Kelley et al., 2024)	Developing specialized certification programs for professionals who work with people with co-occurring IDD and mental health needs can enhance the quality of care	These programs can provide advanced training in areas such as behavioral interventions, crisis management, and the use of assistive technologies to support mental health
Most medical, mental health, and behavioral health professionals are not adequately trained in supporting and treating people with disabilities	Increased cross-training and education for medical, mental health, and behavioral health professionals	Training to help build capacity to recognize mental health and behavioral crises and support needs for people with disabilities and mental and behavioral health support needs	Promote training to help professionals identify specific needs, demonstrate cultural competence, address environmental factors that impact mental health, and recommend effective interventions
High DSP turnover rates make it difficult to maintain trained and qualified staff to support people well	Increase provider resources and infrastructure for certification and recognition	Continue to professionalize and build DSP capacity and engagement through certification, aligning wages more closely with skills	Offer DSP certification or another way for DSPs to build their skills and receive incentives

Recommendations to Increase Service Access and Availability

In Washington, while there are several policies and structures in place to increase coordination and quality of mental and behavioral health services for people with IDD, the availability of quality support is a prominent issue for many people with disabilities and families.

Invest in the growth of community-based mental and behavioral health services, crisis supports, and qualified professionals across the state.
Using strategies from President Biden's policy package to address the national mental health crisis, and programs such as CMS's Connect Americans to Care policy strategy, Washington can promote integrated mental health services by bridging the gap between services the system offers and people's ability access needed support. Initiatives to make behavioral health services more available, affordable, and tailored for the people who need them, such as implementing mobile crisis response teams that specialize in supporting people with co-occurring IDD and mental health needs, can provide timely and appropriate interventions during crises. This is especially important in rural environments where people have more trouble accessing needed services.

Increase coordination between IDD and mental and behavioral health services to decrease referral and service acquisition time.
Because IDD and mental and behavioral health services tend to be disjointed, many people report high wait times or difficulty getting referrals to needed services, particularly for mental and behavioral health supports. Creating clear pathways for referral, including shared electronic health records and interagency agreements, can facilitate seamless transitions between services and ensure that people receive timely and appropriate support.

Expand the capacity and diversity of the behavioral health workforce to ensure a full continuum of behavioral health support.
Targeted recruitment and development of behavioral health specialists, particularly from communities that represent underserved populations, could help to not only increase service availability, but increase cultural competency and connection between service providers and service users. A replicable example is the Minority Fellowship Program (MFP) from the Substance Abuse and Mental Health Services Administration's (SAMHSA's), which awards grants to organizations supporting the training of behavioral health professionals. The goal of the MFP is to increase the workforce of practitioners with the skills to serve racial and ethnic minority communities, with the ultimate objective of reducing health disparities and improving behavioral health outcomes for these populations.

Engage in outreach and trust building with traditionally underserved communities to increase utilization of needed services.

Initiatives such as community health programs, partnering with religious and community groups, outreach services, telemedicine, working with traditional healers, and working with non-profit,

private sectors, and non-governmental organizations including faith-based organizations are the key to improve healthcare access for traditionally underserved populations (Gizaw et al., 2022). Outreach efforts to build trust, partnerships, and relationships with leaders of underserved communities and community groups may help build trust with people who are less likely to access services or feel secure in the quality of supports they receive.

Address access challenges for people in rural areas, such as network connections and access to telehealth.

 Studies have found that the biggest barrier people with IDD face accessing technology is affordability and a lack of funding (Boot et al., 2020). Providing financial access for assistive technology and/or expanding HCBS's funding for devices, apps, and software that support daily living and independence, as well as training programs for people and their support staff would be helpful (Friedman, 2023). Another policy strategy to explore is a statewide implementation of a digital inclusion initiative to ensure people have access to free or subsidized assistive technology and digital literacy training. This could be modeled after The Arc's *Empowering Through Technology* initiative (The Arc, 2024). The state could allocate resources to purchase adaptive devices, software, and internet services specifically designed for people with IDD.

Improve transportation, especially in rural areas, so that people can access supports.
According to researchers (Friedman, 2024), increasing transportation options by expanding transportation services and funding under HCBS, promoting self-directed transportation services, and increasing awareness of available transportation services for people with IDD are promising policies to enhance transportation services. Unreliable, underfunded, or restricted transportation often limits the mobility of people with IDD. Many people rely on unpaid family members or caregivers to aid with transportation; some states have considered including transportation support as options for paid family caregivers as a sustainable solution when increasing transportation services is not a timely option.

Additionally, Washington can promote self-directed transportation services, allowing people with IDD more control over how their transportation needs are met (Friedman, 2024). While self-direction is a key component of HCBS, less than half of stand-alone transportation services are eligible. This considerably impacts how service recipients secure reliable transportation. A multipronged approach that introduces creative solutions, such as vehicle modification services, may allow people to customize their own vehicles for accessibility, enhancing transportation availability (Friedman, 2024). Currently, very few people with IDD receive vehicle modifications through HCBS, and expanding this option could greatly improve accessibility.

Increase data collection about underserved communities to better understand access challenges.
The small proportion of the surveyed NCI sample who reside in rural areas (2.02%) and small towns (5.20%) or represent BIPOC and Native communities (less than 15% of respondents) show

that there is a gap in knowledge about the experiences of Washingtonians from underserved communities. Increasing outreach and sampling goals to better include underserved populations in data collection will ensure that data-based policy decisions and systems priorities address the needs of people who have less access to reliable, responsive, and quality services. Figure Fifty-Three summarizes policy issues related to increasing service access and availability, evidence-based recommendations for policies, models or initiatives, and implementation examples.

Figure Fifty-Three Issues and Recommendations for Building Workforce Capacity

Policy Issue	Recommendation	What It Looks Like	Implementation
Access to mental health professionals trained in both IDD and behavioral health can be limited, particularly in rural and underserved areas	Telehealth Services (Rosen et al., 2022)	The use of telehealth to facilitate consultations between primary care providers, IDD specialists, and mental health professionals	Expand telehealth services to increase access to specialized care. People receive mental health support without travel barriers or limited local availability
	Mobile Crisis Response Teams (Fix et al., 2023; Watson et al., 2019)	Implementing mobile crisis response teams that specialize in supporting people with co-occurring IDD and mental health needs	Offer in-home or community-based crisis support, reducing the need for hospitalization or institutionalization
The referral process between IDD and mental/behavioral health services is too complex, causing delays in care	Streamlined Referral Processes (Cabral, 2020)	Simplifying the referral process between IDD and mental/behavioral health services to reduce delays in care	Create clear pathways for referrals: shared electronic health records, interagency agreements, etc.
Current supports lack cultural competence or do not represent underserved communities with less access to support	Increase targeted outreach to underserved communities and grow the diversity of the workforce	Engage in targeted outreach and meaningful partnerships within underserved communities to recruit potential professionals and identify access solutions collaboratively	Community outreach, partnership with community organizations, religious groups, traditional healers, etc. to create pathways to accessing supports

Recommendations to Improve Quality of Services and Supports

Focus on building cultural competence of service professionals in the IDD and mental and behavioral health systems

There are opportunities to promote culturally competent services that are sensitive to the needs of all racial and ethnic groups, including training for staff on cultural awareness and the provision of materials in multiple languages. Training programs should include concepts and strategies for embracing cultural competency (building knowledge of others' beliefs, customs, and values) and cultural humility (building relationships in ways that honor the beliefs, customs and values of another person) (Stubbe, 2020; Tervalon & Murray-García, 1998).

Researchers have created a comprehensive framework for developing culturally competent interventions that could inform training and development efforts and curricula (Betancourt et al., 2003). This framework can serve as a road map for designing culturally competent services for people with co-occurring support needs in Washington. Figure Fifty-Four outlines strategies to build three types of cultural competence.

Figure Fifty-Four Strategies for Building Culturally Competent Services

Intervention	Description	Example
Organizational cultural competence	Efforts to ensure that the leadership and workforce of a service delivery system is diverse and representative of its patient population e.g., leadership and workforce diversity initiatives.	DEI recruitment initiatives within the State Departments, systems bureaucrats, academic centers, providers, and educational settings.
Structural cultural competence	Initiatives to ensure that the structural processes of care within a health care delivery system guarantee full access to quality health care for all its patients —e.g., interpreter services, culturally and linguistically appropriate health education materials.	Developing specific quality measures for diverse populations; improving service referral processes; and ensuring culturally and linguistically appropriate health education materials, signage, and health promotion and disease prevention interventions
Clinical cultural competence	Efforts to enhance provider knowledge of the relationship between sociocultural factors and health beliefs and behaviors and to equip providers with the tools and skills to manage these factors appropriately with quality health care delivery as the gold standard — e.g., cross-cultural training.	Equipping providers with knowledge, tools, and skills to better understand and manage sociocultural issues in service provision, including "categorical" or "multicultural" approaches, in which specific information about certain cultures is taught to providers, to a more "cross-cultural" approach, which focuses on the key process issues of supporting service recipients from diverse backgrounds (e.g., communication issues).

Scale up and enhance the skills of service professionals working in agencies that directly support people with co-occurring service needs to provide person-directed services.

In addition to the recommendations outlined above related to enhancing workforce capacity, improving the quality of IDD and mental/ behavioral services that people receive must adopt individualized and person-directed approaches. Service professionals including DSPs, frontline workers, support coordinators, and more would benefit from training that aligns person-centered approaches, self-determination, and best practices in supporting people with IDD who have mental and behavioral support needs. Professionals should be equipped with resources and skills to center people they support in decision making, to help people understand their rights, and to help people make informed decisions. Several training models including comprehensive training from the NADD be adopted and scaled up in Washington. Figure Fifty-Five summarizes policy issues related to increasing culturally competent services, evidence-based recommendations for policies, models, or initiatives, and implementation examples.

Figure Fifty-Five Issues and Recommendations for Increasing Cultural Competence

Policy Issue	Recommendation	What It Looks Like	Implementation
People from underserved communities often receive supports that do not respect or honor their cultural background or traditions	Using the framework outlined above (Bentcourt, 2003) to develop training and information to help people provide culturally responsive supports	Implement cultural competency training and development programs for field professionals	Provide training and education opportunities to professionals that incorporate cultural competence and humility in their roles
The complexity of co-occurring IDD and mental health needs requires a highly individualized approach to care	Individualized Support Plans (Bellegarde et al., 2022)	Support plans should be person-centered, focusing on the unique strengths, preferences, and goals of each person	These plans should include input from the individual, their family, and a multidisciplinary team of professionals to ensure that all aspects of the person's wellbeing are addressed
Involving people with co-occurring IDD and mental health support needs and their families in the decision-making process is crucial for ensuring that services meet their needs	Involvement of people and families (Friedman, 2021)	Empowers people and families to take an active role in managing their health and well-being	Regularly soliciting feedback and incorporating it into service planning and delivery can improve the quality and relevance of care

Recommendations to Reduce Reliance on Institutional Models of Support

For all of the advancements that Washington has made to better support people with co-occurring IDD and mental and behavioral health support needs, the state still relies on and has committed to growing institutional supports that will likely cause people with the highest support needs to remain segregated from their communities and loved ones. Recommendations to reduce reliance on institutional supports require multipronged approaches to build community capacity at the same time as deinstitutionalization efforts occur.

Commit, as a system, to moving away from institutional services
Knowing that institutional services perpetuate exclusion, isolation, and segregation, the state of Washington has an opportunity to discontinue the growth and reduce its reliance on institutional supports for people with IDD who have high mental and behavioral health support needs. Some states have reduced reliance by investing in transformation initiatives, supporting consultants to aid in transitioning people into appropriate community-based supports, and stopping admitting new people into institutional services. Any of these efforts could aid in ensuring that people who have been relegated to institutional supports have opportunities to live fulfilling, included, lives that they control.

Invest in building community service capacity
A few study participants echoed many families of people with disabilities across the country whose loved ones have been failed by or removed from community supports and services. They felt that their loved ones could only live and thrive in institutional settings. Their concerns were exacerbated by previous experiences with low provider capacity, traumatic injuries or neglect due to inexperience or misunderstanding support needs, or service denials. In order for the state of Washington to effectively reduce its reliance on institutional supports, it must invest in growing community capacity. To enhance the impact of the recommendations outlined in the sections above, Washington may consider investing innovation funds in building support capacity for people with IDD who have higher medical and behavioral support needs via expert consultants, paying to implement and grow evidence-based models, enhanced community-based crisis supports, or enhanced rates for more intensive individualized services. Medicaid offices and Managed Care Organizations can also consider rate restrictions for community services that necessitate people utilizing institutional services to access their needed level of support. These types of restrictions disincentivize community providers to serve people with highest support needs if they cannot get approval to fund the level of services needed. Figure Fifty-Six summarizes policy issues related to reducing institutionalization, evidence-based recommendations for policies, models, or initiatives, and implementation examples.

Figure Fifty-Six Issues and Recommendations for Reducing Reliance on Institutional Services

Policy Issue	Recommendation	What It Looks Like	Implementation
Washington continues to rely on institutional services to support many people with co-occurring IDD and mental and behavioral health support needs	Commit to closing or reducing reliance on institutions	State issued order, funding, or support to close institutional services and transition people to their communities	Invest in transformation initiatives, reduce or stop admittance into institutional settings, and commit to not building more and closing institutions in the future
Washington offers limited services for people with high support needs to be appropriately supported in their own communities	Commit to building community capacity to support people with the highest mental and behavioral health support needs	Investment in building capacity to enhance advanced services and reduce restrictions for people with highest mental and behavioral support needs	Invest in innovative supports to grow community capacity to effectively support people with highest support needs, enhance rates or make rate exceptions accessible for people who would traditionally only get level of support needed in institutional settings

Recommendations to Gain Systems Support for Change

Support coordinated efforts in Washington to build leadership and advocacy momentum and pressure to enhance services for people with IDD and mental and behavioral support needs.
While there have been significant advocacy efforts by statewide and local organizations, including SAIL and Allies in Advocacy, additional support for coordinated advocacy in the form of grants, technical support, or collaborative opportunities would enhance advocates' capacity to have their voices heard. Further, supporting advocates to be involved in statewide initiatives, opportunities to testify, and policy planning and decision-making would ensure that the decisions made regarding the integration of IDD and mental and behavioral supports would be informed by people who are most impacted by those decisions. Additionally, leadership roles in the Department of Health, the Developmental Disabilities Administration, and the Behavioral Health Administration for people with co-occurring support needs would ensure that people with lived experiences are involved in shaping policy, setting systems priorities, and supporting recommendations above related to agency coordination, funding innovation, and more. State agencies and departments can create positions that are specifically held for people with co-occurring support needs; they can also review and adapt application requirements and hiring processes to remove barriers for

people with co-occurring support needs, or invest in training and leadership development opportunities that could help people qualify for more leadership roles in state offices.

Hold a collaborative event to bring together stakeholders from across the Washington system to develop systems priorities and plans based on the findings and recommendations from this report This report shows that many efforts may enhance the quality of services available to people with IDD and mental and behavioral health needs. It is important that people with lived experience in the system, including people with disabilities, family members of people with disabilities, disability sector professionals, mental and behavioral health professionals, and systems professionals have an opportunity to consider the recommendations and determine a path forward that is most useful to Washingtonians. It is even more critical that the people involved in determining the next steps include people from traditionally underserved communities so that gaps in service access, availability, and quality can be addressed head-on. A coordinated event that includes an educational component and facilitates strategic planning and buy-in from leaders across the system would move the ideas in this report to actionable next steps for the Washington system. Figure Fifty-Seven summarizes policy issues related gaining support for change, evidence-based recommendations for policies, models, or initiatives, and implementation examples.

Figure Fifty-Six Issues and Recommendations for Gaining Systems Support for Change

Policy Issue	Recommendation	What it Looks Like	Implementation
Advocacy efforts are needed to raise awareness of the unique needs of people with co-occurring IDD and mental health supports needs	Advocacy for Policy Change (Saha, 2021; Pinals et al., 2022)	Support advocates and to collaborate, coordinate, and participate in policy and legislative decisions	Involve self-advocates in policy reform to bridge the gap between IDD and mental health services
		Ensure people with co-occurring support needs have meaningful leadership roles in state agencies and offices	Create positions and decrease barriers to applying for and hiring people with co-occurring support needs
A need for coordinated efforts to determine next steps in advancing mental and behavioral health supports for people with IDD	Create opportunities for collaboration and coordinated decision making across stakeholders	Hold an event for stakeholders across the IDD and mental and behavioral support system to collaborate and determine priorities and next steps for systems change	Provide education about current issues, national and state models and opportunities, and recommendations and facilitate strategic planning sessions to aid participants in determining future plans to enhance IDD and mental and behavioral services

Conclusion

Closing the gaps in the existing system is essential to mitigate the disparities and inequities that disproportionately impact BIPOC, rural, and underserved communities of people with co-occurring intellectual and developmental disability and mental and/or behavioral support needs. Implementing integrated care models, which coordinate IDD and mental health services, can foster collaboration among providers, ensuring that care is coordinated and holistic. By enhancing workforce capacity through cross-training initiatives, we can equip professionals with the necessary skills to understand the complex interplay between IDD and mental health. Furthermore, improving access to support can address geographical barriers, ensuring that timely and appropriate support is available to those who need it most. Enhancing the quality of services offered, and at the same time committing to deinstitutionalization efforts can ensure that community providers have the capacity they need to support people with a range of complex IDD and mental and behavioral health support needs. Finally, investing in systems change efforts can enhance the reach and widespread support for needed change in the Washington systems. Overall, comprehensive and inclusive strategies across systems will lead to better health outcomes and quality of life for people with co-occurring support needs in these communities across the state.

APPENDIX A DETAILED METHODOLOGY OF THE NCI DATA ANALYSIS

Data collection: 2022- 2023 NCI-IDD data for the state of Washington was obtained through a collaboration with the Developmental Disabilities Administration (DDA). Researchers reached out to this state NCI contact and coordinated the data transference.

Data Cleaning and Preparation: The data obtained comprehended 2,525 observation on 494 variables. A sub-sample of the data was prepared for the analysis considering the variables of interest for this research. The subsample used contains 346 observations and 29 variables from five constructs. The variables selected for this analysis are the following:

#	Variable name	Indicator	Constructs
1	METROCAT_21	*Rural/Metro classification based on zip code*	
2	AGE_21	Age at end of survey year	
3	GENDER22	Sex	
4	RACE_21_AMERIN	Race/ethnicity: American Indian or Alaska Native	
5	RACE_21_ASIAN	Race/ethnicity: Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or Other Asian)	
6	RACE_21_BLACK	Race/ethnicity: Black or African-American	
7	BI-4.4 RACE_21_HAWAII	Race/ethnicity: Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)	Background Information
8	RACE_21_WHITE	Race/ethnicity: White	
9	RACE_21_LATINO	Race/ethnicity: Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)	
10	DIAGMR_21	Person diagnosed with ID	
11	OTHDIAG_21_1	Other conditions: Mood disorder (e.g. depression, mania, bipolar disorder, etc.)	
12	OTHDIAG_21_2	Other conditions: Anxiety disorder (e.g. obsessive disorders, panic disorders, etc.)	

13	OTHDIAG_21_3	Other conditions: Behavior challenges (e.g. aggression, self-injurious behavior, pica, etc.)	
14	OTHDIAG_21_4	Other conditions: Psychotic disorder (e.g. schizophrenia, hallucinations, etc.)	
15	OTHDIAG_21_5	Other conditions: Other mental illness/psychiatric diagnosis	
16	MEDS_21	Person takes medications for mood, anxiety, and/or psychotic disorders	Health
17	MEDBEHAV_21	Person takes medications for behavioral challenges	
18	BEHPLAN_21	Person currently has a behavior plan	
19	SELFINJ_21	Self-injurious behavior	Behavioral Support Needs
20	DISBEH_21	Disruptive behavior	
21	UNCPBEH_21	Behavior that is destructive or harmful to others	
22	STAFFCULTURE_21	Are your staff respectful of your culture? This can be things like respecting your religion, your beliefs, the food you prefer, or the holidays you celebrate.	Staff
23	STAF_21	Do your staff treat you with respect?	
24	STAFFLANG_21	Can you talk or communicate with your staff in your preferred language?	
25	ADDSERVED_21_7	Do you want help with…: Finding or getting more reliable transportation – being able to have a way to always get places you want or need to go	
26	ADDSERVED_21_8	Do you want help with…: Getting or using technology to help in your everyday life to do more things on your own (like apps to get around, alerts to remind you of things to do like take medication)	Access to Needed Services / Supports
27	ADDSERVED_21_9	Do you want help with…: Healthcare – finding a doctor, making appointments	

28	ADDSERVED_21_10	Do you want help with...: Understanding medication – what medication is used for, side effects, how to take medication	
29	ADDSERVED_21_11	Do you want help with...: Finding, getting or setting up behavioral or mental health supports – like being able to meet with a therapist or counselor	

Data analysis: Secondary data set analysis was performed on the data shared by the developmental disabilities administration. Data tabulations were performed through descriptive analysis to identify basic demographics and service distribution. Crosstabulation was also conducted to explore service allocation for observations corresponding to people that indicated cooccurring support needs. Statistical cross tabulations of self-identified people with cooccurring support needs were performed for constructs of *Staff* and Access *to Needed Services / Supports*.

APPENDIX B STATEWIDE SURVEY PARTICIPANT DEMOGRAPHICS

Data from people with co-occurring support needs who completed the survey themselves was combined with data from caregivers of people with co-occurring support needs to complete "Person with Co-Occurring Support Needs" profiles.

"Caregiver of Person with Co-Occurring Support Needs" shows the demographic information for caregivers of people with co-occurring support needs who responded to the survey.

Variable	Caregiver of a Person with Co-Occurring Support Needs		Person with Co-Occurring Support Needs	
	n	%	n	%
Gender				
Male	50	20.4	139	44.1
Female	185	75.5	153	48.6
Non-Binary/Third Gender	2	0.8	8	2.5
Other			5	1.6
I Would Prefer Not to Answer	8	3.2	10	3.2
Age				
Under 18*			9	2.9
18-21	3	1.2	44	14.2
22-34	34	13.8	120	38.7
35-44	46	18.7	76	24.5
45-54	63	25.6	32	10.3
55-64	55	22.4	19	6.1
65 or Older	45	18.3	10	3.2
Race/Ethnicity				
American Indian or Alaska Native	8	3.3	7	2.9
Asian	6	2.5	10	4.2
Black or African American	20	8.2	26	11.4

Hispanic or LatinX	15	6.2	17	7.2
Native Hawaiian or Other Pacific Islander	5	2.1	2	0.9
White	166	68.3	163	69.1
I Would Prefer Not to Answer	19	7.8	10	4.4
Primary Language				
English	231	94.2	290	91.5
Spanish	6	2.5	9	2.8
Chinese	1	0.4	2	0.6
Vietnamese			0	0.0
Tagalog	1	0.4	1	0.3
Russian	2	0.8	0	0.0
Korean	1	0.4	2	0.6
Amharic, Somali, or Other Afro-Asiatic Languages			1	0.3
Hindi			0	0.0
Other	3	1.2	12	3.8
Home Location				
Urban	62	25.7	130	41.0
Suburban	91	37.8	117	36.9
Rural	88	36.5	70	20.1
County**				
Adams			5	1.3
Asotin			1	0.3
Benton			8	2.0
Chelan			6	1.5
Clallam			10	2.5
Clark			18	4.6
Columbia			7	1.8

Cowlitz	5	1.3
Douglas	1	0.3
Ferry	1	0.3
Franklin	5	1.3
Garfield	3	0.8
Grant	5	1.3
Grays Harbor	6	1.5
Jefferson	0	0.0
King	89	22.6
Kitsap	13	3.3
Kittitas	1	0.3
Klickitat	1	0.3
Lewis	1	0.3
Lincoln	0	0.0
Mason	8	2.0
Okanogan	4	1.0
Pacific	3	0.8
Pend Oreille	0	0.0
Pierce	34	8.6
San Juan	1	0.3
Skagit	8	2.0
Skamania	0	0.0
Snohomish	47	11.9
Spokane	48	12.2
Stevens	6	1.5
Thurston	20	5.1
Walla Walla	4	1.0
Wahkiakum	0	0.0

Whatcom			11	2.8
Whitman			3	0.8
Yakima			9	2.3
Region*				
1			118	30.0
2			158	40.1
3			118	30.0
Live on an Indian Reservation*				
Yes			19	4.8
No			376	95.2
Highest Education Level				
Some High School	48	19.6	56	18.0
High School/GED	32	13.1	125	40.2
Trade or Vocational Degree	14	5.7	12	3.9
Some College	48	19.6	28	9.0
Associate's Degree	24	9.8	17	5.5
Bachelor's Degree	58	23.7	31	10.0
Master's Degree	48	19.6	8	2.6
Doctoral Degree	6	2.5	2	0.6
I Prefer Not to Answer	7	2.9	32	10.3
Employment Status				
Full-Time	116	47.9	46	14.6
Full-Time and Have an Additional Part-Time Job	19	7.9	12	3.8
One Part-time Job (no full-time job)	32	13.2	56	17.8
More Than One Part-Time Job (no full-time job)	11	4.5	6	1.8

Full-Time Student (more than 18 years old)	-	-	12	3.8
Unemployed and on Disability	8	3.3	75	23.8
Unemployed	18	7.4	64	20.3
Unemployed and Retired	24	9.9	11	3.5
Other	14	5.8	33	10.5
Household Income				
$0-10,000	17	7.1	113	36.1
$10,001-20,000	15	6.3	66	21.1
$20,001-30,000	12	5.0	27	8.6
$30,001-40,000	26	10.9	11	3.5
$40,001-50,000	17	7.1	9	2.9
$50,001-60,000	15	6.3	8	2.6
$60,001-70,000	18	7.5	9	2.9
$70,001-80,000	18	7.5	10	3.2
$80,001-90,000	10	4.2	4	1.3
$90,001-100,000	15	6.3	7	2.2
$100,001-200,000	30	12.6	2	0.6
$200,001-300,000	8	3.4	0	0.0
$300,001-500,000	2	0.8	0	0.0
More than $500,000	-	-	1	0.3
I Don't Know	4	1.7	19	6.1
I Prefer Not to Answer	32	13.4	27	8.6

*An "Under 18" response option was mistakenly left off the survey until it was identified after the survey had been open for responses for a few weeks

**Data related to caregivers' locations was not collected

Differences Between Disability and Mental Health Service Accessibility

People in Washington with co-occurring IDD and Mental and/or Behavioral Health support needs said these things in a 2024 survey about the differences between about the services they receive:

RESULTS SHOWED IMPORTANT DIFFERENCES BETWEEN IDD SERVICES AND MENTAL HEALTH SERVICES:

IDD SERVICES

MH SERVICES

People felt their **IDD SERVICE PROVIDERS** *respected their cultural background*, religion, and/or values *more than* their **MENTAL AND BEHAVIORAL HEALTH PROVIDERS**

People felt their **IDD SERVICE PROVIDERS** *aligned with their cultural* background, religion, and/or values *more than* their **MENTAL AND BEHAVIORAL HEALTH PROVIDERS**

People felt that it was *easier to find information* about **IDD SERVICES** *more than* **MENTAL AND BEHAVIORAL HEALTH SERVICES**

People were more *concerned about being denied* **MENTAL AND BEHAVIORAL HEALTH SERVICES** because of their disability support needs than *being denied* **IDD SERVICES** because of their mental health needs

IN GENERAL, ABOUT 1 OUT OF 3 PEOPLE ARE UNHAPPY WITH THE SERVICES FOR THEIR CO-OCCURRING NEEDS:

35% rated the *quality* of their **IDD services** were *Fair or Bad*

37% rated the *quality* of their **Mental or Behavioral Health** was *Fair or Bad*

31% rated their *overall satisfaction* of their **IDD services** was *Fair or Bad*

36% rated their *overall satisfaction* of their **Mental or Behavioral Health** services was *Fair or Bad*

30% said that their Disability providers and Mental or Behavioral Health provider do not communicate with each other

29% said that their Disability provider and Mental or Behavioral Health provider do not work well together

This infographic shows results from a 2024 web-based survey about the experiences of 398 Washington residents with co-occurring support needs. More key findings can be found at **www.natleadership.org/reports**.

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

WADDC

Historically Underserved People with Co-Occurring Support Needs Have More Challenges Getting and Keeping Services

People in Washington who belong to a historically underserved or minority population (for example, Black, Indigenous, and People of Color (BIPOC), people who live in a rural area, people who live on an Indian Reservation, low-income people, LGBTQ+, etc.) said these things in a 2024 survey about getting and keeping IDD and Mental and Behavioral Health services:

Compared to the general population, people from historically underserved or minority populations are:

ACCESSIBILITY OF SERVICES

AFFORDABILITY — About **2.8 times more likely** to say that **IDD** services are "Somewhat" or "Very" Expensive

DISTANCE — Only about **16%** said their services were a "Very Easy" distance away

SCHEDULING — About **2 times more likely** to say that scheduling **IDD** appointments is "Somewhat" or "Very" Hard

About **2.1 times more likely** to say that scheduling **Mental/Behavioral Health** appointments is "Somewhat" or "Very" Hard

TRANSPORTATION — It was "Somewhat" or "Very" hard to get transportation to their services

CULTURAL COMPETENCY

3.1 times more likely to say that **IDD** providers only respect their culture, religion, and values "A Little Bit"

3.5 times more likely to say that **Mental/Behavioral Health** providers only respect their culture, religion, and values "A Little Bit"

2.2 times more likely to say that **IDD** services are only "Sometimes" available in their preferred language

4.9 times more likely to say that **Mental/Behavioral Health** services are only "Sometimes" in their preferred language

RISK OF INSTITUTIONALIZATION

3.0 times more likely to experience institutionalization once because community-based supports were not available

2.6 times more likely to experience institutionalization more than once because community-based supports were not available

2.6 times more likely to be "Very Concerned" about institutionalization because community-based supports were not available

42% less likely to rate their IDD services as "Excellent"

51% less likely to rate their Mental Health services as "Excellent"

Results in this infographic showed statistically significant differences between people who identified as underserved (n=164) from other respondents (n=201) of the survey. More key findings can be found at **www.natleadership.org/reports**.

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

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