Utah Mental Health and Intellectual and Developmental Disabilities (MHIDD): Needs and Challenges

Prepared by the Institute for Disability Research, Policy & Practice

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List of Figures

Acronyms and Terminology

Throughout this report, several acronyms are used for ease of reading and continuity of the text. These acronyms, using terminology chosen intentionally, are described below:

IDD: Intellectual and Developmental Disability

Intellectual and developmental disability (IDD) is an umbrella term that includes a variety of disability diagnoses. Specifically, IDD in this report refers to disability diagnoses that occur during developmental periods and may include either or both intellectual and physical impairments.

MHP: Mental Health Provider

Mental health providers (MHPs) referred to in this report are individuals who are licensed to provide mental health services in the state of Utah.

DSP: Disability Service Provider

Disability service providers (DSPs) in this report include any professionals who work in the disability service system with adults (18+ years of age) with developmental disabilities.

MHC: Mental Health Concern

In this report, the term mental health concern (MHC) is used to refer to any mental health related concern, including self-reported and diagnosed, regardless of clinical intensity. Several other terms are often used to refer to mental health (e.g., serious mental illness, mental health issue). Mental health concerns (MHCs) is the term used here to be inclusive of a broad spectrum of mental health related concerns.

PWD: People with Disabilities

The language used to talk about disability has evolved over time. Currently, there is discussion among disability self-advocates regarding person-first (i.e., "person with down syndrome" rather than "a down syndrome person) language and labelling; some individuals with autism prefer to be called autistic while others prefer the person-first approach. In this report, we use a general person-first approach with the term "people with disabilities" to refer to an aggregate group of individuals with IDD.

Executive Summary

The Utah Mental Health and intellectual and Developmental Disabilities (MHIDD) Training Project is a National Training Initiative (NTI) funded through the U.S. Administration on Community Living (ACL). During this 5-year project, the Utah State University (USU) Institute for Disability Research, Policy & Practice (IDRPP) will develop and implement a coordinated, culturally responsive, trauma-informed cross-systems training plan to increase the capacity of direct support professionals and case managers/support coordinators to meet the mental health needs of individuals with mental health concerns (MHC) and intellectual and developmental disabilities (IDD) in Utah. The first phase of this project is to conduct a "landscape analysis" of current systems and processes in Utah that support the mental health of individuals with intellectual and developmental disabilities.

Results from this landscape analysis are consistent with national estimates and show that approximately 50% of the people with a disability (PWD) who participated in this study reported experiencing one or more symptoms of anxiety, depression, or other mental health concern (MHC). The findings of this analysis emphasize the need for this work. This report will cover the findings of the landscape analysis based on quantitative and qualitative data collected from mental health providers (MHPs), family members and caregivers, PWD, and disability service providers (DSPs). While the primary purpose of this project is to increase the capacity of direct support professionals and case managers/support coordinators, landscape analysis results indicated a need for a collaborative approach to providing education and training to both DSPs and MHPs, which we discuss in recommendations and next steps.

Introduction

Background and Context

An awareness that people with intellectual and developmental disabilities (IDD) also experience MHCs or serious mental illness (e.g., depression, anxiety, schizophrenia, bipolar disorder etc.) is relatively new. Today, it is generally accepted that people with IDD can experience the same range of MHC experienced by people without IDD, but individuals with cooccurring MHC and IDD face significant barriers to receiving quality mental health services, experience difficulties living in the community, and tend to experience especially high rates of abuse, neglect, and criminal victimization. These experiences negatively impact individuals with MHC and IDD and their families, and lead to additional health disparities and negative health outcomes. These factors make it especially urgent that states develop coordinated systems of care and social support that can address the needs of this specific population.

One of the primary challenges to diagnosing MHCs in individuals with IDD is the wide variety of conditions or impairments that can affect this population. The National Institutes of Health (NIH) defines IDD as “differences that are usually present at birth and that uniquely affect the trajectory of the individual’s physical, intellectual, and/or emotional development” (Office of Communications, 2021). Developmental disabilities may include an intellectual disability but also includes physical disabilities; all intellectual disabilities are considered developmental disabilities, but not all developmental disabilities include intellectual disability. All developmental disabilities occur before age 22 and have life-long implications for the affected individual. Developmental disabilities can be the result of congenital conditions but may also be the result of an injury or illness. For example, cerebral palsy, spina bifida, muscular dystrophy, blindness and/or deafness are examples of developmental disabilities that primarily result in physical impairments but do not necessarily include intellectual impairment; whereas conditions like Down Syndrome, fetal alcohol syndrome, Fragile X syndrome primarily result in intellectual impairments but may also include physical impairments. Conditions like learning disabilities, epilepsy, attention deficit hyperactivity disorder, and autism spectrum disorders are examples of developmental disabilities that have cognitive effects, but do not necessarily result in an intellectual impairment. Injuries such as a traumatic brain injury, spinal cord injuries, lead poisoning or other injuries that result from environmental exposure to toxic substances that occur prior to the age of 22 are examples of acquired developmental disabilities. The wide variety of conditions that may be classified as intellectual or developmental disabilities, and the diversity of effects lead to an especially complex set of diagnostic and treatment considerations for clinicians to consider.

Commonly accepted estimates of prevalence of IDD in the general population are 1% (Boyle et al., 2011; Maulik et al., 2011), with commonly accepted estimates of the prevalence of IDD and co-occurring MHC range between 30% and 50% (Adams & Matson, 2015; Einfeld et al., 2011). Individuals specifically with intellectual disabilities may experience significant limitations in cognitive functioning (e.g., problem solving, judgment, abstract thinking) and adaptive skills (e.g., communication, social skills, activities of daily living) (Fletcher et al., 2017; Schalock et al., 2009) that make an accurate diagnosis of mental health conditions via traditional clinical interviewing or diagnostic protocols difficult.

Purpose of the Landscape Analysis

This landscape analysis generated data that paints a picture of the multiple systems in the state that serve PWD and co-occurring MHC and identifies the supports that are working well, areas for improvement, and specific targets for focused training efforts. The primary purpose of this landscape analysis was to:

1. Evaluate the efficacy and impact of the **current disability service system** with regards to supporting the mental health needs of individuals with IDD.
2. **Identify current gaps** in mental health support for individuals with IDD.
3. **Identify training needs** to help build the capacity of service providers to support the mental health of individuals with IDD.

Study Methodology

The study methodology included primary data collection through online surveys, interviews, and focus groups, as well as the use of existing data from Utah's Behavioral Risk Factor Surveillance System (BRFSS) database. Data from all data sources were aggregated and analyzed by the project team using the appropriate quantitative and qualitative methodologies to obtain a comprehensive picture of the MHC and IDD landscape in the state of Utah.

The online surveys were created using Qualtrics in both English and Spanish, and participants were directed to the appropriate set of questions based on their role in the disability service role (PWD, family member/caregiver, DSP, MHP etc.). The survey questions were primarily multiple choice, with a few allowing for open-ended text responses. This survey was available online we offered to assist individuals in completing the survey if they requested it.

The survey data gathered for this project were supplemented by interviews and focus groups to provide more in-depth qualitative data. Interviews and focus groups were conducted online using Zoom and recorded for transcription and analysis. Interview participants were selected from a list of key stakeholders, while focus group participants self-selected through the survey and social media. The questions asked in the interviews and focus groups focused on barriers to supporting the mental health needs of adults with developmental disabilities in Utah, knowledge of innovative work being done, and policy changes that could be helpful.

Participant recruitment occurred through a variety of media, including existing email lists, contact referrals, social media, and snowball and convenience sampling through key contacts. Convenience and snowball sampling is a non-probability sampling method that involves selecting participants who are easily accessible and readily available for a study. While this method is convenient and cost-effective, it has several limitations.

First, the sample obtained through convenience sampling may not be representative of the entire population, as it may not include individuals who are difficult to reach or who may have different characteristics from those who are accessible. This can lead to biased results and limit the generalizability of the findings. Second, convenience sampling may result in a self-selection bias, where individuals who are more motivated or interested in the topic may be more likely to participate, leading to skewed results. Finally, convenience sampling may not allow for the calculation of statistical measures, such as sampling error or confidence intervals, which are necessary to determine the accuracy and reliability of the results.

Overall, while convenience sampling can be useful it does have limitations and potential biases. As a result of this approach to participant recruitment we cannot definitively state that our sample is representative or balanced. Although the study included a sizeable number of participants ($N = 1{,}207$), it is important to note that all results should be viewed as a broad snapshot of patterns, trends, and potential issues, not a definitive epidemiology. Copies of the survey instruments, interview questions, and focus group protocols are available for review and use by contacting project staff.

Utah Prevalence Data

Data from the Utah Behavioral Risk Factor Surveillance System (BRFSS) shows that approximately 1 in 4 adults (25%), almost half a million (573,350), in Utah are living with a disability (Centers for Disease Control and Prevention [CDC], 2023a). These numbers are consistent with national prevalence data on disability. Of these adults with disabilities, the most reported disability types were cognitive (13%) and mobility (9%), followed by hearing (6%), independent living (7%), vision (3%), and disabilities that impact self-care (2%; CDC, 2023a).

Importantly, BRFSS data regarding mental and emotional health indicates that the percent of people with disabilities who report poor physical or mental health is significantly higher than the percent of people without disabilities. Nearly half (49%) of Utah adults with disabilities report experiencing depression, compared with 17% of adults without a disability (CDC, 2023a). When asked to report on mental health over the past 30 days, 38.8% of Utah adults with disabilities reported experiencing more than 14 days of poor mental health, compared with 10.4% for adults without a disability (CDC, n.d.). Additionally, BRFSS data indicates that adults with disabilities in Utah are more likely to experience costly adverse health conditions and less likely to access essential preventive healthcare services (CDC, n.d.).

Stakeholders, including family members/caregivers, policymakers, DSPs, and MHPs, have recognized the need for increased efforts at addressing mental health needs of individuals with IDD. Groups across the state of Utah have begun working towards improved access to mental health and disability services, including legislation (e.g., the Disability Ombudsman Program [Division of Services for People with Disabilities [DSPD], n.d.], House Bill 248 [Kim, 2023], the new 988 crisis line [University of Utah Health, 2022]), and surveys exploring the needs of direct support professionals (Utah Department of Health & Human Services [UDHHS], 2022). However, these approaches have primarily been siloed within the separate, but parallel, divisions of disability and mental health services. There is a marked lack of coordination between the disability and mental health service divisions within the Utah Department of Health and Human Services (UDHHS). While progress has been made within these siloes, there is a growing concern that the intersection of mental health and IDD requires a more focused and intentional effort on the part of state program staff, service providers, clinicians, community organizations, families, and individuals with co-occurring IDD and MHC to develop coordinated and comprehensive programs to support the needs of this population.

Survey Data Analysis Results

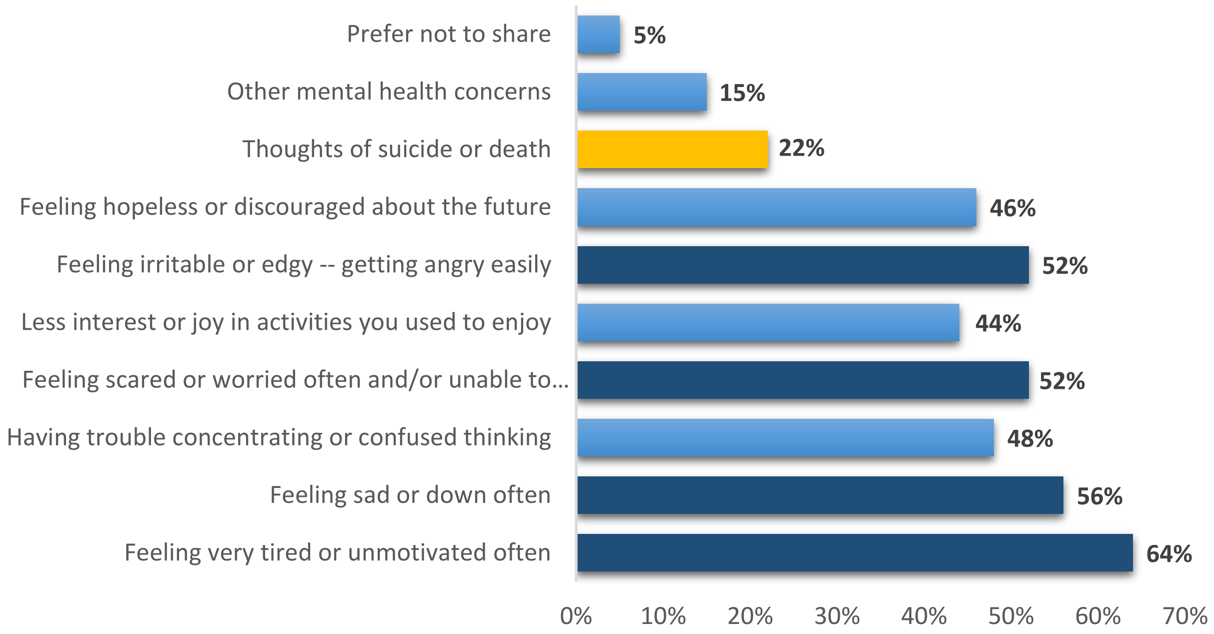
This summary provides an overview of self-reported MHC faced by individuals with IDD in Utah. We also examine the current issues related to the availability and quality of disability and mental health services for individuals with IDD and some of the gaps and potential challenges in the provision of these services. The research team collected information from four targeted groups: (1) PWD (*N* = 91), (2) Family members/caregivers of people with disabilities (*N* = 564), (3) DSPs (*N* = 192), and (4) MHPs (*N* = 360). This data summary will provide selected findings about disability and mental health services in the state of Utah for individuals with co-occurring IDD and MHC. This is not a comprehensive overview of all the survey results, only the findings that were deemed significant based on a review by the research team and project advisory board. A comprehensive summary of the results for each survey item is available upon request from the project team.

People with Disabilities and Mental Health Concerns

PWD who participated in the survey were provided with a list of mental health concerns and asked which of them, if any, they experienced. As highlighted in Figure 1, 50% of PWD reported experiencing symptoms representative of anxiety or depression. Furthermore, 22% of respondents reported thoughts of suicide or death.

Figure 1

Mental Health Concerns by Percentage as Reported by People with Disabilities (n=84)



It is generally accepted that approximately 50% of PWD in the U.S. experience co-occurring mental health concerns. This data from Utah is consistent with national estimates on the prevalence and severity of MHC among PWD (Bradley et al., 2019). It is important to note that thoughts of suicide or death are much higher among the individuals with disabilities who responded to this survey than the typical population. The most recent estimates from the CDC indicate that approximately 4.3% of the adult population in the U.S. reported having had suicidal thoughts during the preceding year (Ivey-Stephenson et al., 2022). This percentage is slightly higher in the Western region of the U.S. (4.8%), but even that number is significantly less than the prevalence reported by PWD through this study (22%). This finding is a clear indicator of mental health concerns for this population, although this finding is slightly lower than national estimates of suicidal ideation among individuals with disabilities (30.6%; CDC, 2023b).

The survey also asked PWD to report on whether they had received a formal mental health diagnosis. Results showed that 78% of respondents (n=76) had received a mental health diagnosis. This is slightly higher than national estimates of mental health diagnoses among individuals with disabilities in the U.S. which vary between 44% and 51% (Bradley et al., 2019). This data from the National Core

Indicators dataset indicates that the diagnosis rate is directly correlated with age, meaning that the older an individual with IDD, the more likely it is that they have a psychiatric diagnosis. The fact that this survey reports a higher proportion of individuals with a mental health diagnosis may reflect a sample bias; meaning that individuals with co-occurring MHC and IDD were more likely to complete this survey than those without. It is also important to note that COVID-19 had an impact on MHCs for PWD. PWD respondents (*n* = 65), 72% reported that their mental health concern began or got worse during the COVID-19 pandemic.

This finding is consistent with national trends that indicated that mental health concerns dramatically increased across all populations in the U.S. during the COVID-19 pandemic. National estimates indicate that 30%-50% of the typical population saw an emergence or increase in MHC during the pandemic (Blanchflower & Bryson, 2022). The results from this survey indicate that adults with disabilities in Utah experienced much higher rates of mental health concerns than the typical population.

People with Disabilities and Access to Mental Health Services

The survey asked PWD and family members/caregivers whether they felt that mental health was prioritized enough by DSPs. Answers from PWD and family members/caregivers varied, but generally indicated that PWD and family members/caregivers both perceive that mental health was not a significant priority for the DSPs that they worked with or received services from.

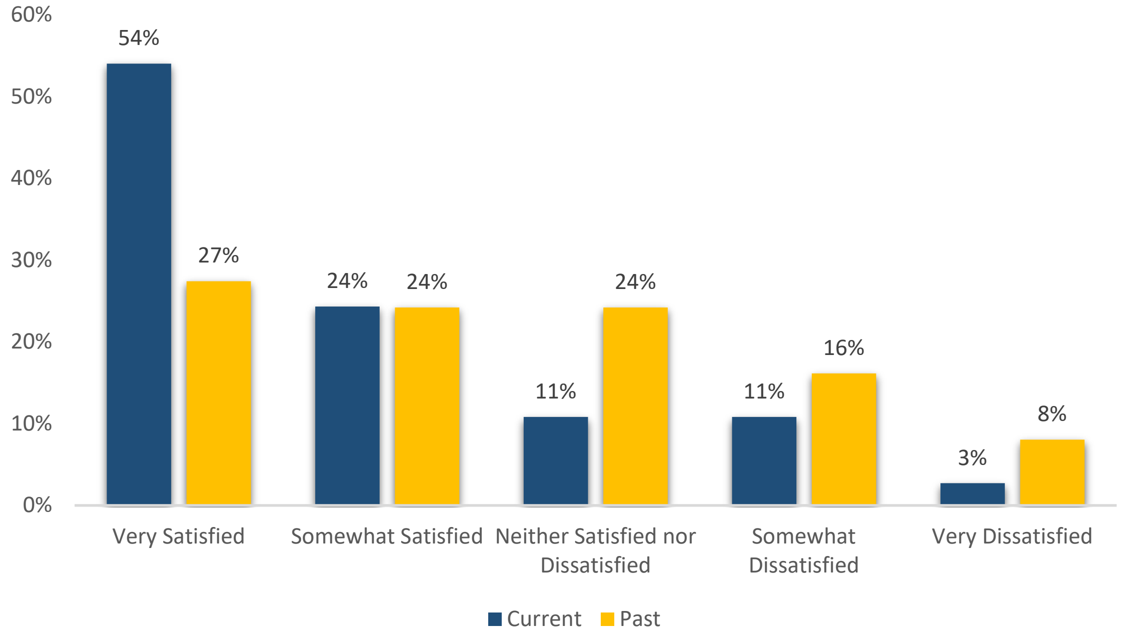
The survey also asked PWD to report on their current and past access to mental health services. Respondents with disabilities indicated that 46% (*n* = 80) were currently receiving mental health services, and that 79% (*n* = 78) had received mental health services in the past.

Although there are not consistent or reliable numbers on access to mental health services for PWD nationwide, these numbers are higher than we anticipated. Existing data seems to indicate that many PWD, especially those with IDD, face barriers in accessing mental health services (Whittle et al., 2019). Additionally, the data later in this report shows that many MHPs do not feel that they have the training to meet the needs of the population of individuals with IDD. Therefore, as with earlier items in this survey, the fact that our data was higher than anticipated may indicate that the PWD and family members/caregivers who responded to this survey were more aware and attuned to mental health care options and, therefore, do not constitute a representative sample.

The survey asked how satisfied PWD are with previous and current mental health services. Figure 2 indicates a higher level of satisfaction with the services PWD are receiving now compared with mental health services they had received in the past.

Figure 2

PWD Satisfaction with the Mental Health Services they are Currently Receiving (n = 37) vs. in the Past (n = 62)



PWD report having more mental distress and having significantly higher adjusted odds of dissatisfaction of mental health services compared with people without disabilities (CDC, 2023; Iezzoni et al., 2002). In this survey we see lower levels of dissatisfaction with current service experiences rather than past service experiences. Many factors can be associated with these reported changes including improved awareness of the complexity of disabilities and mental health as well as improved systems in place. This reported increased satisfaction with current mental health services is a potential indicator of an increase in quality in service delivery.

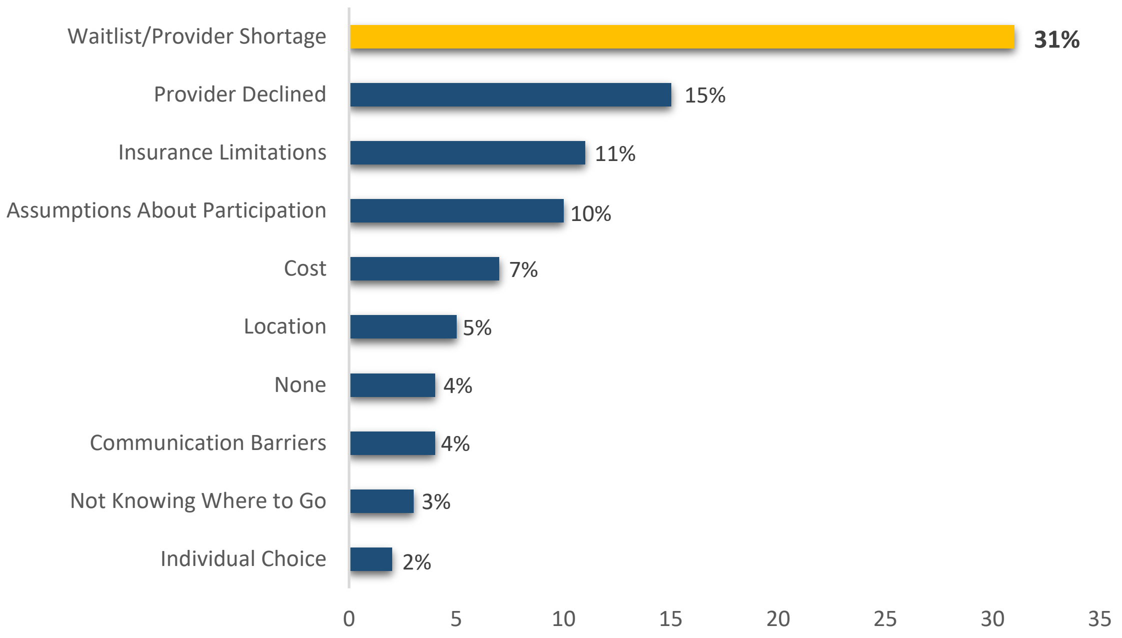
Family Members/Caregivers and Access to Mental Health Services

There are a variety of barriers that prevent PWD from accessing the mental health services they need (Alvarado Parkway Institute, 2022). Some of the most common barriers include limited financial resources, lack of adequate insurance coverage, challenges in communication and transportation, experiences of discrimination, and lack of knowledgeable providers. These national reported barriers align with results from our survey.

Our survey asked family members/caregivers of PWD to report on challenges they have experienced with accessing mental health services for their family member(s) with IDD. A total of 202 family members/caregivers answered this question, with the majority indicating that the greatest obstacle was a shortage of providers or long waitlists to get into a qualified provider (see Figure 3).

Figure 3

Percentage of Responses Addressing Listed Topics in Accessing Mental Health Services for a Family Member with a Disability (n = 202)



One of the most significant barriers to mental health care for people with disabilities is the lack of knowledgeable providers. Many MHPs are not adequately trained to work with PWD. Therefore, many providers might limit the availability and/or may not be willing to serve PWD. In addition, financial resources are another factor to consider as it is related to insurance limitation, service costs, and service location barriers. Of our survey's MHP respondents, 49% (n=340) reported that they do not accept medical assistance programs such as Medicaid. On a national level, even as Medicaid access expands, fewer psychiatrists accept Medicaid (Carroll, 2019). Furthermore, people with disabilities experience a far greater poverty rate than those without disabilities (Paul et al., 2020). Thus, even if PWD can find adequate mental health care, they may not be able to afford it.

The survey also asked family members/caregivers of individuals with IDD if they knew where to go for mental health services if needed. Two out of three family members/caregivers who responded to the survey reported that they did not know where to take their family member for mental health services if needed. Finding a local mental health provider with adequate experience and training is certainly challenging. Training on IDD is not currently a required part of psychiatric residencies, and many mental health providers have not had experience working with the IDD community (Margolis, 2021).

The findings from family members with relation to accessing mental health supports for their family member with IDD indicate that there is a significant shortage of MHPs who are willing to serve this population, and that there is a general lack of awareness among family members regarding the resources available to support the mental health of their loved one with IDD.

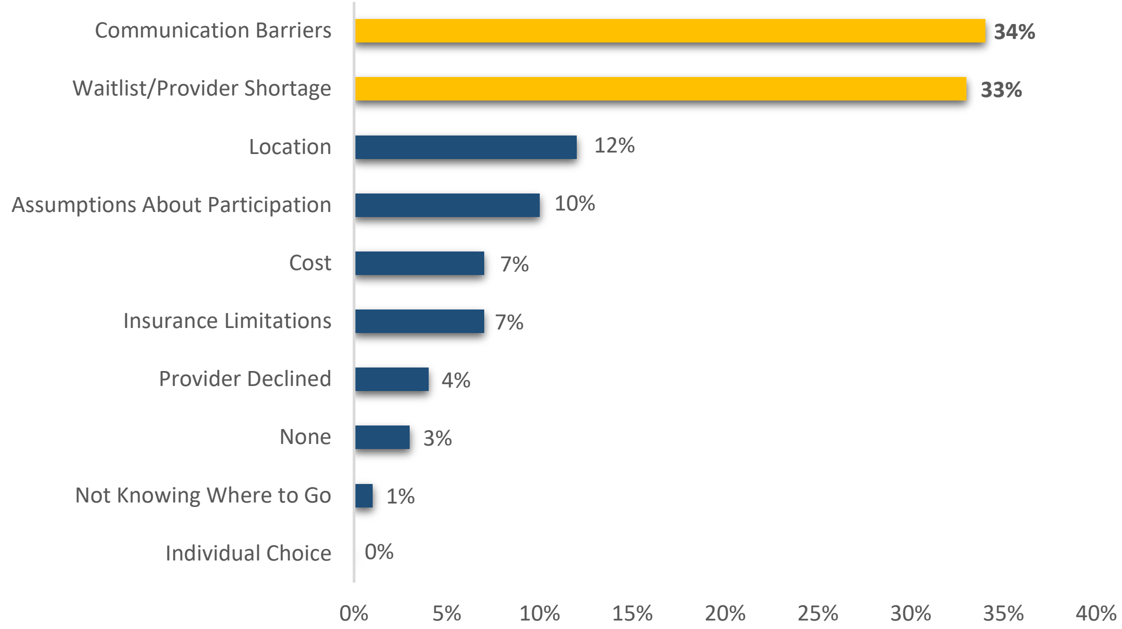
MHPs and Provision of Services for People with Disabilities

A total of 349 MHPs responded to our survey. Each of the MHPs were asked to identify their licensure type. Respondents were primarily social workers (53%) and clinical mental health counselors (20%), followed by marriage and family therapists (11%), psychologists (8.6%), and "other" (7.5%).

The MHIDD survey asked MHPs if they had ever provided mental health services for a person with a developmental disability. The 279 MHPs who indicated yes were then asked what challenges, if any, they had experienced in providing mental health services to people with developmental disabilities (see Figure 4). Responses were provided in an open-ended format. Examples of accessibility, communication or language barriers, and explanation of topics were provided at the end of the question. A total of 208 MHPs provided answers, with the majority reporting communication barriers and waitlists/provider shortages as challenges. It is important to note that, for the purposes of this report, the category "communication barriers" includes any response that mentioned communication and/or communicating. For example, one answer was "difficulty communicating therapy techniques," and another was "explanation of topics." The communication barriers category also encompasses language barriers.

Figure 4

Percent of Responses Identifying Related Challenges MHPs Experienced When Providing Mental Health Services to PWD (n=208)



Survey data highlighted perspective differences among family member and caregiver responses compared with MHP responses regarding barriers faced in accessing services. For family members/caregivers, the communication barriers were at the bottom of their worries; however, for MHPs it is at the top of the barriers. PWD may experience difficulty communicating their needs to others. If a provider feels that they are unable to communicate effectively with their client, they likely will not feel confident in their ability to provide services.

MHPs who indicated that they had provided services for PWD before were also asked if they were *currently* providing mental health services to a person with a developmental disability. Responses showed that 1 out of 3 MHPs (*n* = 278) who had provided services for PWD in the past were not currently providing mental health services to PWD, indicating a reduction of the number of providers working with PWD. Importantly, MHPs who had previously provided services to PWD reported being much more comfortable recognizing mental health concerns in PWD. Additionally, most (*n* = 321, 78%) of the MHPs who had ever received training on working with PWD reported feeling comfortable identifying MHCs among PWD.

Many service providers do not feel competent in serving this population (Whittle et al., 2019). Historically, MHCs have been overlooked and underdiagnosed in people with IDD as symptoms have been falsely attributed to disability-related behaviors (i.e., diagnostic overshadowing). Also, a lack of targeted education in working with PWD has led to students feeling ill-prepared to diagnose or work with people with IDD (Bean & Hedgpeth, 2014; Dykens, 2016; Graesser, 2014). Only 64% (*n* = 321) of MHP respondents to our survey reported that they had received training about cooccurring MHC and IDD. In addition, most of the MHPs (*n* = 319, 85%) felt that college education did not provide enough information on working with PWD. Individuals with MHC and IDD and their families also report feeling uninformed and frustrated with service providers (Alexander & Schmid, 2019). Statewide surveys conducted by the Utah University Center for Excellence in Developmental Disabilities (UCEDD) highlight service gaps and training needs. For example, a 2018 State of Utah survey of service providers and family members indicated the need for more services and supports for individuals with MHC and IDD, a lack of service providers available, and the need for increased training for behavioral health providers who serve people with IDD (USU Center for Persons with Disabilities, 2018). Another multi-year UCEDD needs assessment (2017-2019) focused on health disparities in Utah found mental health services and supports was a primary gap in the current IDD service system, especially in rural areas (USU Center for Persons with Disabilities, 2019. Finally, a 2021 needs assessment focused on abuse and neglect. Utah's Adult Protective Services (APS) program found inadequate supports and services in Utah to address MHCs of vulnerable adults in Utah, many of whom have IDD (USU Center for Persons with Disabilities, 2021).

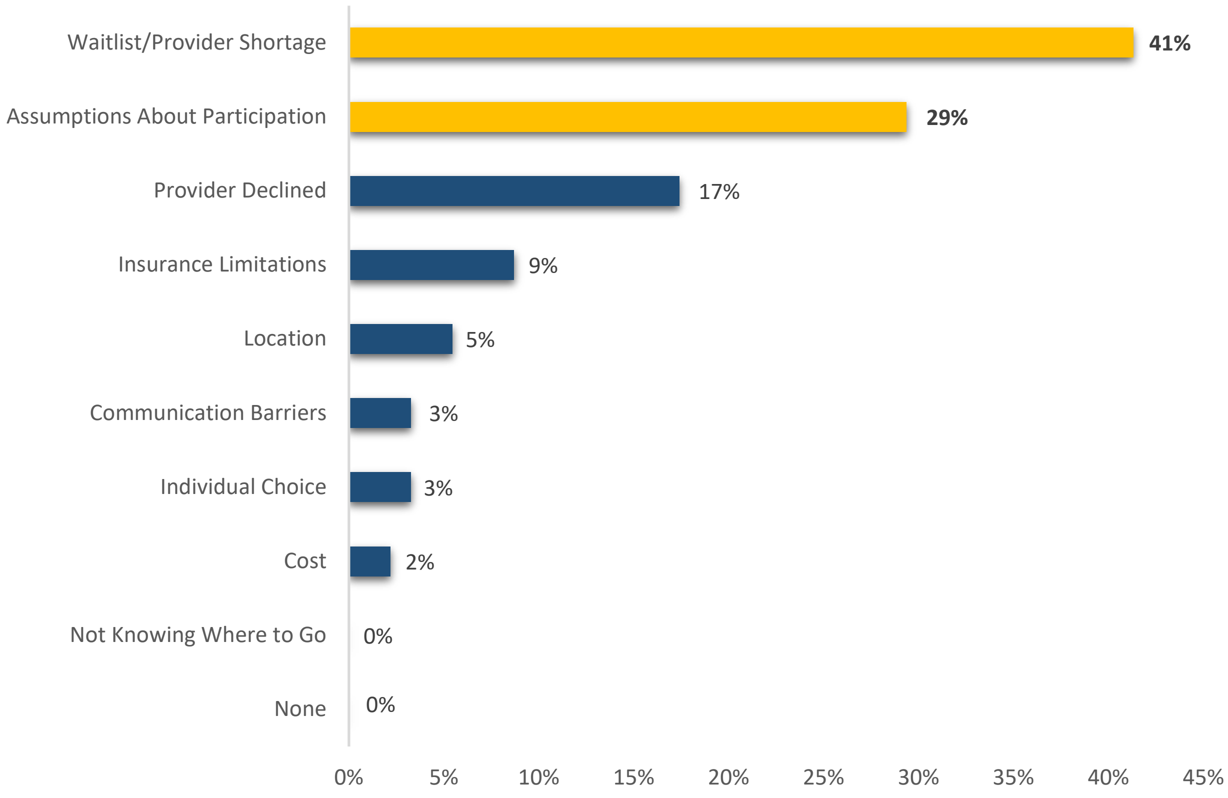
Communication and collaboration among service agencies are additional critical factors that are needed to improve services and maximize available limited resources. Many examples of best practice models have demonstrated its effectiveness (Bauer et al., 2019; Reist et al., 2022). One out of 3 (*n* = 241) MHP survey respondents reported that they do not collaborate with disability services agencies, indicating a need for increased efforts to promote collaboration across systems.

Disability Service Providers (DSPs) and Facilitating Access to Mental Health Services

The Utah MHIDD survey asked DSPs if they have ever worked with an adult with a developmental disability whose MHCs were not addressed. DSPs who indicated yes were asked to provide some information on why or how the MHCs were not adequately addressed. A total of 92 DSPs responded to this question. Figure 5 outlines the barriers reported by DSPs, with waitlist/provider shortages and assumptions about the ability of PWD to participate in mental health services being the most prominently reported.

Figure 5

Challenges Reported by DSPs When Facilitating Mental Health Services to PWD (n =9 2)

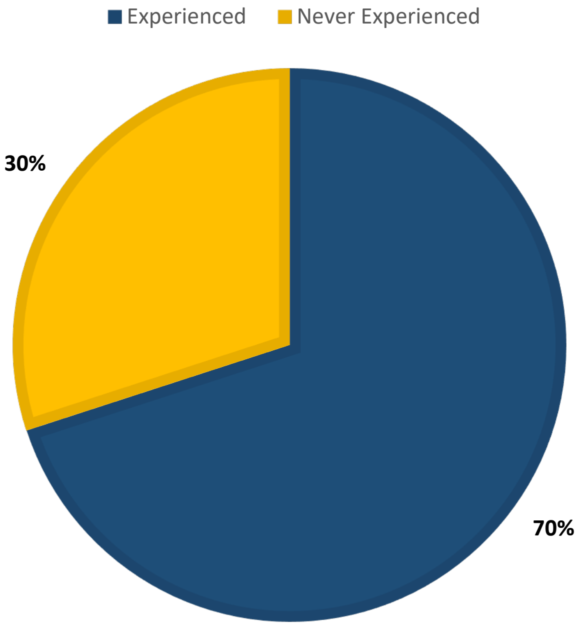


The survey also asked DSPs if they had received training on co-occurring MHC and IDD. Seven out of ten (*n* = 131, 70%) DSPs reported having received training about co-occurring MHC and IDD. This demonstrates a need for further training opportunities for DSPs related to MHC and IDD. The survey asked DSPs how confident they are in identifying MHCs among PWD. A high percentage DSPs (84%, n=131) responded that they feel confident identifying MHCs in PWD, regardless of education level.

Additionally, the survey asked DSPs if it is difficult to find an MHP for an adult with a developmental disability in their area, to which 79% (*n* = 105) responded yes. Furthermore, we asked DSPs if there was a time when they tried to refer an adult with developmental disabilities for mental health services and they were turned away or denied. Figure 6 indicates that the majority of respondents had experienced being turned away or denied when seeking to refer an adult with IDD for mental health services.

Figure 6

Percentage of DSPs Who Have Tried to Refer an Adult with Developmental Disabilities for Mental Health Services and Was Turned Away or Denied (n = 103)



The survey also asked questions to DSPs related to Mental Health and Disability Services interactions. One out of 5 (*n* = 134) DSPs reported that they did not know where to refer PWD for mental health crisis services. DSPs were equally likely to know where to refer an adult with a developmental disability to receive either crisis services or on-going mental health services.

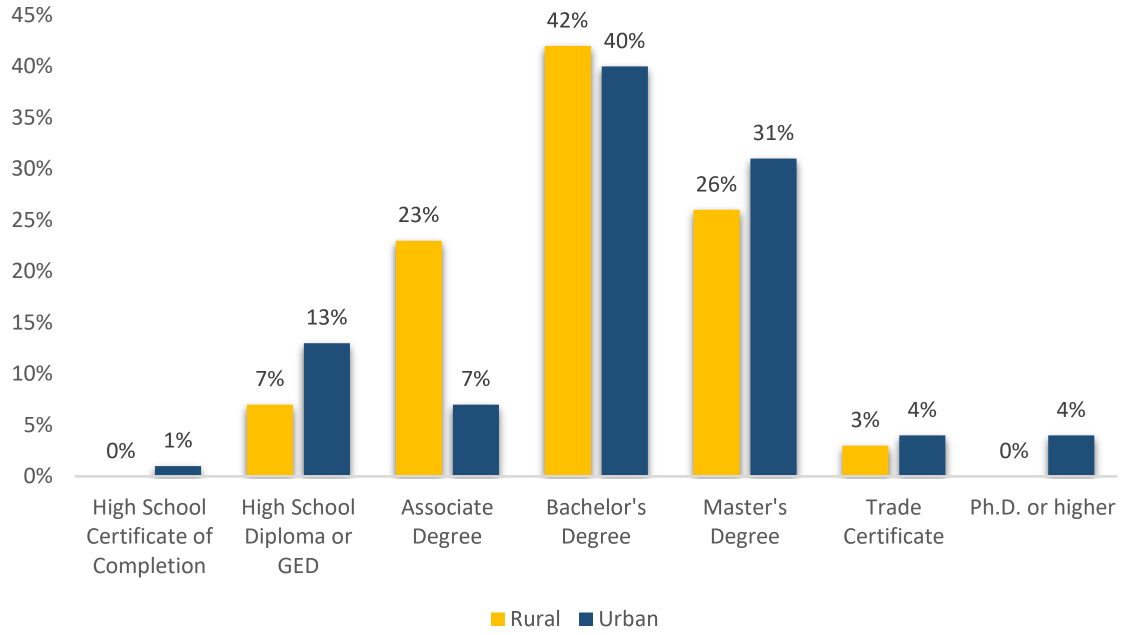
Rural Versus Urban Considerations

It is widely agreed that rural communities have a different set of challenges than urban communities. Rural Utah includes 9% of the state's population where many socioeconomic, educational, health, transportation, employment, and technological (among other) factors represent risks and opportunities for its inhabitants (America's Health Rankings, n.d.; Rural Health Information Hub, 2021). While all families regardless of where they live need services, many rural families might face particular challenging situations and special circumstances to access mental health assistance for PWD living in these areas.

Figure 7 outlines DSPs (*n* = 152) with various education levels in rural versus urban areas. Survey results indicated a larger percentage of DSP respondents with associate degrees serving rural areas (23%) compared with urban areas (7%). Also, we saw relatively similar percentages in both bachelor's and master's degrees in these regions. However, urban areas had a few DSPs with Ph.D.s (4%) compared with none at rural areas.

Figure 7

Percentage of DSPs with Varying Levels of Education in Rural Versus Urban Areas (n = 152)



Figures 8 and 9 outline the distribution of MHP respondents (*n* = 284) by education and rural versus urban status. There were equally common percentages of MHP respondents with master's degrees (77%) serving rural as well as urban areas. Also, we saw a higher percentage of MHPs with a doctorate degree or higher serving in urban areas (17%), compared with rural areas (10%).

Figure 8

Number of MHPs by Education in Rural Versus Urban Areas (n = 284)

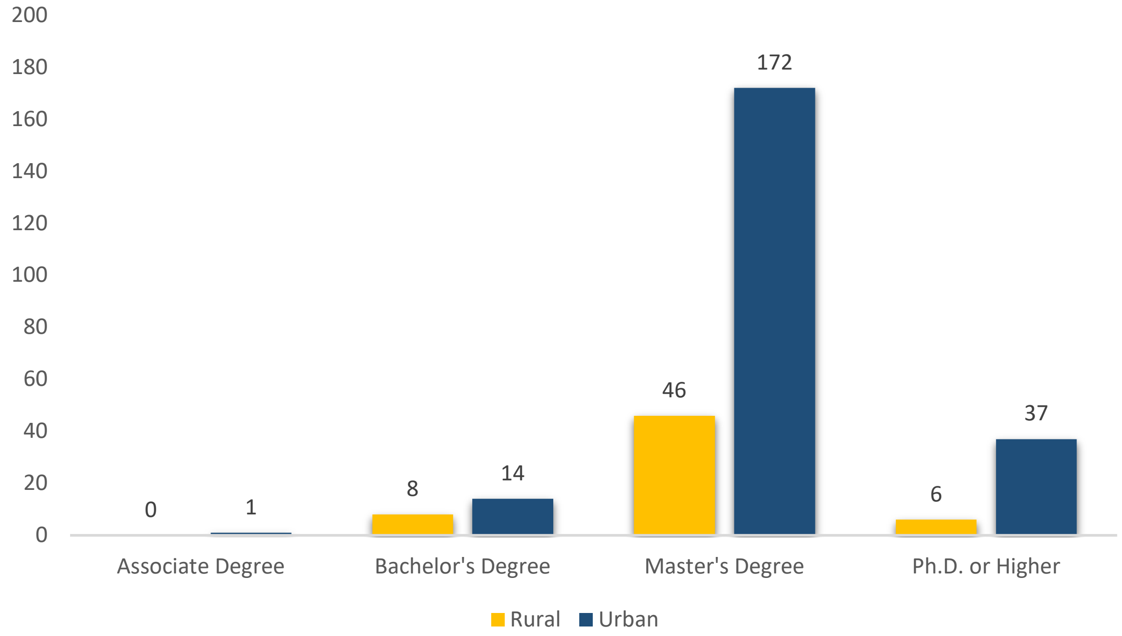
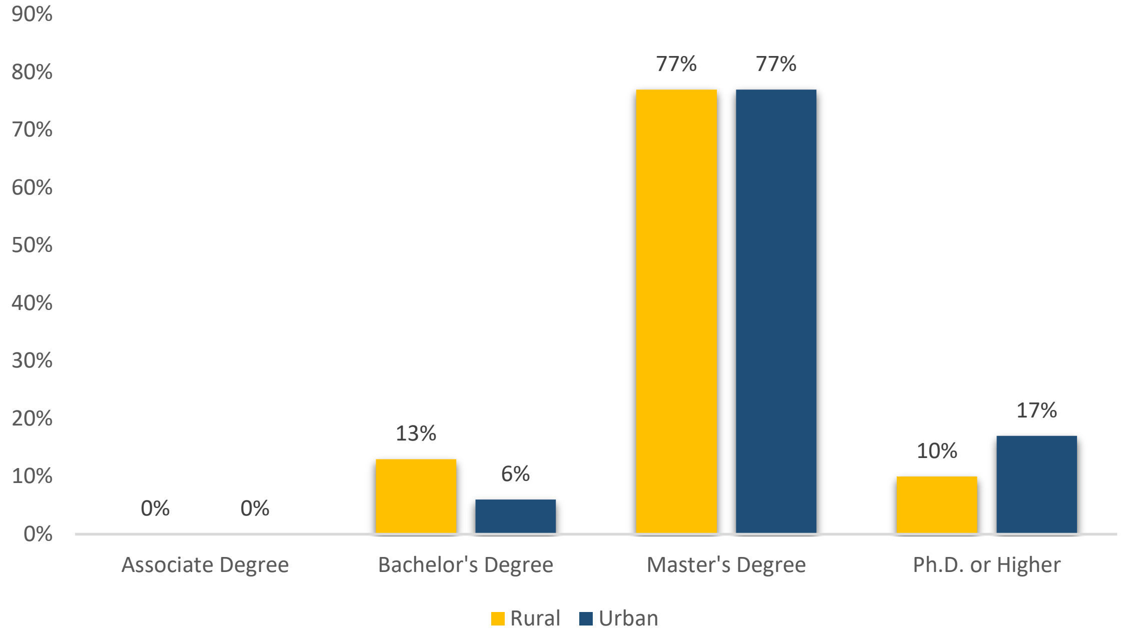


Figure 9

Percentage of MHPs by Education in Rural and Urban Areas (n = 284)

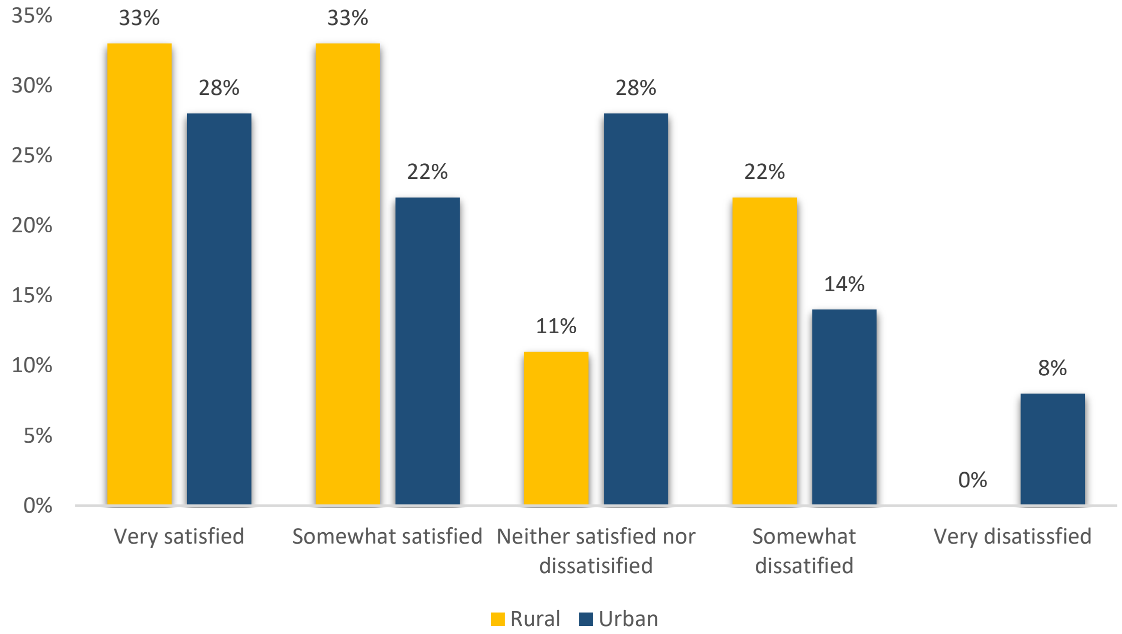


Outlined previously in this report was the experience of denial of services when a DSP referred a PWD for mental health services. DSPs from Utah rural areas (*n* = 20) responded that 6 out of 10 have experienced this situation. In addition, DSPs from urban areas (*n* = 78) followed a similar pattern considering that approximately 7 out of 10 also have experience denied mental health services they have referred for PWD. These large numbers of denied referred services might represent another potential opportunity to work on collaborative efforts between mental health and disability systems in both rural and urban areas.

The survey also asked PWD from both rural and urban areas about their level of satisfaction with the mental health services they have received. Figure 10 outlines that PWD from rural areas 2 out of 3 (*n* = 9) (or 66%) are "very satisfied or somewhat satisfied" with these services. However, 1 out of 2 (50%) PWD in urban areas (*n* = 50) are within the same categories of "very satisfied or somewhat satisfied" with the mental health services they have received. This comparison indicates a potential higher satisfaction level for rural PWD receiving mental health services, however, the small sample size of respondents limits this comparison. Notably, both rural and urban areas have similar levels of dissatisfaction (*n* = 59, 22%) across selections of "very dissatisfied" or "somewhat dissatisfied."

Figure 10

Satisfaction of PWD with the Mental Health Services They Were Receiving in Rural Versus Urban Areas (n = 59)



The survey asked family members/caregivers of PWD about their experience finding a MHP for their family member(s) with disabilities. Family members/caregivers from Utah rural areas (n=36) responded that 1 out of 2 (or 50%) found a MHP for their family member with disability. On the other hand, family members and caregivers from urban areas who responded to this question (n=129) had a higher success rate because 3 out of 4 reported being able to find a MHP for their family member with disabilities. This highlights a need for addressing barriers to accessing mental health services for PWD in rural areas.

Finally, the survey asked DSPs about policies and procedures in place within their agencies to address MHCs. Approximately 8 out of 10 (or 77%) DSPs from rural areas (*n* = 26) responded that yes, they had policies and procedures in place within their agencies to address mental health concerns. DSPs from urban areas who responded to this question (*n* = 89) had a lower proportion (57%) of policies and procedures in place within their agencies to address mental health concerns.

Summary of Quantitative Data

In summary, existing quantitative data on state and national levels indicate similar challenges and needs to those presented by the results of our survey. Our data revealed high prevalence rates of MHCs experienced by PWD, accompanied by a general sentiment among PWD and their family members/caregivers that mental health is not prioritized enough by DSPs.

Our data supports existing knowledge indicating significant barriers faced by PWD when seeking to access mental health services including provider shortages, refusal of referrals, insurance and other financial limitations, stigma and misconceptions held by providers, location and transportation, and communication barriers. A useful component of this quantitative analysis was the comparison of perspectives on service delivery barriers across groups, such as the varying emphases placed on the barrier of communication.

This quantitative analysis provided insight as to how future training and education efforts should be directed. Notably, MHPs who responded to our survey indicated that they feel that their education and training did not adequately prepare them to work with PWD. Thus, we conclude that many providers are aware of the need for greater training and education on working with co-occurring MHC and IDD and would be highly receptive to training opportunities. Additionally, a portion of MHP respondents reported that they do not collaborate with disability services agencies, which highlights a need for greater education and facilitation regarding cross-systems collaboration.

Finally, our quantitative analysis highlighted some notable trends in differences between Utah's rural and urban areas in access to and satisfaction with mental health services by PWD. While sample sizes for rural comparison were small, this illuminates an area for future research. In future efforts addressing MHC and IDD, special attention may be needed to increase rural sample sizes for more accurate comparisons.

Ultimately, our quantitative analysis has revealed a variety of needs and challenges and,. Importantly, our analysis indicates that there is an awareness of a need for training and education to improve cross systems collaboration and the overall quality and availability of mental health services for PWD. While this quantitative data provides invaluable insight into current needs and challenges related to mental health services for individuals with MHC and IDD in Utah, we sought additional qualitative data to ensure that the voices of individuals with lived experience were captured and shared in this report. The following sections elaborate on the qualitative data analysis and how this mixed-methods approach allowed for rich data collection.

Qualitative Thematic Analysis Results

IDRPP personnel conducted semi-structured interviews (*n* = 22) and focus groups (*n* = 9) with MHPs, DSPs, family members/caregivers, and individuals with disabilities. Interview and focus group audio recordings were transcribed and prepared for thematic analysis using Otter.ai. Transcriptions were coded to identify common themes. Representative quotes from study participants were selected to illustrate the lived experience informing the themes. Qualitative analysis resulted in the identification of six main themes related to barriers and needs regarding mental health services for individuals with co-occurring mental health concerns and IDD. In this section, the following six themes will be discussed.

1. Healthcare system structure, including agency and provider structure and operational definitions, can prevent individuals with disabilities from accessing services.
2. MHPs who are trained in working with and who feel confident in their ability to provide services for individuals with intellectual and developmental disabilities are hard to find and have long waitlists.
3. Intersecting identities may lead to increased barriers to accessing mental health services for individuals with disabilities.

4. Individuals and families can be severely negatively impacted by the lack of quality and lack of availability of mental health services for individuals with IDD.
5. MHPs, DSPs, family members/caregivers, and individuals with disabilities state that more funding is needed to support mental health services for individuals with IDD.
6. MHPs, DSPs, family members/caregivers, and individuals with disabilities feel strongly that more training and education is needed to better prepare MHPs to provide services for individuals with IDD.

1. Healthcare system structure, including agency and provider structure and operational definitions, can prevent individuals with disabilities from accessing services.

Participants discussed how the healthcare system itself may prevent individuals with IDD from accessing quality mental health services. Specifically, participants indicated that DSPs and MHPs are siloed; that is, that DSPs and MHPs do not communicate well and do not collaborate as they should. Additionally, some participants explained that provider licensure limitations under Medicaid are frustrating and that insurance in general causes great issues in attempting to access mental health services. Across participant groups, particularly MHPs, DSP, and family members/caregivers, there was a general consensus that the existing service systems are challenging to navigate. Mental health providers and DSPs frequently noted that there is not sufficient communication between mental health and disability service systems, and that having to "jump through hoops" is limiting to the ways in which they can collaborate. The following examples of comments from participants elaborate on some perspectives of the siloed systems.

Examples from Family Members/Caregivers

"…I think one of the biggest issues we have is a system of communication that just doesn't work. And perhaps it's not clear to me yet, but perhaps this move to restructure the Department of Health and Human Services and put DSPD there, isn't it an attempt to solve some of those problems, but in a way to me it's compounded it because I've been to the public hearings, I've been to the Council for the Disabled, and been to a lot of those different things, but they don't ask for input. They tell you what they're doing, any questions, and click it's over. And so I don't know that we have in place a structure for true community input and for priority. And there are so many little pieces that go into the system. There's no one-stop shop, this is where you go to get help, and they'll be your case manager and navigate you to the different places. That's a huge failing in this system."

"Do away with the silo. You know, DSPD is saying '[your family member] has a mental health issue, that's their problem, you need to go to a local mental health authority.' And [the mental health authorities] say, 'No, the problem is that [your family member] has an intellectual disability, you need to go to the DSPD,' but neither of them will meet with each other."

"[A major issue is] the poor coordination between divisions. Division of people with disabilities and the Division of mental health are in two different silos and funding. So getting help for those two together is really difficult."

"…there's a severe disconnect between DSPD and mental health services. Mental health services refuse the services to [my family member], because they say he has a substance abuse problem, which he does, but [they also say] he cannot have substance abuse treatment, because his IQ is below 80. So it is the cat that chases the tail."

Examples from Mental Health Providers

"I think professional groups have been very heavily advocating and pushing for their profession to be the better profession so to speak. I'm a social worker. And I've been in conversations where Psychologists say Social Workers suck and Social Workers say Psychologists suck…I've been in conversations where nobody likes Marriage and Family Therapists and nobody likes Licensed Clinical Counselors. And these are all different professions and licensures who should be able to do this work, if they're obviously adequately trained, but every profession wants to lobby for their own profession instead. And it's kind of a waste of time and a pain in the ass because all you're doing at the end of the day is limiting people in access to care."

"As we're talking about… these issues with siloing…we also silo these things out, because from a general funding perspective, the people who are funding it are the ones who don't understand it to any kind of real adequacy."

"But they basically limited [access to ABA services], so people who were doing some of the service already couldn't do it anymore. Because they didn't have the right licensure. So you literally limited access, because…we had one group lobbying for why they were the best one to do it. And because there happened to be a substantial amount of research, particularly from BCBAs, about how their work is better for autism. It literally took us down a path that was the wrong path."

"But all this [siloing] just kind of leaves you feeling like you're playing a game and your hands are tied. I think it directly gets in the way of a lot of therapist's creativity or problem solving, because we're too busy jumping through hoops."

Examples from Disability Service Providers

"I also feel like there's a continued issue of really compartmentalizing the separate departments and not integrating to the extent that they really need to be integrated. Because you have DSPD, and then you have the mental health component where there's not really a good crossover. And we're serving clients that really need both areas of support. And as I'm considering that, DSPD has these very, almost stringent rules and expectations, yet they don't provide the tools and resources that would be necessary to really meet the needs of the clientele…I almost feel like they don't have…[an] understanding of what the clientele that they're supposed to be serving actually needs. I wonder at times [if] there's issues with their structure when it comes to appropriately funding a client."

"But if as providers, we could all learn to play together in the sandbox and maybe streamline some paperwork, where possible, be a little more open to sharing our resources and support, you know, instead of just saying 'that's mine, and I'm the only one that can access that kind of stuff.' That would be helpful. But from where I sit behind my desk, it all comes down to money, we just need more money."

Key Points

As illustrated in the quotes above, there is a need for greater *meaningful* coordinated efforts across both mental health and disability service systems to improve services for individuals with IDD. Ideally, in establishing avenues of coordination and collaboration, perspectives of disability and mental health providers who are providing direct client services should be prioritized. Additionally, leadership across mental health and disability services would benefit from involving family members/caregivers, as well as PWD, directly in identifying ways that people would like to see mental health and disability service providers collaborating. Stakeholders should invest efforts into enabling collaborative care through streamlined communication across disability and mental health service sectors.

2. MHPs who are trained in working with *and* who feel confident in their ability to provide services for individuals with intellectual and developmental disabilities are hard to find and have long waitlists.

Participants consistently expressed difficulty in finding a MHP who was trained in working with individuals with IDD *and* who felt confident in their ability to provide quality services. Participants discussed how the demand appears high for these types of MHPs, as some reported waiting for months for an initial appointment. Important to note here is that, based on participant discussion, MHPs may maintain inaccurate stereotypes regarding people with IDD, including the belief that therapy simply will not work for people with IDD. One interviewee with experience in both the mental health and disability service sectors commented that some mental health provides seem to be afraid to provide services for individuals with IDD. Multiple participants commented that psychiatrists are difficult to access, particularly when looking for a psychiatrist who specializes in working with individuals with IDD. The following examples help provide insight as to the lived experience of participants who have struggled to find a MHP.

Examples from Family Members/Caregivers

“As far as [my family member’s] anxiety goes, I haven't been able to get a doctor who's willing to say anything other than take him to the emergency room if he's got that much trouble. Or, you know, the best advice I got was from his pediatrician who happens to still service him because nobody else will and he loves him. And said, ‘Just give him Benadryl,’ and so if he has anxiety, we give him 50 milligrams of Benadryl to calm him down. And we hope and pray he gets through it.”

“We have been on waiting lists for people that ended up not being that helpful after all.”

Examples from Mental Health Providers

“I served a lot of kids- and adults- who went to, receive mental health services just at the local authorities throughout the system, from clinicians that were not specializing, and they just didn't have the knowledge, the skills, or the commitment to the population. So the outcomes were not great.”

“…and then there are the really old school people out there saying that a person with a disability can't benefit from therapy.”

"I can say for sure that there are some--maybe it's not fair to say the whole mental health authority--but there are definitely some mental health authorities…some people in leadership…[who] hesitate to serve people with disabilities."

"I will tell you some of the mental health authorities will not contract with an organization if they know that their primary purpose in trying to contract to provide mental health services is to serve people with disabilities….In the last probably seven or eight years ago, I've explicitly been told, we're worried that you're wanting to do this primarily to serve people with disabilities. And that's not really where the resources need to go. So that's paraphrasing, that's not a direct quote, but that was the…discussion."

Examples from Disability Service Providers

"…I do know that I have personally [received pushback], and I know a lot of parents get a lot of pushback, because a lot of the mental health services do not want to provide services for someone that has an intellectual disability or related condition. And so…our people are on waitlists constantly, and we're trying to get services for them constantly. And sometimes we don't get services to them before they have a mental health episode. Because they're on waitlists and things."

"[The family members are] the ones that call me back and then say, 'I'm on a waitlist for these services,' I've been told that they're, you know, the waitlist is very long. You know, I've tried to get my child to go to inpatient because they're in crisis, and there's no beds, I have been out on situations where somebody is having a mental health crisis, and there's no beds. And so there's a hesitancy to bring someone into a hospital, who's having a mental health crisis, also having an intellectual disability, when they know there's no beds available. And so there's, there's a hesitancy, I feel in regards to that situation."

"I've learned at this point, when you make a phone call, that we disclose right out of the gate, like, 'Hey, I'm supporting a client with disabilities.' And there are some communication barriers, but they are really in need therapeutic services, is there something that you feel like you could address in your office? And there's far more nos than yeses."

Key Points

Considering that the majority of Utah is considered a mental health shortage area, it is not surprising that it is challenging to find an MHP who is comfortable and confident providing services to individuals with IDD (Summers et al., 2020). Particularly notable takeaways from this theme include the difficulties that family members/caregivers face in accessing regular care outside of crisis services, the hesitancy of MHPs to provide services for individuals with IDD, and the experiences of DSPs who make efforts to connect individuals with IDD to services only to be turned down and/or wait for extensive periods of time that contribute to ultimate crisis. MHPs may benefit from peer-to-peer education opportunities. MHPs who are comfortable and confident in providing services to individuals with IDD may be able to provide invaluable support to their peers who are not as comfortable or confident.

3. Intersecting identities may lead to increased barriers to accessing mental health services for individuals with disabilities.

Participants reported a variety of barriers to accessing mental health services for individuals with IDD, including barriers that are unique to certain identities/circumstances. Individuals living in rural areas may face additional difficulty in accessing services because of their rural location; this could include limited choices of providers for individuals who wish to have in-person mental health services and/or inability to participate in or receive specific services that are limited by geographic location. Individuals from diverse cultural and/or ethnic backgrounds may have difficulty in accessing quality services because of language and/or cultural barriers that may require a therapist with specific background and training. The following examples depict the barriers that some individuals face in accessing mental health services for individuals with disabilities.

Examples from People with Disabilities

"[Someone might offer to translate] and they actually don't know ASL as well as they think they do. They're just a sibling or a cousin or a friend to someone in the deaf community. Or they took ASL classes in college and think that they are well versed enough in ASL and in reality, they don't have the vocabulary that they think they have. Just all those different types of things or they don't understand the Deaf culture. And that our life is completely different."

"I think there's too much reliance on The Church of Jesus Christ of Latter Day Saints, and what they do, and you can access services through them, but it's monitored by, you know…the wards, clergy, or Bishop. So it's hard to get through that."

Examples from Family Members/Caregivers

"…it's actually been really difficult, where we live in a rural community to get [any services]. And it seems like nobody wants to talk about it still. Like it's been it's been years that we've been going over that…It's been decades holy cow, that I've been trying to help my kids the best I can, without having to move to downtown Salt Lake City. And in hindsight, that's what I should have done is to move to Salt Lake City, cause that's where all the help was. There's not any in Weber County."

Examples from Mental Health Providers

"And so to have practices that I know are in mental health deserts, rural parts of Utah, entire practices that say we don't see [people with developmental disabilities], there is a real dearth of mental health providers who are, I'm just gonna say, willing to work with persons with developmental disabilities."

"I work in rural mental health care. And so it is really, really difficult to even find providers… of course the insurance is a problem, right? And then just finding providers and like you said, waitlists are years long, and sometimes those waitlists are just for an evaluation."

"For a while when I started, [I took Spanish speaking clients]...But I stopped, because I realized that at least with a lot of how I do therapy, it's very word specific. And that knowing Spanish well enough to do therapy in Spanish, I just felt like I wasn't getting as quality of service, which, unfortunately, limits a lot of the population that I could work with there. But as far as like, just in general, different cultural backgrounds, definitely, they can impact even what they expect out of therapy. And, and a lot of how therapy can work is built off of expectation. And so I think there are some difficulties for sure, or in a lot of ways that we're unaware of, it impacts the client therapist relationship. And, and so, in general, I'd say it's harder. I don't know if I could particularly point to why or where or how. But, but with at least the English-speaking clients with different cultural or diverse backgrounds, there tends to be just increased challenges. And hard to go and figure out what those would be."

"Most testing from a psychological perspective, from an assessment perspective is only done in English in the United States. If you are only doing testing to, in English, to someone who does not speak English as their first language, they are going to test differently. I have literally been involved in cases where the individual is Spanish speaking primarily, they did a full range of IQ testing, and they came back with a 52 IQ. And I said, 'well how did you do the testing? This person is pretty smart.' 'Well, we did the testing in English.' And I said, 'Cool, go back and do it in Spanish because the person is smarter than a 52 IQ.' 'Well, how are we like, we can just go back and do it, we don't have access to the test….' Because if you're telling me that someone has a 52 IQ, but you are also telling me that you didn't do the test in a way that is culturally sensitive for that person and linguistically sensitive, you missed the entire mark on it, and it's invalid. Plain and simple. And like, outside of the fact that Spanish is one of the top spoken languages in the country, we just do a poor job for this all over the place. And we take cultural considerations out the window, because for most people, and this is really hard for people to understand, because people think I'm blaming, but for most people, it is about what they see as the norm."

Examples from Disability Service Providers

"…I think of some of the language barriers, I can think of one client in particular that we have one staff that is fluent in Spanish, and so communicating with his mom and sometimes communicating with him. So that makes it even more difficult because finding a bilingual therapist, in that scenario, if you were to need therapeutic services, now we're finding a bilingual therapist, who also works with people with a disability. So it just kind of exacerbates it. And I think there's also some cultural competence, like that's something that's come up with our employment team, where they're working with people that are seeking employment, but there's some cultural competence that they don't understand. Like, obviously, going through a program at a university they teach called cultural competence…don't ever make assumptions, let the person you're working with be… the expert at their life and their experience. But then they go in and make assumptions and then they come back and go, 'Well, I was super wrong, and that backfired.' So I feel like even with just the general services, [cultural competence] is lacking at times."

"The other piece that's hard is finding resources for people who speak Spanish. So therapy in Spanish has been really hard for us to find. And they don't have it at the HOME Program."

Key Points

The above quotes are an essential reminder that PWD often face additional barriers to accessing mental health services because of intersecting identities. Additionally, it is important to consider that existing service systems were constructed primarily by and for White males (Lee et al., 2021). In efforts to improve mental health and disability service systems, individuals from diverse backgrounds with lived experience should be directly involved in decision making regarding structure, service delivery, and training. Particular emphasis should be placed on implementing translation and language services that effectively convey therapeutic terms and processes.

4. Individuals and families can be severely negatively impacted by the lack of quality and lack of availability of mental health services for individuals with IDD.

Family members/caregivers shared stories about the negative impacts of the lack of quality and lack of availability of mental health services for individuals with IDD. While details of experiences differed, it was clear that the difficulty of accessing mental health services for individuals with IDD has an overwhelmingly negative impact on the individual with a disability as well as their family members/caregivers. We share the following examples to illustrate how challenging it can be.

Examples from Family Members/Caregivers

"First, so I honestly I think that, um, like, my therapist keeps telling me 'You need your son to have a caseworker who's not you.' Right? So I [am a] case manager at work, I come home and try to case manage my son, and my kids, and I can't do it to the level that he needs and, and connect him with the services that may be out there. But he can't independently get them on his own. So he is involved in a program down here called Crimson Counseling. They're a private day program that he's involved with or has a one-on-one person, I don't even know what to call them. They call them a support person. But I have even asked this person like, you know, he ran out of his medication…if I don't, if I don't case manage my son before that person comes and then have them try to remember to help him go get his medication, then he runs out. So it's almost like I'm case managing the case manager, right? Because they're not really a case manager. They're not a social worker. They're not…they're a college student, which is great support for my son socially, emotionally. But they're not going to connect him with Department of Workforce Services, they're not going to connect him with these other organizations that will help him."

"I have had such a struggle for so many years, the toll of caregiving on me has created my own struggles, plus just what we went through with them. And it seems like people may know something about intellectual disabilities, but have no clue about trauma, about anxiety, about OCD, about scrupulosity, about depression, about all these things that we deal with. But if I go somewhere with the mental health, they don't understand the intellectual disability part and how to communicate and reach them and how to help them where they're at with that. And so a lot of times I'm getting either help with their intellectual disabilities and that or the mental health and they're not connected, it's missing. Very difficult. We've recently had to pull my daughter from a day program because of the lack of understanding of the abuse that was put on my daughter in a place where their caregivers were people where she should be safe. It's ended up being another trauma. Another really traumatic thing."

"[If I took my family member in for services and their] specialty was mental health, then he had mental health issues. And if their specialty was autism, it was all autism and behavioral, even though they were clinicians and they understand both sides. Everybody kind of wants to have someone fit in this pretty package and address it according to the diagnoses, as opposed to there are so many things going on. It's just people are complicated, and brains are complicated. So my personal experience has been that I cannot imagine what parents go through. I feel like I went through a lot of obstacles and roadblocks only being successful at times because I knew people. But I don't, I don't believe that's the case for 99% of the parents out there that are having the same kind of struggles. And it's just really frustrating to think that there are people out there that could access services. There are services that exist, and there's just not easy ways to navigate through those systems."

"…This is another area where this significantly impacts caregivers. Because…I'm okay, I'm fine. But I have this lifetime over the last 21 years of feeling like a failure, because I'm not able to provide everything my daughter needs. And I've been working at it for 21 years, and I'll continue to work at it, you know. But…that's the baggage that parents are bringing with them, right? The fact that they already feel like failures. And do I want to continue to feel like a failure? So that, I think, is also a deterrent in parents pursuing things. Because if it's somebody else's fault, then that's the answer they've gotten. And so digging in further, I don't know, I'm not even sure exactly what I'm saying here. But I do think that that's another important thing to consider that when a child has an unmet need, and the parent can't figure out how to meet that need for them, it creates a problem in the parent too. So now we're not just dealing with the individual who has a mental health concern. Now the parent in addition to every other thing that they may be going through, and the mental health concerns that they may already have, just because of circumstances, there's another one added to it. That eternal guilt that we're not doing enough, and that helpless feeling because there's nothing I feel like I can do to fix it. So we're creating multigenerational problems."

Key Points

It is clear that family members/caregivers experience significant negative effects resulting from the unmet mental health needs of individuals with IDD. When mental health needs of individuals with IDD are unmet, it leads to greater strain on the individual and their natural supports including family members/caregivers. Overall, a lack of effective and quality mental health services further compounds the need for mental health services among individuals with IDD. Of particular importance is the above note from a family member/caregiver, "...we're creating multigenerational problems."

5. MHPs, DSPs, family members/caregivers, and individuals with disabilities state that more funding is needed to support mental health services for individuals with IDD.

Participants across groups emphasized the need for more funding in general to support mental health services for individuals with IDD. These comments were often accompanied by comments related to the siloed nature of service systems. When asked what the biggest challenges or barriers are that affect supporting the mental health of individuals with IDD in Utah, one PWD commented "I would say the gatekeepers and the funding, that's the biggest challenges and barriers." Some participants expressed that they would like more involvement in decision-making regarding funding allotment and allocation. Others simply asked for more funding, stating that the current funding amounts are not enough.

Examples from People with Disabilities

"So there's enough people out there that have the ideas, it's just now we need to provide them with the support and the funding. So I just haven't been...they're innovative people, there's tons, so."

Examples from Family Members and Caregivers

"[Referring to discussion participants] These are the people right here, that should be dictating how these kids and seniors should be taken care of. Because we're in the system. We're dealing with the trauma, we're in the trenches every day, if anybody should be deciding where this money goes, it should be us. We should be sitting together and saying, 'You know what? I was talking to [name] the other day, and I'm thinking we're going to need to put some funding in this area.' I'm not seeing how that would be a hard thing. I mean, do we all need to run for Congress to get this to be taken care of?"

"Maybe [the legislators] feel that we have resources in place to help these individuals, but it's not enough. Not by a longshot. And they need to allocate so much more…I know the legislator has a lot of things that they have to pay for. But if you really want to service people that have these problems, there has to be a lot more. I think what they are allocating is just meeting the needs of very few, very small percentage, maybe not even 5%. I think the analogy is 'There is a fire at the house, the fire department shows up with squirt guns.' That's what's taking place in this field in the State of Utah."

"[A big issue is] anything to do with funding. You know…that's a big thing out there for to support people with disabilities funding. You know, covering speech therapy…I have to pay out of pocket…it's costly. Fortunately, we could do it, but what about all those other people that can't?"

Examples from Mental Health Providers

"Having…a better financial funding stream would be helpful because we just don't have the resources that are adequate to serve people who have these co-occurring needs effectively."

Examples from Disability Service Providers

"But if as providers, we could all learn to play together in the sandbox and maybe streamline some paperwork, where possible, be a little more open to sharing our resources and support, you know, instead of just saying that's mine, and I'm the only one that can access that kind of stuff. That would be helpful. But from where I sit behind my desk, it all comes down to money, we just need more money."

"… the HOME program, is one of the only programs of its type that I'm aware of in Utah. And I have clients served by the HOME program, and I believe that when they started, and I interacted with them, like 20 years ago, when I was working in group homes, the client care was exceptional. The clients I have now, the medical care, still exceptional. [However], access to therapy services, a client going to therapy once every six weeks doesn't have therapeutic value. And that's what they have to offer because they have too many clients and there's not enough people to do the work. And it's unfortunate because I believe the model they have is really good. But they do not have the capacity to serve the number of people that truly need those supports. So yeah, if we can't pay people more money to provide what we need provided, it's not going to change."

"I hate saying that a lot of it comes back to money, but it really does. Because if you're not providing the financial resources to meet the needs of the clients, then the clients aren't receiving the services that they need to receive. And again, it's being willing to look at the model we're using and shifting how the model works. If we're going to be serving clients who have a dual diagnosis need, then we have to have dual diagnosis programs, where we're able to bring in occupational therapy, and mental health care, and all of these components."

Key Points

As with decision making related to service system structure and service delivery, individuals with lived experience, including PWD and family members/caregivers, must be included in decision making related to funding allocation. Service providers from both mental health and disability service sectors may provide valuable insight as to how funding should be allocated and used to support collaboration and communication across systems.

6. MHPs, DSPs, family members and caregivers, and individuals with disabilities feel strongly that more training and education is needed to better prepare MHPs to provide services for individuals with IDD.

Participants, particularly MHPs and DSPs, stated that MHPs need greater education and training to support them in providing services to individuals with IDD. It was mentioned repeatedly that the training that exists is not sufficient. Multiple MHPs suggested that mental health professionals are not adequately trained to provide services for individuals who have co-occurring mental health concerns *and* IDD.

Examples from Mental Health Providers

"…we do a really poor job with training, we do a really poor job advocating for the individuals who need services."

"We do a very good job when people have one problem, we do a very poor job when people have multiple problems. And part of the reason is because I don't think we have adequate training."

"The biggest challenges to serving individuals is professional training, because professionals aren't adequately trained to do both."

Examples from Disability Service Providers

"So number one, there just wasn't a lot of interest [in providing services]. We ask people about comfort, confidence, and competence. Those are three variables that tend to come up in looking at when people are providing services to a given population. And people just weren't very comfortable or very confident."

"… we have staff who are under equipped. They're not paid properly for the type of intervention they would be expected to be offering, and the training just simply isn't there."

"There's no conversation happening to address the challenges that [people with IDD] are facing. Which means if the training is not happening at a university level, then the people going out as professionals are not receiving that education. And I feel like from a social work perspective, these are the people that are going to be case managers, these are the people that are going to be therapists, these are the people that are going to be helping families, and if we aren't educated on how to help them, then we're part of the problem. Which is really frustrating."

Key Points

It is evident from the quotes above that DSPs and MHPs feel strongly that current educational and training programs do not prepare MHPs to provide services for individuals with IDD and mental health concerns. Considering the prevalence of IDD and co-occurring mental health concerns, Utah higher education institutions and training programs must place greater emphasis on preparing professionals to work with this population. Considering the comments from MHPs stating that providers do well with one problem but may struggle when people have multiple problems, MHPs may also benefit from greater investments related to training on collaboration and communication across service sectors.

Providers Who are Doing Innovative Work

During semi-structured interviews and focus groups, participants were asked: “Are there any providers or programs who are doing innovative work to support this population of people with disabilities?”

Individuals with disabilities and their family members/caregivers expressed that they are greatly appreciative of the innovative efforts made by agencies and providers. Participants in interviews and focus groups also expressed gratitude for agencies and providers who are making efforts to improve access to quality mental health services for individuals with IDD. They also emphasized gratitude for individuals and groups who advocate for necessary change and progress. Providers/organizations who were mentioned as doing innovative work include the following.

- Aggies Elevated
- Chrysalis
- Judy’s Playhouse
- National Ability Center
- Psychiatry Call Up
- Rise
- University of Utah’s Neurobehavior HOME Program
- Utah Behavior Therapy Services
- Utah Parent Center
- UTA Flex Trans
- Vocational Rehabilitation’s Choose to Work Program

The following quotes provide some elaboration as to why participants considered these providers/organizations to be doing innovative work.

Examples from Disability Service Providers

“...[Vocational Rehabilitation’s Choose to Work Program] really tr[ies] to find folks that have…the severe disabilities to help get them some supports and get them out on a job…some of the discoveries and different things that they do with those folks [show] that they're really person directed and what do they want and focus on their strengths. I thought that that was a nice change to address it from a strengths-based perspective, then kind of that needs-based perspective.”

“…the HOME program at the U of U. They have... I think it's a few years waitlist. But that's just because it's a very integrative approach they have…[They have] mental health,…psychiatry, they have…a regular doctor, they have specialists, so anything that an IWD could need on their health team is there and so they're all able to communicate together and really just kind of tackle any problem. But like, everyone knows, it's good until everyone you know, wants to be seen there.”

“I would say that my two best experiences have been with the HOME Program, first of all, and then with Utah Behavior Therapy Services. I know that they're kind of an Autism specialty. So as far as who all they serve, I'm not sure beyond the Autism community. But our experiences in those two places have been the best experiences we've had, in terms of people really seeming to understand the person with disabilities and using different techniques and methods to, to build that relationship, to communicate information clearly, to involve the family. I just see them doing a more superior job than other people.”

Example from Family Member/Caregiver

“I do think at least from my experience, UTA Flex Trans for the disabled is a marvelous system. … I don't know how they train their drivers, but we've been riding it now for 10 years or so and have never had a driver who wasn't patient and kind. Even when kids are screaming or angry on the bus or have to be restrained or whatever. They're great.”

Key Points

While the qualitative data outlines many of the challenges and barriers faced by individuals with IDD in accessing mental health services, it is important to acknowledge the organizations and groups that are making efforts to address those challenges and barriers. Out of all responses, the Neurobehavior HOME program was mentioned most frequently, indicating that the coordinated healthcare model has had significant positive impacts on those who are able to access their services (though, as noted by participants, accessibility of the HOME program is limited by geographical location). Other organizations should be supported in working towards models of coordinated care to improve mental health services and outcomes for individuals with IDD.

Summary of Qualitative Data

Ultimately, qualitative data collected throughout this landscape analysis indicates that while there are organizations and groups supporting progress toward improved access to mental health services and improved mental health outcomes for individuals with IDD, there is a clear need for:

1. Increased opportunities for effective training for MHPs;
2. Greater funding to support collaboration and coordination efforts across both mental health and disability service sectors; and
3. Direct involvement of individuals from diverse backgrounds with lived experience in decision making.

Recommendations and Next Steps

While the primary purpose of the Utah MHIDD project is to increase the capacity of DSPs and case managers/support coordinators, landscape analysis results have indicated a clear need for a collaborative approach to providing education and training to both DSPs and MHPs.

The IDRPP strongly recommends that stakeholders, including policymakers and those involved in funding allocation, consider the quantitative and qualitative data shared in this report that highlights the evident need for effective mental health services for individuals with IDD. The IDRPP recommends specific next steps for stakeholder groups.

1. Directly involve individuals with mental health and/or intellectual and developmental disability lived experience, including practitioners and family members/caregivers from diverse backgrounds in the decision-making process regarding allocation and distribution of funds at state and local levels.

   While allocation of funds was not addressed in our quantitative data collection, this topic was mentioned frequently by participants in interviews and focus groups. Participants expressed that they feel that their perspectives and input as individuals with lived experience in the mental health and disability service systems is undervalued and underutilized. Generally, the sentiment was that gathering input from these individuals would facilitate more efficient and effective allocation of funds. This may include focusing efforts on gathering public input at events or through venues that are easily accessible by PWD.

2. Provide support (funding, policies, etc.) for improved collaboration between mental health and disability service sectors to facilitate coordinated care.

   Our quantitative analysis revealed that there are mental health providers in Utah who do not collaborate with disability service providers. It is well demonstrated that successful models of care rely heavily on cross-systems collaboration. Thus, further support is needed to encourage full collaboration between mental health and disability providers. This may include state-sponsored opportunities for networking and establishing working relationships across service sectors.

3. Institutes of higher education and advanced training should review and update their current curricula to reflect specific needs of individuals with IDD in the mental health setting.

   While we acknowledge that curriculum design and adjustment can be challenging when working with accreditation requirements, it is important that we seriously consider that many mental health providers report feeling unprepared to work with individuals with IDD. In conversations with accreditation boards, faculty, and other education stakeholders, it is imperative that we address the lack of essential training in preservice programs.

4. Provide professional development opportunities that support the provision of mental health services for individuals with IDD through increasing mental health provider knowledge and confidence.

   Given the complexities of adjusting higher education and advanced training curriculums, an important step in addressing the training needs of MHPs is providing education and training opportunities outside of traditional preservice programs, to increase provider knowledge and confidence to work with PWD.

5. Demonstrate value for the critical role of direct support professionals in disability service systems through continuing to support competitive wages and providing effective training and ongoing professional guidance.

   While direct support professionals were not targeted specifically by our data collection, consultation with our advisory board regarding recommendations and next steps captured an underlying principle that direct support professionals are key in facilitating access to mental health services for many individuals with MHC and IDD. Clearly demonstrating that their role is valuable through training and competitive wages will enable direct support professionals to identify and address mental health concerns among individuals with IDD within their scope of work.

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