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August 26, 2022

To interested parties:

On behalf of the Wisconsin Department of Health Services (DHS), I am pleased to provide you with a copy of the *State of Wisconsin IDD-MH Service System Evaluation* completed by the National Center for START Services. This evaluation will be a valuable tool for DHS and our partners across the state who are interested in promoting the health, safety, and well-being of individuals with intellectual and developmental disabilities and mental health needs.

Currently, DHS has multiple initiatives underway to address issues included in the report. These include rate reform, workforce reform, crisis intervention reforms and grant opportunities. Visit https://www.dhs.wisconsin.gov/arpa/index.htm to learn how DHS is leveraging funds from the American Rescue Plan Act to improve home and community-based services.

In order to continue to improve the mental health system for IDD members and work to address the recommendations in this report, a task force is being developed that will include stakeholders across the state. DHS is committed to partnering with providers, individuals with lived experiences, advocacy groups, Managed Care Organizations (MCOs), IRIS Consultant Agencies (ICAs), government entities (counties, schools, law enforcement, etc.), and others. It will take a broad coalition coming together to improve this system of care.

If you are interested in learning more about the START model, you can find information at centerforstartservices.org.

Please email dhsdmsstart@dhs.wisconsin.gov to ask questions, provide feedback, or express your interest in contributing as a task force participant.

Sincerely,

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State of Wisconsin IDD-MH Service System Evaluation

June 3, 2022

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Executive Summary

The goal of this evaluation was to learn about the experiences of stakeholders in Wisconsin regarding effective services and supports for individuals with intellectual and developmental disabilities (IDD) and mental health needs (IDD-MH). Approximately 1,380 respondents across the state participated in this process. Constituent participants included service users, families, mental health service providers, service funders, law enforcement, advocates, government agency staff, and IDD service providers.

Four methods were employed for the analysis: (1) an online survey, (2) focus groups, (3) a validated, structured family member interview, and (4) review of Medicaid claims data. In addition, a Professional Learning Community (PLC) was conducted with Wisconsin stakeholders to familiarize them with the START model which is under consideration for the state.

There were five significant findings. Stakeholders identified the need to:

1. Improve crisis response to reduce reliance on hospitals and Institutions for Mental Disease,
2. Expand training and education of providers across the service system to better address mental health needs of people with IDD,
3. Increase the availability of outpatient and preventative mental health services,
4. Improve coordination and collaboration between service systems, and
5. Improve IDD supports to enhance quality of life for individuals with IDD-MH

Based on the findings, the following is recommended for discussion with stakeholders:

1. Further evaluation of emergency department use to determine why this is occurring, what is being requested, and the outcomes. This may be linked with the high mental health medication use also found, as new medications are often prescribed for people with IDD-MH in crisis seeking assistance from emergency departments. The review of crisis related incident reports may be helpful. In addition to training for first responders (police and others) consider the development of a 24-hour mobile crisis response team with training and expertise to evaluate children and adults with IDD to reduce the burden on police and emergency departments.

2. Develop a task force/community of practice made up of representative stakeholders to develop a strategic plan for systems change. This should include review of current Wisconsin policies and requirements regarding services to people with IDD and mental health needs. The National Center for START Services can assist with this process.

3. Explore the need for community based sub-acute and acute care beds across the state. Prior to development and implementation, the mission and methods for these services must be well articulated, for them to be successful (See START Resource Center). Inpatient mental health service capacity should also be examined. These services appear to be largely absent from the

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community system at this time, and may explain the use of state institutions, or they are not utilized as designed, this is unclear.

4. Address the immediate need for training statewide, but this will have limited impact if it is provided without other actions. Training alone does not work without resources and support to change methods and practices in the field and therefore, training should be provided as part of the overall strategy to improve outcomes. In addition to first responder training, the findings indicate that there is also a need to develop more comprehensive crisis response and safety net services to include proactive strategies, mental health coaching, and crisis prevention and intervention planning. Again, training on these methods cannot lead to outcomes without resources and strategies to allow for change.

5. Consider the implications of the significant resources currently dedicated to supporting individuals with IDD-MH through enhanced staffing and waiver spending. Significant cost savings and enhanced life experience could take place through more proactive strategies to address mental health needs. The state may want to consider piloting the START model in one location in Wisconsin. START is designed to work with network partners to improve capacity across the service system. As one Wisconsin representative stated, the START pilot should not duplicate existing services but rather fill in gaps and network with willing partners to infuse resources and training toward evidence based best practices to the community. Piloting allows for the state to ensure that START is effective.

Based on the findings, the START model may be considered as a good fit and may be piloted. The START model, first implemented in 1988, is a service linkage, crisis prevention and intervention program to improve capacity for effective services and supports for children and adults with intellectual/developmental disabilities and mental health needs. On average, the annual cost for START services per recipient is equal to the cost of one week in a psychiatric inpatient hospital in most locations across the country. START is a nationally recognized, evidence-based practice for children and adults implemented across the U.S. Research findings indicate that START services significantly reduce the use of emergency rooms and inpatient services, improve mental health service experiences, and promote improved mental health for people with IDD-MH (1,2,3). For more information about the START model, see Appendix F and G. However, implementation of the START model without engagement and improvement in other essential elements of the community system, namely IDD and MH services and supports, will limit the success of the program in meeting its mission.

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State of Wisconsin IDD-MH Service System Evaluation

Introduction

This report presents the findings of a statewide analysis of services and support experiences regarding the needs of individuals with intellectual/developmental disabilities (IDD) and mental health (MH) needs (IDD-MH) conducted by the National Center for START Services (NCSS) and funded by the Wisconsin Department of Human Services (DHS). The study was conducted in collaboration with stakeholders statewide, with active support of DHS. The evaluation focused on the reported experiences of service users, families, and providers to evaluate the existing service system and develop recommendations in response to participant feedback. Four primary data collection methods were employed: (1) an online survey, (2) focus groups, (3) family caregiver interviews, and (4) analysis of Medicaid claims data provided by DHS. Findings along with recommendations for follow-up are included in this report.

START Professional Learning Community (PLC)

One of the goals of this analysis was to determine the goodness of fit of the START model for the state of Wisconsin. It is important for stakeholders to be familiar with the model as we learn about the state service system. A Professional Learning Community (PLC) was conducted by NCSS in April and May 2022 to provide Wisconsin stakeholders with a detailed description of the START model, its core philosophies and practices, and components of START program implementation. Readings and pre-recorded trainings accompanied the sessions to enhance the group learning process. The PLC was held on Zoom for six (6) 90-minute sessions, scheduled twice per month, so stakeholders have information to make recommendations about whether START would be a good fit in Wisconsin.

A total of 53 stakeholders participated in the PLC, and most indicated that the START model would be a good fit for Wisconsin. One PLC participant expressed concern about START duplicating services that are may already exist in the state. The aim of all START programs is to network and partner with community providers to build capacity of the system as a whole and increase access to existing services and supports already available and needed by people with IDD-MH.

Background

Across the United States, approximately 1.5% to 2.5% of the population has an intellectual/ developmental disability (IDD). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM5) defines IDD as a disability that involves impairments of general mental abilities that impact adaptive functioning in three domains that determine how well individuals cope with everyday tasks (4). Epidemiological studies have established that the incidence and prevalence of mental health conditions for people with IDD is typically 2 to 3 times that of the general population, and these mental

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health conditions often contribute to challenging behavior (5). For people with IDD, aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services (6). Research indicates that a significant percentage of people with severe difficulties live with family caregivers and rely on them as informants regarding service needs and outcomes (6).

Current census data estimates the population of Wisconsin to be 5.9 million people with approximately 1.6% of the population (90,591) diagnosed with IDD (7). Based on epidemiological studies, it is estimated that about one-third (29,900) of those of individuals with IDD may also have mental health need (8). This statewide analysis evaluates community experiences and proposes next steps to improve the lives of citizens of Wisconsin who have IDD-MH. The National Center for START Services at the University of New Hampshire/Institute on Disability appreciates the opportunity to assist in this effort.

Methods of Analysis

Aims

The aims of this analysis were to address the following questions:

1. How effective is the current community system of care in Wisconsin in addressing the needs of individuals with IDD-MH?
2. How can the existing service delivery system be enhanced to improve services and supports to individuals and their families?

Data Collection Methods

Four primary methods were employed to learn about individual experiences with the existing service system and to create opportunities for constituents to provide feedback about how to address issues.

Method 1: Online survey of stakeholders
Method 2: Focus groups
Method 3: Family caregiver structured interviews
Method 4: Medicaid Claims analysis

Methods were reviewed with the Wisconsin Service System IDD-MH Task Force, a group of stakeholders invited to participate by DHS. The online survey was modified based on stakeholder feedback. The IDD-MH Task Force played a key role in distributing the survey across Wisconsin and identifying volunteers to participate in focus groups and family interviews.

Online Survey of Stakeholders

The Wisconsin IDD-MH Task Force distributed the online survey link to constituents across the state including, but not limited to, IDD service providers, service users, mental health providers, family members, policy makers, medical personnel, juvenile justice personnel, advocates, funders, and

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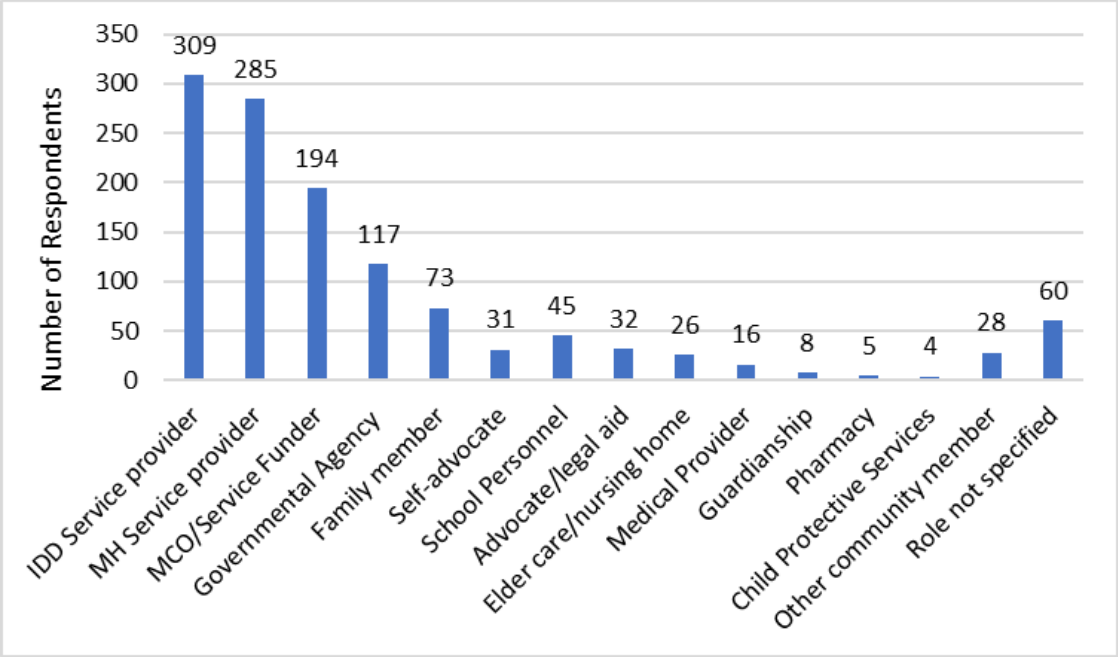
educators. In addition, the survey link was made available on several websites and social media pages for Wisconsin service providers. The goal was to receive feedback from as many citizens of Wisconsin as possible.

The 3 A's Framework of Effective Services was used to examine mental health and other service experiences for people with IDD. The 3 A's are: Access (timeliness, location, ability to use), Appropriateness (services match needs/wants, expertise is available), and Accountability (individuals are satisfied with the services, feel that services were helpful, they are responsive in times of need) (9).

Survey Respondents

A total of 1,233 people completed the survey between February 25 and April 15, 2022. Figure 1 shows the self-reported role of respondents. Providers of MH and IDD services represented just under half of respondents (25% (n=309) self-reported IDD providers; 23% (n=285) self-reported MH providers). People with lived experiences (family members and self-advocates) represented 8% (n=104) of respondents.

Figure 1: Number Online Survey Respondents by Self-Reported Role (n=1233)



Respondents were also asked to identify the county from which they provide/receive services. Appendix A shows the number of respondents by county. Some respondents specified that they provide/receive services across multiple counties, provide services regionally (e.g., NW Wisconsin), or statewide. All counties had at least some representation with an almost equal distribution of those who identified as representing rural (35%), urban/suburban (31%) and mixed urban/rural areas (34%).

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Online Survey Design and Analysis Methods

Survey participants responded to a series of questions about mental health and related services for people with IDD-MH. For each service, there was a five-point Likert rating scale: '*works well;'* '*available, but not sufficient;'* '*needs improvement/does not meet need;'* '*do not have access;'* and '*do not know.'*

Analysis first consisted of identifying and clustering participants into five stakeholder groups based on self-reported role within the community system: 1) family members/self-advocates (people with lived experiences) (n=104), 2) IDD service providers (n=309), 3) MH service providers (n=285), 4) Government agency representatives (n=117), 5) MCO staff/funders (n=194) and 6) 'Other' (n=224). "Other" was comprised of a varied group of representatives that did not fit into the other four categories. Then, a frequency distribution analysis was conducted for each question response (works well; available, but not sufficient; needs improvement; do not have access; do not know). To determine whether significant differences in responses between service types were present, a chi-squared test was conducted for each question. The chi-squared statistical test represents a measure of the association between categorical survey responses.

Second, each response category was recoded to a numerical value so that mean (average) scores could be calculated. For this method, responses of '*do not know'* were eliminated to ensure that scores reflected the opinions of respondents with some exposure to the service. Scores were reported on a 0-3 scale with 0=no access, 1=needs improvement, 2=available, but not sufficient and 3=works well. An Analysis of Variants test, or ANOVA, was run to analyze overall mean differences between groups. When results were significant, they are noted in the report. The analysis provided in this report offers an overall picture of perceived quality of services between service types. For a more detailed presentation of each question and corresponding statistical analysis tables, see Appendix B.

Focus Groups

A series of sixteen (16) focus groups were facilitated statewide via Zoom with a total of 118 participants. Focus groups were conducted with family caregivers, self-advocates (persons with lived experiences), MH service providers, IDD service providers, MCO staff/funders, law enforcement, protection and advocacy personnel, and Community Ties providers (Appendix C: List of Focus Groups). Each focus group began with an introduction to the purpose of the analysis, followed by discussions in response to two questions, *"How well is the current service system meeting the needs of individuals with IDD who need mental health services?"* and *"What, if anything, would you change or add to the system to better support the mental health service needs of individuals with IDD and their families?"*

Responses were recorded and a qualitative analysis was conducted using a modified content analysis approach where common ideas and viewpoints were identified and grouped by the study team. This method allowed for major themes to emerge that guided the findings, discussion, and recommendations identified in this report (10). Focus groups provided greater depth and context to understanding survey results and were consistent with needs identified in the survey.

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Family Caregiver Experiences Interviews (FEIS)

A comprehensive assessment of service systems requires the inclusion of family perspectives and experiences. Most children, and many adults, with IDD-MH primarily depend on the support of their families (6). Therefore, this study included the input of family caregivers about recent experiences with mental health and other services for their family member with IDD-MH. The Family Experiences Interview Schedule (FEIS), developed by Tessler and Gamache (11), was employed to conduct 34 interviews of family caregiver volunteers who cared for 37 family members with IDD-MH at the time of the interviews. The surveys were conducted via telephone by interviewers trained in FEIS administration.

The FEIS is a 28 question, validated, family caregiver informant interview tool that has been used in other studies (2,3). Informants are asked to use a four-point Likert scale to rate their experiences with mental health service providers as: '*All that was wanted/needed;' 'Some but not as much as I wanted/needed;' 'Very little;'* or '*Not at all.'* While '*Did not answer/do not know'* was not a choice presented, if an informant could or did not answer a question, the interviewer marked this response. There are also two open-ended questions at the conclusion of the survey where informants were asked to assess whether their family member with IDD-MH experienced unmet service needs, and to give advice to service planners about the mental health needs of individuals with IDD.

In addition, respondents provided basic demographic information for their family member with IDD as well as themselves. Data collected included family makeup, total annual family income, and age, educational level, and overall health of the family caregiver. Information about day, home, and educational services that their family member with IDD receives was also gathered.

Description of Family Caregiver Respondents (n=34)

With the help of IDD-MH Task Force members, volunteer family caregivers were identified to participate in FEIS interviews. Nearly all (n=30) participants were parents of individuals with IDD-MH. One sibling, one grandparent, and two legal guardians were also interviewed. Most respondents were female (88%) and married (82%), with an average age of 53 (34-73). Most respondents were college graduates (93%) and reported working full or part-time (76%) at the time of the interview. Some families declined to report household income, but for those that did (n=25), 56% reported an annual income of at least $100,000. Fifty-six percent (56%) rated their own health as good or excellent. All family caregivers reported strong involvement with the mental health services of their family member and 92% reported that they attend mental health appointments with their family member.

Description of Service Recipients (n=37)

Family caregivers also provided non-identifying, demographic information about their family member with IDD-MH. Just over half (56%) of the people with IDD-MH were female, with an average age of 21. Living situation was also provided and 24 (65%) of the individuals resided with in their family home at the time of the interview. An additional 7 (19%) lived independently with supports, and the remainder (n=6) lived in paid residential settings (adult family home, group home, supported living). Two-thirds

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(68%; n=25) reported that the person with IDD-MH received school or day services (64% attended school, 28% worked part-time or were doing vocational training, 8% attended day services), and 32% (n=12) reported no structure day activities or programs.

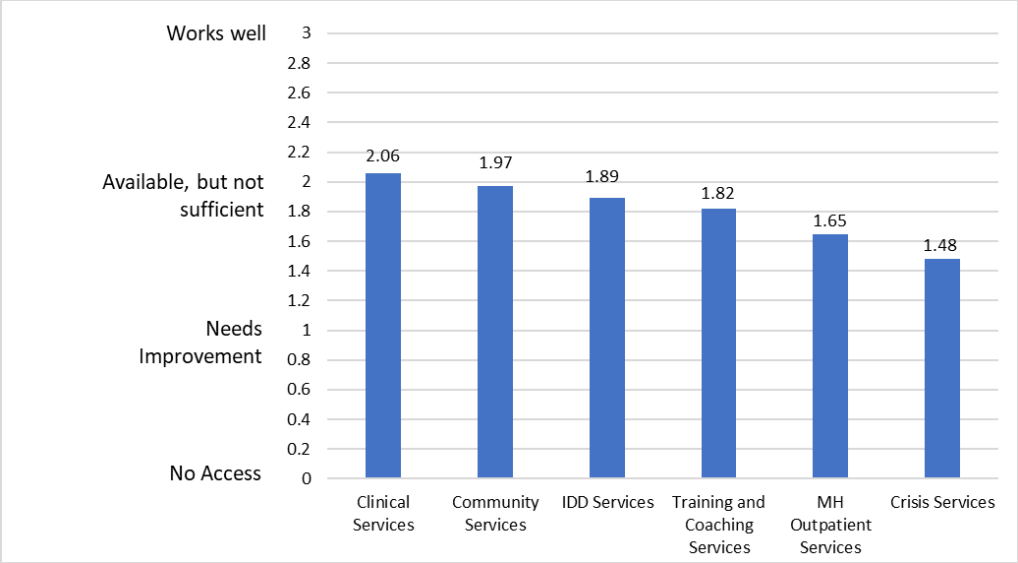
The findings of the FEIS are integrated into the conclusion section of this report. For a sample of respondent comments from all methods, please see Appendix D.

Findings

Over 1,380 respondents across Wisconsin participated in this analysis to learn about service experiences of individuals with IDD-MH.

Preliminary analysis of 1,233 online surveys examined whether there were significant differences between specific service types. A comparison of mean scores for each broad service category found all services were reported to either need improvement/unavailable or available but insufficient. The greatest services gaps pertained to crisis prevention and intervention services, followed by outpatient mental health services, training, and coaching services. However, it should be noted that none of the services that respondents were asked to rate were rated as working well. (Figure 2)

Figure 2: Mean Scores for Each Service Category



This preliminary quantitative analysis, coupled with qualitative findings from focus groups and FEIS interviews resulted in five prevailing themes. Overall, participants identified the need to improve services across the spectrum for people with IDD-MH, with the most frequent discussions centered on crisis services. Of interest was the emphasis on the development of expertise and training needed across the state. System collaboration was equally requested with improvement needed in mental health services.

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Below are the five themes regarding need for change that arose from this analysis:

1. Improve crisis response to reduce reliance on hospitals and Institutions for Mental Disease
2. Expand training and education of providers across the service system to better address mental health needs of people with IDD
3. Increase the availability of outpatient and preventative mental health services
4. Improve coordination and collaboration between service systems
5. Improve IDD supports to enhance quality of life for individuals with IDD-MH

The next sections of the report provide a description of each theme and associated findings.

Theme 1: Need to Improve Crisis Response

Description

The first major theme identified is that people with IDD and mental health service needs report a lack of crisis intervention services in the community. According to study participants, there is a lack of mobile crisis supports in the state, resulting in an over-reliance on local police departments, emergency departments and state hospital admissions. The majority (60%) of respondents reported that crisis services were either unavailable (13%) or did not meet the needs (47%), and that response was even more limited in rural areas (Figure 3). Police intervention was rated as the most available (26%), but family member FEIS respondents and focus group participants reported that the reliance on police often resulted in restraints, emergency detentions, and state hospital admissions when community crisis options were unavailable. **The need for community-based crisis supports (de-escalation and stabilization outside of the hospital) was the most cited recommendation from focus group participants (25%).** Focus groups emphasized that improved training and better access to proactive mental health services were essential elements to reduce the need for acute intervention.

Findings within Methods

Online Survey Results: The online survey delineated six questions to assess participant views on the system's capacity to respond to crises. These are:

1. Mobile crisis services
2. Crisis stabilization/hospital diversion beds
3. Community-based psychiatric inpatient beds
4. In-home crisis respite services
5. Out-of-home crisis respite services
6. Police response

For each specific crisis service option, respondents were asked to rate the availability. Table 1 provides a summary of the differences in respondent group reports about the availability of these crisis services

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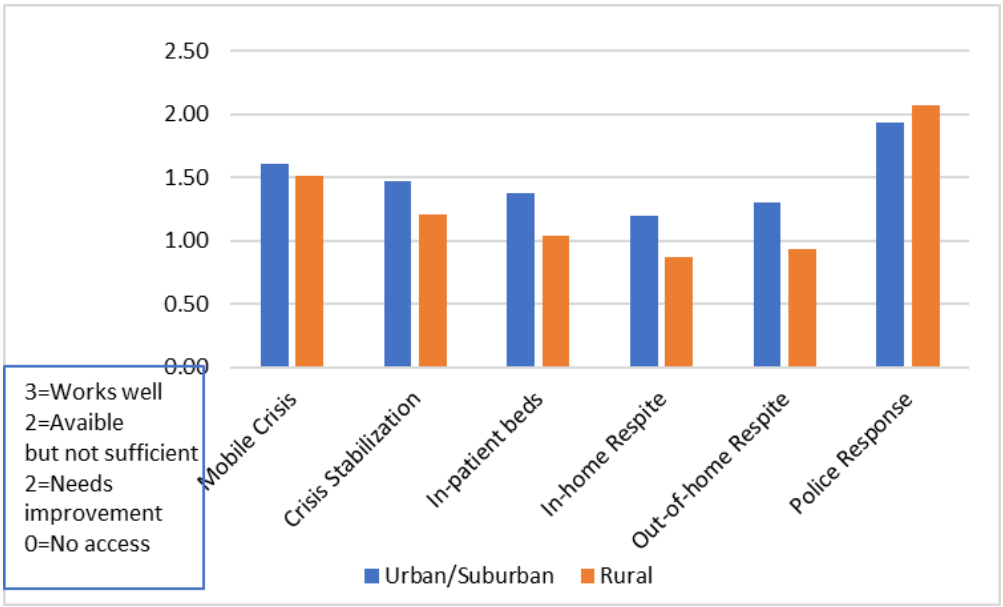
to meet the needs of Wisconsin citizens with IDD-MH and their families. Differences between services in urban/suburban and rural settings were significant (F=5.81), p=.02 (Figure 3). This means that rural communities reported less satisfaction with services that urban communities, with one exception. Police response was rated as higher in rural communities. For all services, it is important to note, the vast majority did not report that crisis services work well in Wisconsin.

Table 1: Reported Effectiveness of Crisis Services by Respondent Group

Services Work Well	Families/Self -Advocates	IDD Providers	MH Providers	Govt Agency	MCO/ Funders	Other
Mobile Crisis Services (people other than police to assist)	10%	11%	21%	25%	15%	7%
Crisis Stabilization/Hospital Diversion Beds	6%	10%	13%	8%	10%	7%
Community-Based Psychiatric Inpatient Beds	4%	8%	11%	8%	9%	7%
In-Home Crisis Respite	4%	7%	9%	4%	5%	4%
Out-of-Home Crisis Respite Services	4%	6%	8%	4%	7%	7%
Police Response	27%	29%	28%	25%	25%	19%

Figure 3: Crisis Supports Compared Between Urban and Rural Respondents (Mean Score)



When online survey respondents rated the availability of crisis service options as '*do not have access*' or *'needs improvement'* (n=258), they were asked to provide an explanation for their response. **More than half (60%) reported that community crisis resources beyond the police were not available.** Long distances, wait lists, and a lack of hospitals willing to admit people with IDD were the most

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frequently reported barriers. Nearly one-third of respondents (32%) reported that crisis responders (police, medical personnel, mental health practitioners) did not have training or expertise to support people with IDD experiencing mental health crisis. Sixteen percent (16%) reported that interactions with crisis providers were not helpful and, in some cases, exacerbated the crisis or resulted in criminal charges.

Approximately 60% of all survey respondents reported that acute crisis services are not available for individuals with IDD. According to study participants, there is a lack of mobile crisis supports in the state, resulting in an over-reliance on local police departments and hospital emergency rooms for assistance. The issues are across both the IDD and MH systems. The reluctance of mental health inpatient providers to admit people with IDD is reported to be directly related to the fear that people with IDD will not have a discharge plan when clinically stable. Conversely, poor collaboration and systems linkages along with lack of confidence in inpatient care, particularly interventions that cannot be maintained in the community, also reportedly contribute to community providers' reluctance for a person to return upon hospital discharge. Study participants universally identified a need for proactive support to prevent/de-escalate crises and increased training across the service system (IDD, MH, and justice system) as essential elements to reduce the need for acute care. While access to crisis stabilization was an identified need, less than 7% of survey respondents listed additional hospital beds as a need.

Focus Groups: **Within the focus groups, respondents reported the lack of appropriate response in times of crisis.** While some focus group participants cited examples where access to crisis support and trained mental health responders were successful, these were limited in scope and largely in urban areas. There was wide consensus that the lack of community crisis supports results in an over-reliance on the state hospitals and restrictive police intervention including emergency detentions and restraints. Respondents expressed concern that hospitalizations often functioned as temporary placements, or respite, due to the lack of capacity within the system to provide crisis support in the community setting.

Both mental health and IDD providers reported that a lack of communication and collaboration between systems often resulted in increased emergency service use. This concern was reported as a barrier across all themes and will be addressed later in the report.

Family Caregiver Interviews: Most family caregiver respondents reported that they did not know where to get help when needed and that there were limited, or no crisis service options. Table 2 shows responses from FEIS participants when asked four questions related to the availability of crisis services for their family members.

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Table 2: FEIS: Crisis Service Availability

	All wanted/ needed	Some	None/ very little	Do not know
Are there crisis options outside the hospital?	5%	8%	59%	30%
How much assistance did you receive about what to do in a crisis?	8%	27%	54%	11%
How much information did you get about whom to call in a crisis?	19%	19%	51%	11%
How much crisis help was available nights or weekends?	16%	8%	54%	22%

Limited cross-systems collaboration was also reflected in FEIS responses. Of the families who utilized inpatient hospitalization within the last year (n=8), 75% reported that the treatment had little to no effect, poor transition planning, and lack of community-based follow up care. While FEIS respondents reported little to no availability of crisis services, when asked, "*"Was there any particular service that your family member needed that was not available?"* they were more likely to **report a need for preventive crisis support and increased access to outpatient treatment than the need for acute response and out-of-home crisis intervention.**

Theme 2: Need to Expand Training and Education

Description

The second major theme identified is a lack of capacity within the service system to meet the mental health needs of individuals with IDD resulting in an increased reliance on crisis services. Respondents across constituency groups reported that a lack of providers with training in IDD-MH limited crisis planning and family education and support before the need for crisis services arise. No statistical differences were found across geographic regions and providers were more likely than families and government agency staff to rate education and training as available ($F=4.12$), $p=.001$. **Focus group respondents rated capacity building and training as the second most needed systemwide improvement (24%) and reported that a lack of recognition that individuals with IDD may also have mental health conditions along with the lack of collaboration within the service system exacerbated the need.** Focus group and family caregiver FEIS respondents stated that the inadequate expertise and training contributed to poor access to outpatient MH services for people with IDD resulting in further strain on the crisis system (Theme 3).

Findings within Methods

Online Survey: The survey was designed to assess respondents' views on the overall capacity of the service system to meet the mental health needs of individuals with IDD. The availability of the following services was evaluated:

1) *Mental health staff trained and qualified to support individuals with IDD*

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2) *Crisis prevention and intervention planning*
3) *Family education on mental health conditions and where to go for help*

One-quarter (25%) of survey respondents reported that mental health providers have adequate training to effectively support people with IDD, and approximately one-fifth (21%) reported the availability of crisis prevention and intervention support in the community. Only 17% of survey respondents reported that education to families on mental health conditions and where to get help was available. Family caregivers responded to the question, "*How much information did you receive from your family member's mental health professional regarding his/her illness?"* and only 35% felt that they got all the information they needed.

Table 3: Reported Effectiveness of Professional Training and Education by Respondent Group

Services Work Well	Families/Self -Advocates	IDD Providers	MH Providers	Govt. Agency	MCO/ Funders	Other
Trained Mental Health Staff	16%	32%	30%	15%	21%	21%
Crisis Prevention and Intervention	14%	25%	25%	18%	19%	18%
Family Education	10%	21%	22%	10%	17%	14%

Survey respondents who rated the availability of qualified mental health staff and specialists as '*no access'* or *'needs improvement'* were asked to provide their thoughts on the perceived service gaps across Wisconsin. Of those that commented (n=195), 46% reported that training on mental health support and treatment for individuals for IDD was difficult to find and often not part of the curricula for mental health and medical providers, law enforcement, or criminal justice personnel.

Respondents also reported that the lack of qualified and trained professionals often resulted in mental health providers who were unwilling to provide services because they felt they did not have the expertise (11%). An additional 20% of respondents reported that even when training on IDD-MH was available, few available staff and training costs made access difficult. Lastly, 14% of respondents stated that training was limited to crisis response with no focus on improved understanding of the IDD-MH population, crisis prevention, or overall support.

Focus Group Results: When asked about barriers to mental health care, constituency focus groups identified limited trained and qualified staff in both the IDD and MH systems. Participants reported that a dearth of qualified staff often exacerbated reactive responses to mental health symptoms and increased the demand for acute care. Most groups agreed that there are some experts within the state, but availability is not adequate to meet the demand (waiting lists, lack of Medicaid providers), while community mental health services were largely limited to medication management. One focus group participant stated," Services *from qualified folks can be life changing."*

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Theme 3: Need for Outpatient and Preventative Mental Health Services

Description

Theme 3 is the need to increase access to community-based outpatient mental health services for individuals with IDD in Wisconsin. While over two-thirds of survey respondents (67%) reported access to some mental health services, only 14% reported services worked well for individuals with IDD-MH. Participants noted that mental health services vary widely by county and lack of collaboration often resulted in fragmented care. Focus group participants pointed to an overall lack of providers, particularly psychiatrists, often resulting in long waitlists. Focus group participants and family caregivers also reported MH provider reluctance to provide mental health services, due to presentation being behavioral or 'part of the IDD.' Several respondents noted a trend towards behavior support plans or Applied Behavior Analysis (ABA) rather than mental health treatment for many individuals. One mental health provider stated, "*ABA does not treat mental health and the two need to be very different services. In my opinion, ABA is not the answer for adults (with IDD) in crisis that we typically serve. We need (a) provider that can understand IDD and provide therapeutic approaches modified to meet the needs of IDD like DBT, CBT, and ACT."*

Findings within Methods

In addition to access to training and education, the online survey asked for respondents to report their experiences with specific mental health services in the state of Wisconsin in the context of access, appropriateness, and accountability.

Online Survey Results: The online survey consisted of eight questions that assessed the participant's views on outpatient mental health care.

1) *Outpatient mental health therapy*
2) *Outpatient psychiatry*
3) *Diagnostic assessment (Practitioners trained to diagnose IDD and co-occurring MH)*
4) *Expressive therapies (Music, art, drama, or other expressive therapies)*
5) *Substance abuse treatment*
6) *Intensive outpatient mental health therapy*
7) *Behavioral supports*
8) *Mental health case management*

As shown in Table 4, about 14% of respondents reported that general mental health services work well for individuals with IDD. Once again, families and government agency staff were less likely to rate services as available compared to providers others. The results for IDD and MH providers were almost identical, suggesting that both service systems report limitations in the state. Again, it is noteworthy that services are reported to be less available in rural than urban centers of the state (Figure 4)

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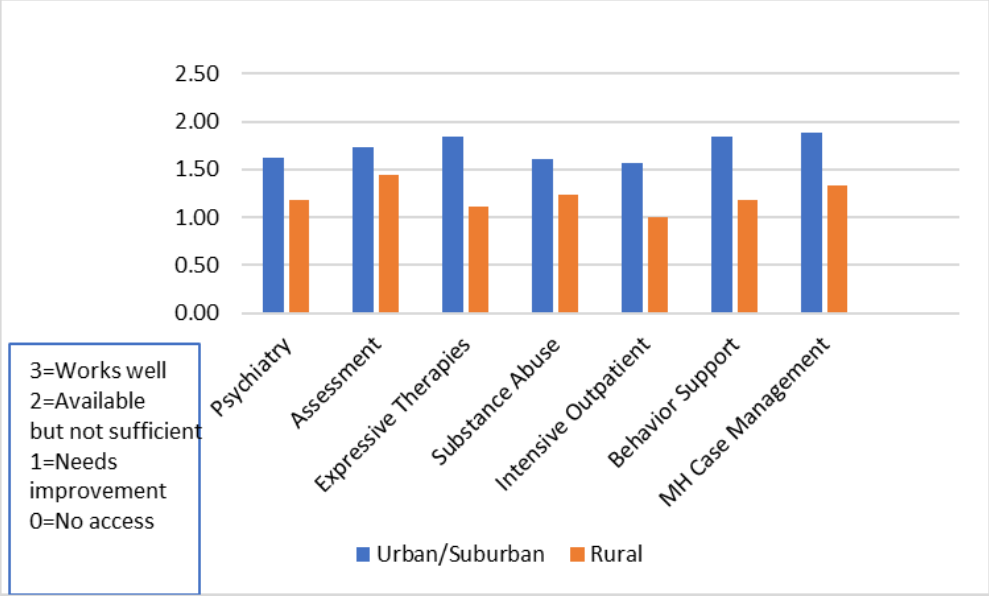
Table 4: Reported Effectiveness of Outpatient Mental Health Services by Respondent Group

Services Work Well	Families/Self -Advocates	IDD Providers	MH Providers	Govt. Agency	MCO/ Funders	Other
Outpatient MH Therapy	13%	21%	27%	12%	15%	14%
Psychiatry	9%	18%	16%	9%	12%	11%
Diagnostic Assessment	13%	19%	17%	9%	11%	15%
Expressive Therapies	9%	13%	14%	11%	11%	11%
Substance Abuse Treatment	9%	14%	18%	9%	13%	9%
Intensive Outpatient MH Therapy	6%	9%	14%	8%	11%	7%
Behavior Supports	6%	13%	18%	9%	14%	11%
MH Case Management	11%	21%	23%	12%	20%	14%

Figure 4: Availability of MH Outpatient Services by Urban and Rural Respondents (Mean Score)



Access to Qualified Prescribers/Psychiatrists in IDD-MH

An overwhelming number of participants reported that access to qualified psychiatrists is a statewide challenge, and even when they can access services, they may have to pay out of pocket for treatment. Online Survey: Two survey questions related to the availability of trained psychiatrists and common psychiatric medication prescribing practices were:

1) *In your community, who primarily prescribes medications to individuals with IDD and MH needs?*

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2) *Are there barriers to accessing prescribed mental health medication? If so, what are the barriers?*

Over 86% of survey respondents reported a dearth of qualified psychiatrists with treatment experience serving those with IDD and families. Of family members who reported barriers to obtaining medications, 88% identified a lack of providers as a factor. Additionally, 41% reported that psychiatric medications were prescribed by general practitioners or pediatricians rather than a psychiatrist.

Respondents also reported that family members with psychiatric needs often have long wait times to schedule appointments and many traveled significant distances to access providers. The lack of outpatient mental health providers was also cited as a barrier to successful discharge from the hospital.

Family Caregiver Interview Results: As part of the FEIS interview, family members were asked several questions regarding the availability of mental health services. When asked, *"Were the available mental health services for your family member the ones you thought were needed?"* only 11% responded that everything they needed was available. When asked about service and provider choice, only 14% of families reported as having some options, and 19% of family caregiver respondents reported satisfaction with the mental health services their family member received often citing lack of experience/expertise in working with people with IDD and an overreliance on medication as the sole treatment approach. As one family caregiver reported: "*I am grateful for the services that we have had. I don't want to sound ungrateful. Take families seriously when they are on the phone asking for help and crying. Some way to make the services out there not that hard to find, (so) it doesn't take years to find service providers."* When asked, *"Was there any particular service that your family member needed that was not available?"* 92% (n=34) of caregiver respondents who reported yes. Of that group, 65% said that they needed outpatient mental health therapy that is trauma informed.

Concerns about access and appropriateness were also reflected by FEIS respondents. When asked, *"Was there any particular service that your family member needed that was not available?"* 92% (n=34) of caregiver respondents reported yes. Of that group, 65% said that they needed trauma-informed, outpatient mental health therapy.

Table 5: FEIS: Mental Health Service Availability

	All	Some	None/ Very Little
Were the available mental health services for your family member the ones you thought were needed?	11%	36%	53%
How much opportunity did you or your family member have to choose between different mental health service options?	14%	24%	62%
How much opportunity did you or your family member have to choose a particular therapist?	11%	16%	73%
How satisfied were you with the outpatient mental health services your family member received?	19%	38%	44%

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Focus Groups: **There was broad consensus that lack of mental health providers, particularly those that accept Medicaid, is a significant challenge.** Once again, respondents noted that a lack of training for mental health providers often contributed to an unwillingness to provide needed services. One mental health provider reported that a limited preventative services contributes to high rates polypharmacy for individuals with IDD-MH. Individuals with lived experience of IDD-MH reported that even when providers were available, they often downplay mental health concerns or *"do not take our problems seriously."*

Theme 4: Need to Improve Coordination and Collaboration Between Systems

Description

Cross-system collaboration and coordination was not specifically addressed in the online survey, however, it emerged as a major theme within the focus groups and family caregiver interviews. Focus group participants pointed to a widely disparate system of county services and the lack of clearly defined roles within IDD and MH systems as barriers to integrated and timely care. Family caregiver FEIS respondents reported difficulty navigating the mental health system and more than one-third expressed concern for the welfare of families with fewer resources, education, or time required to find and access needed services and supports for their family members with IDD-MH.

Findings within Methods

Participants reported that collaboration between providers of care was the major need. The lack of role clarity was frequently cited as a barrier, with respondents reporting that there is a lack of shared responsibility between IDD and MH service systems. One family member reported, "*It felt like I was being told to pick one system and that there was no knowledge of how the two could work together*."

Focus group respondents also reported lack of collaboration made discharge from restrictive placements more difficult. MCO/Funders noted that a lack of collaboration and coordination between hospitals and community providers, making stepdown difficult, especially when interventions used successfully in the institution cannot be implemented in community settings. Providers noted that plans created in in-patient settings oftentimes cannot be generalized to the community.

In addition, participants reported barriers in system navigation to access services. When FEIS respondents were asked about satisfaction with their role in their family member's treatment, only 24% responded that they were completely satisfied and 30% reported that they were not satisfied at all. Family members pointed to stress and exhaustion related to system navigation as one reason for their dissatisfaction.

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Theme 5: Need to Improve IDD-MH Services

Description

The final theme to emerge was the **need for greater access to ordinary IDD services for people with IDD-MH.** Families report that opportunities that focus on emotional well-being are needed such as employment, social/recreational activities, and all elements of community inclusion. Respondents across the spectrum noted this would improve quality of life and decrease the need for mental health and crisis services, but that access is often difficult.

Findings within Methods

The online survey asked respondents about the effectiveness of IDD services (works well). As shown in Table 6, 23% of respondents reported that community IDD services are readily available. The biggest differences in perspectives were found between IDD providers and government agency staff. Families and self- advocates were least satisfied with most IDD services. The highest approvals were found in supported employment and self-directed services. However, none of the services were reported to work well for the majority within any representative groups. In addition, differences between rural and urban settings were less pronounced with regard to variability of services, where the overall finding was that all of what is wanted/needed is not available (Figure 6).

Table 6: Effectiveness of IDD Services by Respondent Group

Services Work Well	Families/Self-Advocates	IDD Providers	MH Providers	Govt. Agency	MCO/ Funders	Other
Residential Services	17%	42%	30%	15%	20%	25%
Supportive Home Care	18%	28%	21%	16%	17%	21%
Home and Community Based Supports	18%	35%	25%	18%	23%	23%
Adult Day Services	17%	37%	24%	22%	39%	17%
Pre-Vocational Services	18%	28%	20%	21%	42%	15%
Supported Employment	22%	29%	25%	20%	31%	20%
IDD Behavioral Supports	12%	21%	14%	5%	13%	13%
Case Management/Service Coordination	31%	42%	28%	29%	53%	28%
In-Home Respite	15%	15%	14%	9%	10%	8%
Out-of-Home Respite	6%	10%	11%	9%	12%	10%
Self-Directed Supports	23%	25%	19%	16%	42%	19%

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Figure 5: Availability of IDD Services within Urban and Rural Respondents (Mean Score)

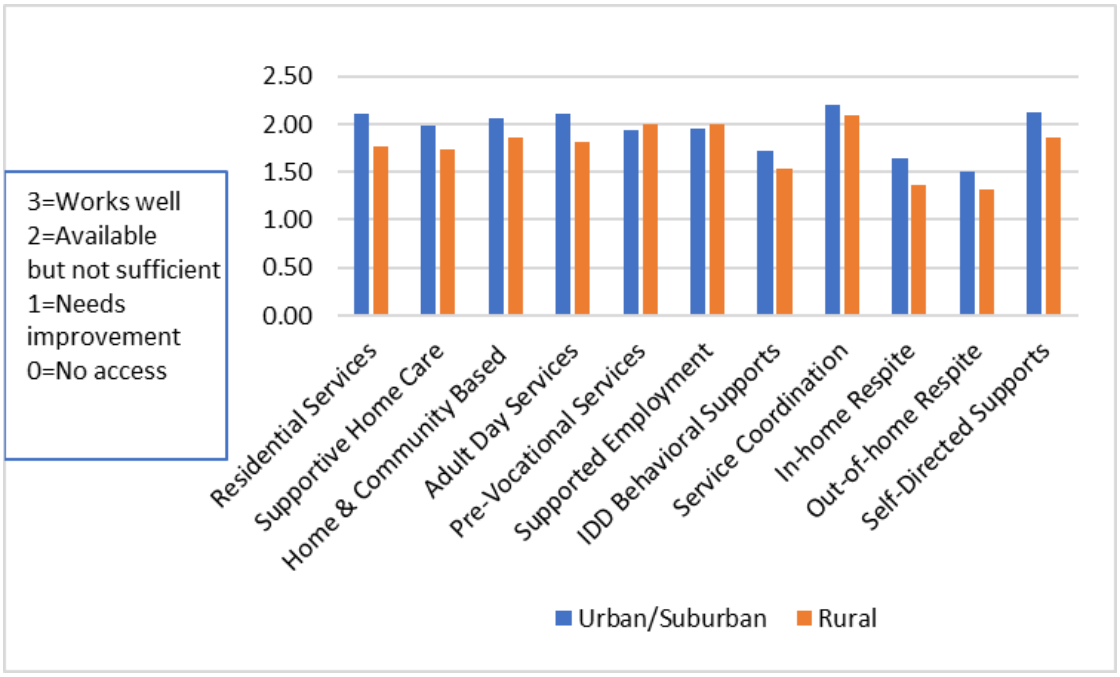
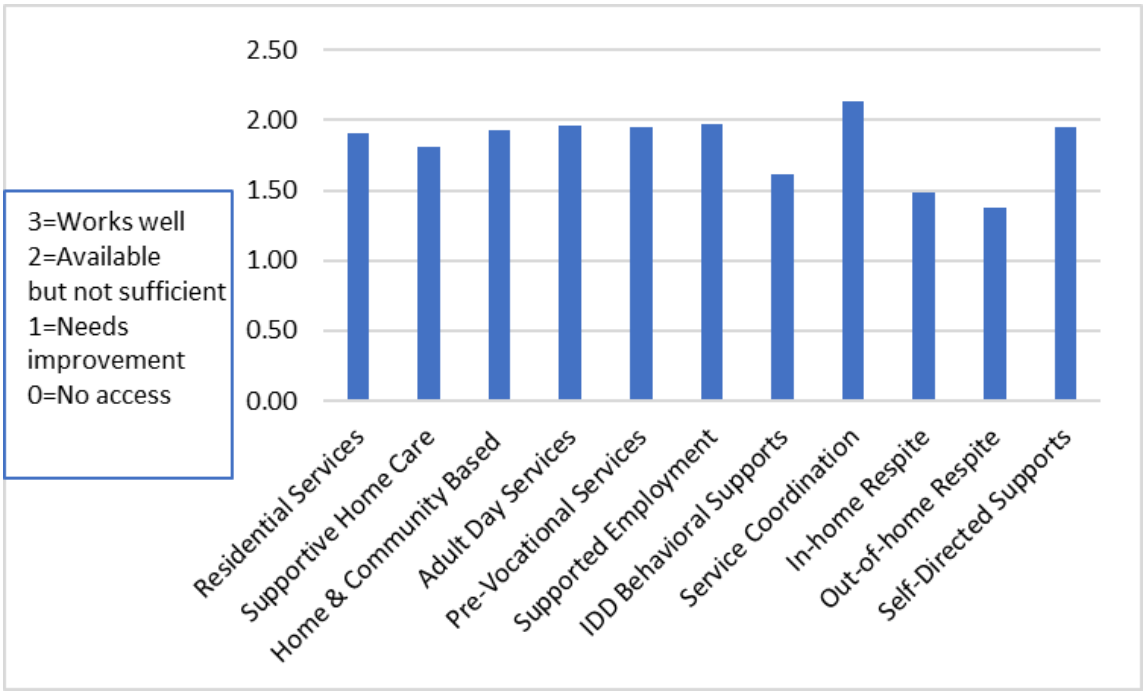


Figure 6: Overall Availability of IDD-MH Services by Type



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When online survey respondents rated the availability of service options as '*do not have access'* or *'needs improvement,'* they were asked to provide an explanation for their response. Of the 480 respondents who provided an explanation, 40% cited staffing shortages as the biggest barrier to access. It was also reported that people with IDD and mental health needs were even less likely to have access to needed IDD services further limiting their opportunities for community inclusion. Other respondents noted increased isolation, caregiver burnout, and risk of abuse due to lack of staff.

Focus Groups: Within focus groups, 20% of respondents reported the lack of IDD services for people with IDD-MH. They noted in-home supports, employment, respite, and community-based recreational activities as the biggest areas of need. Respondents reported that even when services were available and authorized, it was difficult to find qualified staff which oftentimes prevented individuals with IDD-MH from receiving them. They also noted low wages and the lack of professional recognition as limiting factors to finding skilled staff. Even when not identified as the biggest need, the direct care workforce crisis was a dominant theme in group discussions and informed this analysis.

Family Caregiver Interviews: While FEIS interviews focused on experiences with the mental health system, when asked, *"Was there any particular service that your family member needed that was not available?"* 35% of caregiver respondents reported a need for more community support services, particularly day and recreational services. One family member stated: *"My daughter has nowhere to go during the day. Places in the community tend to be overcrowded and overstimulating. Lack of consistent opportunities in the community makes required activities (i.e., doctors' appointments and going to the dentist) more difficult due to loss of tolerance and overall flexibility."*

Overall, there was an expressed need for more community and social activities and meaningful employment. Within all focus groups, the lack of services was identified as a contributing factor that exacerbates the need for mental health services due to few opportunities for people with IDD to thrive in their community. The despair people feel when excluded was viewed as a trigger for mental health concerns for some individuals. Families reported that improvement in quality of life would likely decrease the need for mental health and crisis services. People with IDD-MH are reported to be the last and least served by the IDD service providers in Wisconsin regarding services that promote community inclusion.

When family caregivers were asked, *"What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?"* forty-one (41%) of family caregivers expressed a desire to be listened to and have their significant role within the system acknowledged.

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Medicaid Claims Data Review

The Wisconsin Department of Human Services (DHS) provided a summary of Medicaid mental health expenditures for individuals receiving developmental disability services in calendar years 2019, 2020, and 2021. For these years, Medicaid paid $13 million for psychiatric inpatient stays and emergency room visits for psychiatric/behavioral challenges. Medicaid payments in the totaled more than of $161 million for Psychotropic drugs.

A total of 58,499 individuals identified by DHS as eligible for IDD services were included in this analysis of Medicaid claims between 2019-2021. Three outcomes were evaluated: 1) psychiatric emergency department visits; 2) inpatient psychiatric hospitalizations, and 3) psychotropic drug prescriptions. For each of these outcomes, we have included the number of instances, number of individuals, dollar amount billed, and dollar amount paid. Criteria for these claims (diagnoses and drug types) were based on codes identified from a list by psychiatric professionals (see Appendix E for the list of diagnoses and drugs included in the queries).

For emergency department use, there were 120,886 claims among 28,886 individuals. This represents an average of 2.1 psychiatric emergency claims per eligible individual (total # claims/eligible population). The percentage of individuals with at least one claim is 49% (individuals with claims/eligible population).

A total of $157,078,353 was billed to the system for psychiatric emergency department claims, of which, $9,736,389 was paid. This represents $2,685 and $166 that was billed and paid, respectively, per eligible individual over the reporting period.

For psychiatric inpatient use, there were 517 claims among 269 individuals. This represents <1 psychiatric inpatient claim per eligible individual (total # claims/eligible population). The percentage of individuals with at least one claim is <1% (individuals with claims/eligible population). A total of $26,715,664 was billed to the system for these psychiatric inpatient claims of which $3,353,758 was paid. This represents $457 and $57 that was billed and paid, respectively, per eligible individual over the reporting period.

For psychiatric medication use, there were 1,168,595 claims among 19,264 individuals. **This represents 19.9 psychiatric drug claims per eligible individual (total # claims/eligible population). The percentage of individuals with at least one claim is 33% (individuals with claims/eligible population). A total of $482,212,327 was billed to the system for these psychiatric drug claims of which $161,737,093 was paid**. This represents $8,243 and $2,764 that was billed and paid, respectively, per eligible individual over the reporting period.

These services combined represent a total of $11,385 billed and $2,988 paid by the system for each of the 58,499 eligible service recipients included in this analysis over the three-year period (approximately $3,795 billed and $995 paid per year). It is important to note the total cost billed to the system since it reflects a cost that hospitals in Wisconsin are absorbing even if it is not reimbursed.

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The considerable number of people with emergency room visits is of interest as it represents a significant percentage of the IDD population in Wisconsin. Emergency department visits should be a last resort as their ability to assist is limited. It is noteworthy that $157,000,000 was billed in psychiatric emergency room claims.

Table 7: Claims Data Summary of Psychiatric Related Expenditures 2019-2021

	Psychiatric ED Visits	Psychiatric Admissions	Psychiatric Drug Claims	Total Cost over 3 years	Cost per Eligible Individual (n=58,499)
# of Individuals	28,886	269	19,264		
# of Incidents	120,886	517	1,168,595		
Total Paid	$9,736,389	$3,353,758	$161,737,093	$174,827,240	$2,988.55
Total Cost	$157,078,353	$26,715,664	$482,212,327	$666,006,344	$11,384.92

The claims data show a very high emergency department use by eligible people with IDD for mental health events along with a tremendous burden on emergency departments with nearly 29,000 individuals who have IDD presenting with a mental health crisis, on average 4 times over the reporting period, with a reported cost of 157 million dollars. It is noteworthy that many people with IDD may be dual eligible and therefore they would also receive Medicare as the first payor prior to Medicaid. More information is needed. The findings indicate that a very high percentage, just under half of DHS enrolled individuals in Wisconsin, visited emergency rooms in mental health crises. This data indicates a significant need to improve proactive services and supports in the community.

The greatest expenditure was in medication claims, with polypharmacy a prevailing finding. This is concerning as it is known that polypharmacy can lead to increased crisis service use and long-term health conditions. Research also shows that polypharmacy can be the direct result of a lack of alternative mental health supports and interventions. These issues were prevalent in the reports of stakeholders who participated in the analysis.

It is noteworthy that the claims data did not capture the cost of first responders and police who are reportedly most often involved with people who visit emergency departments. The claims also do not capture other outcomes associated with crisis events including loss of employment for families, institutionalization and costs associated with waiver services to enhance management of complex presentations when a lack of alternatives arise, as was reported by stakeholders. They do not capture other insurance expenditures such as Medicare. Perhaps most importantly, every crisis event resulting in an emergency department visit represents a social cost, trauma to the person, and to their family. While presenting only a snapshot, the claims analysis provides and important snapshot for consideration.

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Enhanced Staffing Medicaid Waiver Data

DHS provided waiver cost data on approximately 2500 high-cost individuals for years 2019-2021. Of these individuals, between 26-31% had enhanced staffing costs each year totaling between $42 and $68 million dollars per year (Table 8).

Table 8: Enhanced Staffing Costs by Year

	2019	2020	2021
Individuals in analysis (n)	2497	2368	2633
Number (%) with enhanced staffing costs	649 (26%)	680 (29%)	805 (31%)
Cost for enhanced staffing	$45,887,533	$42,591,419	$68,264,991

In 2021, DHS supported 64 individuals each with a total service cost (minus medical expenses) of $400,000 or more. The cost for these individuals in 2021 was $35,453,794. Table 9 shows the costs (minus medical) for this group of individuals for the three-year period of 2019-2021 as well as the money that could be saved by a 10% reduction in these costs.

Table 9: Expenditures for Individuals with Costs Over $400,000 in 2021 (n=64)

	2019	2020	2021
Costs (minus medical)	$27,214,860.61	$31,935,428.87	$35,453,794.32
10 percent reduction	$2,721,486.06	$3,193,542.89	$3,545,379.43

The majority of cost was for residential support (89%) and most of the remaining expenditures (9%) were for enhanced staffing (attendant care/adult companion care). Targeted case management, day/employment services and expenditures for skill building and psychiatric treatment made up less than 2%. As shown in the data provided, the lack of alternatives can be reflected in the high use of enhanced staffing. Enhanced staffing for 64 high cost individuals is used to help manage difficulties and can be costly and restrictive. Should the state develop remedies to reduce dependence on enhanced staffing by only 10%, this saving could fund a statewide IDD-MH crisis prevention and intervention program to serve up to 200 individuals a year. The savings associated with the implementation of an effective safety net team may also reduce out of home placement, incarceration, and homelessness often associated with this population.

Limitations

The Wisconsin service system analysis provides a comprehensive analysis of service experiences of many community stakeholders across the state regarding the mental health service experiences of people with intellectual and developmental disabilities. The brief time of the study, number of

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participants, and the use of volunteer respondents limit the generalizability of the findings. However, statistically significant constituency group comparison results indicate that the findings are likely representative of a wider population of people with IDD and mental health needs in Wisconsin, making findings important for consideration in service planning and policy going forward.

Recommendations

The interest and active participation of stakeholders and state representatives are indicative of a community motivated to work together to improve services and supports for people with IDD-MH. Participation in this analysis includes the perspectives of citizens from across the state of Wisconsin, in both rural and urban settings, and across stakeholder groups. The need to improve IDD-MH services and supports was a clear and consistent finding. In addition, the Medicaid claims data, while limited in scope, provided important information about the frequent use of emergency rooms (for nearly half of the population) and psychiatric medications, to meet the mental health needs of people with IDD and the associated costs of those services

Based on the findings, the following is recommended for discussion with stakeholders:

1. Further evaluation of emergency department use to determine why this is occurring, what is being requested, and the outcomes. This may be linked with the high mental health medication use also found, as new medications are often prescribed for people with IDD-MH in crisis seeking assistance from emergency departments. The review of crisis related incident reports may be helpful. In addition to training for first responders (police and others) consider the development of a 24-hour mobile crisis response team with training and expertise to evaluate children and adults with IDD to reduce the burden on police and emergency departments.

2. Develop a task force/community of practice made up of representative stakeholders to develop a strategic plan for systems change. This should include review of current Wisconsin policies and requirements regarding services to people with IDD and mental health needs. The National Center for START Services can assist with this process.

3. Explore the need for community based sub-acute and acute care beds across the state. Prior to development and implementation, the mission and methods for these services must be well articulated, for them to be successful (See START Resource Center). Inpatient mental health service capacity should also be examined. These services appear to be largely absent from the community system at this time, and may explain the use of state institutions, or they are not utilized as designed, this is unclear.

4. Address the immediate need for training statewide, but this will have limited impact if it is provided without other actions. Training alone does not work without resources and support to

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change methods and practices in the field and therefore, training should be provided as part of the overall strategy to improve outcomes. In addition to first responder training, the findings indicate that there is also a need to develop more comprehensive crisis response and safety net services to include proactive strategies, mental health coaching, and crisis prevention and intervention planning. Again, training on these methods cannot lead to outcomes without resources and strategies to allow for change.

5. Consider the implications of the significant resources currently dedicated to supporting individuals with IDD-MH through enhanced staffing and waiver spending. Significant cost savings and enhanced life experience could take place through more proactive strategies to address mental health needs. The state may want to consider piloting the START model in one location in Wisconsin. START is designed to work with network partners to improve capacity across the service system. As one Wisconsin representative stated, the START pilot should not duplicate existing services but rather fill in gaps and network with willing partners to infuse resources and training toward evidence based best practices to the community. Piloting allows for the state to ensure that START is effective.

Based on the findings, the START model may be a good fit and may be piloted. Resources currently dedicated to emergency and enhanced restrictive services could be saved once the program is in place allowing for greater access to effective care for many more people in Wisconsin. The START model, first implemented in 1988, is a service linkage, crisis prevention and intervention program to improve capacity for effective services and supports for children and adults with intellectual/developmental disabilities and mental health needs. START is a nationally recognized, evidence-based practice for children and adults implemented across the U.S. Research findings indicate that START services significantly reduce the use of emergency rooms and inpatient services, improve mental health service experiences, and promote improved mental health for people with IDD-MH (1,2,3). For more information about the START model, see Appendix F and G. However, implementation of the START model without engagement and improvement in other important elements of the community system, namely IDD and MH services and supports, will limit the success of the program in meeting its mission.

Thank you for this opportunity to evaluate the service system in Wisconsin. While there is a lot of work to be done, the commitment and dedication of all who participated has been clear throughout the process. We look forward to the follow up discussion.

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Appendix A: Number of Respondents by County

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Appendix B: Pearson Chi-Squared Tables

Crisis Services

Mobile Crisis

	Group						
Crisis-mobile	Fam/SA	Gov. Agency	IDD Provider	MCO/ funder	MH Provider	Other	Total
No Access	13.82	14.29	9.68	6.25	10.34	11.41	10.39
Needs Improvement	17.07	27.62	22.87	25.57	21.84	18.12	22.28
Available	17.07	21.90	13.78	27.84	21.84	14.77	18.73
Works Well	9.76	24.76	10.56	14.77	20.69	7.38	13.76
Don't Know	42.28	11.43	43.11	25.57	25.29	48.32	34.83
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 91.87 Prob = 0.0000

Crisis Stabilization

	Group						
crisis-csu	Fam/SA	Gov. Agency	IDD Provider	MCO/ funder	MH Provider	Other	Total
No Access	13.93	18.69	8.21	8.43	13.64	10.67	11.17
Needs Improvement	27.05	42.06	30.50	39.89	31.25	20.00	31.47
Available	10.66	17.76	14.08	20.22	20.45	16.67	16.48
Works Well	5.74	8.41	9.68	9.55	13.07	6.67	9.22
Don't Know	42.62	13.08	37.54	21.91	21.59	46.00	31.66
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 79.49 Prob = 0.0000

Community Inpatient

	Group						
crisis-inpatient	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	18.70	24.76	9.88	14.12	14.20	12.00	14.05
Needs Improvement	23.58	39.05	30.52	36.72	39.20	23.33	32.00
Available	11.38	14.29	10.47	20.34	17.05	10.00	13.58
Works Well	4.07	7.62	8.43	9.04	11.36	7.33	8.28
Don't Know	42.28	14.29	40.70	19.77	18.18	47.33	32.09
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 96.37 Prob = 0.0000

In-Home Respite

	Group						
crisis-inrespite	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	25.20	34.91	12.54	24.86	19.89	16.67	20.00
Needs Improvement	22.76	32.08	27.99	31.64	27.84	19.33	27.16
Available	7.32	7.55	10.79	10.17	11.93	7.33	9.67
Works Well	4.07	3.77	7.29	5.08	9.09	4.00	6.05
Don't Know	40.65	21.70	41.40	28.25	31.25	52.67	37.12
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 66.64 Prob = 0.0000

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Out of Home Respite

	Group						
crisis-outrespite	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	20.49	28.30	12.57	24.29	15.43	13.42	17.55
Needs Improvement	23.77	37.74	26.90	32.77	31.43	25.50	29.13
Available	9.02	10.38	12.87	13.56	14.86	7.38	11.86
Works Well	4.10	3.77	5.85	6.78	8.00	6.71	6.07
Don't Know	42.62	19.81	41.81	22.60	30.29	46.98	35.39
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 62.00 Prob = 0.0000

Police Response

	Group						
crisis-police	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	3.28	2.83	1.17	2.81	0.58	3.33	2.05
Needs Improvement	26.23	27.36	25.07	24.72	26.01	18.00	24.53
Available	19.67	32.08	20.99	37.08	27.17	18.00	25.19
Works Well	27.05	25.47	29.15	25.28	27.75	18.67	26.21
Don't Know	23.77	12.26	23.62	10.11	18.50	42.00	22.01
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 78.00 Prob = 0.0000

Training and Education

Trained Providers

	Group						
MH-training	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	4.76	1.85	2.87	3.89	1.69	3.23	3.01
Needs Improvement	40.48	37.96	25.21	33.89	23.16	18.71	28.40
Available	19.84	25.93	25.21	28.89	31.64	20.65	25.66
Works Well	15.87	14.81	31.52	21.11	29.94	20.65	24.57
Don't Know	19.05	19.44	15.19	12.22	13.56	36.77	18.36
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 85.05 Prob = 0.0000

Crisis Prevention

	Group						
MH-crisisprev	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	6.35	4.63	3.72	5.56	2.29	2.61	4.03
Needs Improvement	30.16	31.48	28.37	31.11	29.14	24.84	28.96
Available	29.37	31.48	24.93	33.89	32.00	18.30	27.77
Works Well	13.49	17.59	24.93	18.89	25.14	17.65	20.90
Don't Know	20.63	14.81	18.05	10.56	11.43	36.60	18.33
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 65.33 Prob = 0.0000

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Family Education

	Group						
MH-fameduca	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	7.14	4.63	2.89	6.11	1.14	2.58	3.76
Needs Improvement	37.30	39.81	25.14	32.22	31.25	22.58	29.79
Available	25.40	28.70	24.86	30.56	31.25	18.71	26.40
Works Well	10.32	10.19	20.52	16.67	21.59	13.55	16.87
Don't Know	19.84	16.67	26.59	14.44	14.77	42.58	23.19
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 82.62 Prob = 0.0000

Outpatient Mental Health

Therapy

	Group						
MH-out	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	6.30	2.86	2.60	2.26	1.70	6.54	3.41
Needs Improvement	37.01	34.29	29.77	27.12	28.41	27.45	30.07
Available	24.41	38.10	23.41	46.33	34.66	18.30	29.80
Works Well	12.60	12.38	20.52	15.25	26.70	14.38	18.08
Don't Know	19.69	12.38	23.70	9.04	8.52	33.33	18.63
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 104.43 Prob = 0.0000

Psychiatry

	Group						
MH-psych	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	10.24	7.62	5.76	5.68	4.00	11.76	7.02
Needs Improvement	38.58	41.90	33.43	45.45	42.86	24.84	37.12
Available	19.69	27.62	19.02	25.57	26.86	15.03	21.70
Works Well	9.45	8.57	17.58	11.93	16.00	11.11	13.67
Don't Know	22.05	14.29	24.21	11.36	10.29	37.25	20.50
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 83.80 Prob = 0.0000

Diagnostic Assessment

	Group						
MH-assess	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	7.87	2.83	3.77	3.43	1.72	10.53	4.73
Needs Improvement	35.43	44.34	28.41	38.29	31.61	23.03	32.16
Available	25.20	31.13	21.74	31.43	35.63	19.08	26.51
Works Well	13.39	8.49	18.55	11.43	17.24	14.47	15.01
Don't Know	18.11	13.21	27.54	15.43	13.79	32.89	21.59
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 80.84 Prob = 0.0000

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Expressive Therapy

	Group						
MH-expressive	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	18.25	12.26	9.28	11.86	8.67	9.87	11.03
Needs Improvement	30.95	33.02	22.61	31.07	31.21	20.39	27.06
Available	14.29	23.58	21.45	20.34	24.86	17.11	20.57
Works Well	9.52	11.32	13.33	10.73	14.45	11.18	12.14
Don't Know	26.98	19.81	33.33	25.99	20.81	41.45	29.19
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 43.34 Prob = 0.0018

Substance Abuse Treatment

	Group						
MH-aod	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	7.09	4.72	3.79	5.71	1.14	7.95	4.73
Needs Improvement	24.41	35.85	22.16	30.29	27.84	21.19	25.88
Available	14.96	31.13	16.91	32.00	30.68	17.22	22.82
Works Well	8.66	9.43	13.99	13.14	17.61	8.61	12.62
Don't Know	44.88	18.87	43.15	18.86	22.73	45.03	33.95
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 96.91 Prob = 0.0000

Intensive Outpatient

	Group						
MH-intenout	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	13.49	9.62	6.19	9.66	14.94	10.60	10.00
Needs Improvement	27.78	36.54	23.01	28.98	28.74	23.84	26.92
Available	15.87	25.96	14.45	23.30	21.26	16.56	18.60
Works Well	5.56	7.69	9.14	10.80	14.37	6.62	9.35
Don't Know	37.30	20.19	47.20	27.27	20.69	42.38	35.14
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 72.15 Prob = 0.0000

Behavioral Treatment

	Group						
MH-behav	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	10.24	10.48	4.36	6.29	7.39	9.87	7.23
Needs Improvement	33.86	40.00	25.00	29.71	31.82	21.71	28.92
Available	20.47	21.90	20.93	22.29	23.30	17.76	21.13
Works Well	6.30	8.57	12.50	14.29	17.05	11.18	12.23
Don't Know	29.13	19.05	37.21	27.43	20.45	39.47	30.49
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 49.69 Prob = 0.0002

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Case Management

	Group						
MH-casemanag	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	8.66	4.72	4.64	4.60	1.16	8.50	5.11
Needs Improvement	37.80	34.91	23.48	28.16	29.07	24.84	28.13
Available	21.26	36.79	23.48	36.78	36.05	17.65	27.86
Works Well	11.02	12.26	21.16	20.11	22.67	14.38	18.20
Don't Know	21.26	11.32	27.25	10.34	11.05	34.64	20.71
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 97.13 Prob = 0.0000

IDD Services

Residential

	Group						
IDD-CBRS	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	9.09	6.03	2.13	1.57	4.69	5.33	4.13
Needs Improvement	30.07	35.34	24.80	36.13	23.44	26.63	28.33
Available	14.69	31.90	23.47	38.22	21.88	20.12	24.87
Works Well	16.78	15.52	42.13	20.42	29.69	25.44	28.58
Don't Know	29.37	11.21	7.47	3.66	20.31	22.49	14.08
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 158.76 Prob = 0.0000

Supportive Home Care

	Group						
IDD-homecare	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	3.47	2.59	3.65	2.67	2.17	2.29	2.93
Needs Improvement	31.94	42.24	27.53	41.18	28.80	27.43	31.93
Available	20.83	29.31	26.40	36.90	22.28	26.86	27.11
Works Well	18.06	15.52	28.37	16.58	21.20	21.14	21.69
Don't Know	25.69	10.34	14.04	2.67	25.54	22.29	16.35
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 83.36 Prob = 0.0000

Home & Community Supports

	Group						
IDD-comm	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	2.82	1.74	1.94	1.60	1.64	0.58	1.73
Needs Improvement	30.28	34.78	25.76	29.95	26.78	28.65	28.47
Available	34.51	38.26	29.09	42.25	31.69	26.90	32.87
Works Well	18.31	18.26	35.18	22.99	24.59	22.81	25.97
Don't Know	14.08	6.96	8.03	3.21	15.30	21.05	10.96
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 69.18 Prob = 0.0000

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Adult Day

	Group						
IDD-day	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	9.03	9.73	3.64	1.08	8.24	7.19	5.74
Needs Improvement	14.58	22.12	18.49	19.35	22.53	20.36	19.41
Available	20.14	27.43	26.33	34.41	20.88	23.95	25.76
Works Well	17.36	22.12	36.97	38.71	24.18	16.77	28.37
Don't Know	38.89	18.58	14.57	6.45	24.18	31.74	20.71
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 122.68 Prob = 0.0000

Pre-Vocational

	Group						
IDD-voc	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	7.80	2.63	4.83	1.61	3.28	4.22	4.12
Needs Improvement	18.44	28.95	19.60	16.67	19.67	21.08	20.14
Available	24.82	29.82	25.00	29.03	26.78	18.07	25.39
Works Well	17.73	21.05	28.41	41.94	20.22	15.06	25.31
Don't Know	31.21	17.54	22.16	10.75	30.05	41.57	25.04
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 95.63 Prob = 0.0000

Supported Employment

	Group						
IDD-jobcoach	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	4.90	2.63	3.35	1.61	2.70	4.14	3.20
Needs Improvement	23.78	24.56	20.39	19.89	20.54	22.49	21.47
Available	21.68	37.72	31.01	36.02	28.11	15.38	28.57
Works Well	21.68	20.18	29.05	31.18	25.41	19.53	25.63
Don't Know	27.97	14.91	16.20	11.29	23.24	38.46	21.13
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 76.14 Prob = 0.0000

Behavioral Supports

	Group						
IDD-behav	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	7.09	7.96	5.92	5.38	3.28	4.71	5.57
Needs Improvement	39.72	43.36	32.68	44.09	28.42	24.71	34.58
Available	21.99	27.43	24.79	26.34	26.23	18.82	24.30
Works Well	12.06	5.31	21.13	13.44	14.21	12.94	14.90
Don't Know	19.15	15.93	15.49	10.75	27.87	38.82	20.64
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 87.26 Prob = 0.0000

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Service Coordination

	Group						
IDD-coord	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	2.84	0.88	1.67	2.15	1.09	1.73	1.73
Needs Improvement	27.66	25.44	20.89	7.53	24.04	25.43	21.19
Available	26.24	37.72	28.13	33.87	34.43	24.86	30.28
Works Well	31.21	28.95	42.06	53.23	28.42	27.75	36.94
Don't Know	12.06	7.02	7.24	3.23	12.02	20.23	9.86
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 90.18 Prob = 0.0000

In-Home Respite

	Group						
IDD-inhome respite	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	12.06	8.85	10.76	7.53	7.69	5.92	9.00
Needs Improvement	27.66	36.28	30.59	45.70	26.37	28.40	32.26
Available	12.06	27.43	20.40	21.51	18.68	18.93	19.76
Works Well	14.89	8.85	14.73	9.68	14.29	8.28	12.33
Don't Know	33.33	18.58	23.51	15.59	32.97	38.46	26.66
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 62.25 Prob = 0.0000

Out of Home Respite

	Group						
IDD-outrespite	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	11.51	13.91	11.85	10.27	7.87	5.99	10.27
Needs Improvement	28.78	40.00	33.53	43.24	27.53	28.74	33.54
Available	15.83	19.13	17.92	22.16	17.98	16.77	18.32
Works Well	6.47	8.70	9.54	11.89	11.24	9.58	9.73
Don't Know	37.41	18.26	27.17	12.43	35.39	38.92	28.14
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 57.17 Prob = 0.0000

Self-Directed Supports

	Group						
IDD-selfdirect	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	4.32	3.51	3.98	1.08	2.75	2.91	3.15
Needs Improvement	20.86	30.70	20.17	15.14	26.37	20.93	21.59
Available	15.83	29.82	23.86	34.59	19.78	18.60	23.78
Works Well	23.02	15.79	25.00	41.62	18.68	19.19	24.65
Don't Know	35.97	20.18	26.99	7.57	32.42	38.37	26.84
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 104.62 Prob = 0.0000

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Clinical Services

Occupational Therapy

CS-OT	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	5.59	4.39	0.82	1.62	4.35	4.12	2.93
Needs Improvement	14.69	15.79	10.44	11.89	12.50	9.41	11.90
Available	27.97	30.70	24.73	23.24	23.37	18.24	24.31
Works Well	25.87	25.44	32.97	49.73	27.72	28.82	32.59
Don't Know	25.87	23.68	31.04	13.51	32.07	39.41	28.28
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 69.71 Prob = 0.0000

CSPT

Physical Therapy	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	3.52	3.54	0.82	1.08	3.83	2.33	2.16
Needs Improvement	11.97	11.50	10.16	7.03	8.74	8.72	9.58
Available	26.06	28.32	20.88	22.16	19.67	17.44	21.74
Works Well	29.58	30.09	39.56	58.38	35.52	33.14	38.83
Don't Know	28.87	26.55	28.57	11.35	32.24	38.37	27.70
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 69.04 Prob = 0.0000

CSSLP

Speech/Language	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	10.64	5.26	1.38	2.70	4.32	3.55	3.89
Needs Improvement	10.64	12.28	12.98	9.19	10.27	9.47	11.07
Available	24.11	28.95	24.03	26.49	23.24	15.98	23.62
Works Well	26.24	28.07	29.28	45.41	24.86	29.59	30.71
Don't Know	28.37	25.44	32.32	16.22	37.30	41.42	30.71
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 72.14 Prob = 0.0000

Hearing

CS-hear	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	2.80	6.14	1.11	1.63	3.26	4.76	2.78
Needs Improvement	6.99	16.67	10.28	15.22	10.87	14.29	11.97
Available	20.98	27.19	18.61	27.17	19.57	11.90	20.29
Works Well	13.29	19.30	23.33	31.52	16.85	23.21	21.94
Don't Know	55.94	30.70	46.67	24.46	49.46	45.83	43.02
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 76.58 Prob = 0.0000

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Vision

	Group						
CS-vision	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	5.59	7.02	2.22	1.62	3.83	4.71	3.64
Needs Improvement	12.59	15.79	11.39	15.68	10.38	16.47	13.25
Available	18.88	29.82	16.67	28.11	19.67	12.94	20.00
Works Well	13.29	16.67	24.17	29.19	17.49	20.59	21.30
Don't Know	49.65	30.70	45.56	25.41	48.63	45.29	41.82
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 67.09 Prob = 0.0000

Traumatic Brain Injury

	Group						
CS-TBI	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	6.34	11.50	1.93	4.84	3.76	7.10	4.92
Needs Improvement	17.61	26.55	18.23	20.97	17.74	17.75	19.26
Available	12.68	22.12	21.55	31.18	27.42	17.75	22.45
Works Well	9.15	11.50	18.23	24.73	11.83	15.38	16.06
Don't Know	54.23	28.32	40.06	18.28	39.25	42.01	37.31
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 90.54 Prob = 0.0000

Feeding/Nutrition

	Group						
CS-feeding	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	2.84	3.51	1.94	1.63	3.26	5.36	2.86
Needs Improvement	14.89	13.16	11.36	13.59	11.41	9.52	12.07
Available	14.18	29.82	20.78	19.57	23.37	19.05	20.83
Works Well	20.57	24.56	28.53	42.93	19.57	20.83	26.91
Don't Know	47.52	28.95	37.40	22.28	42.39	45.24	37.33
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 64.42 Prob = 0.0000

Applied Behavior Analysis

	Group						
CS-ABA	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	9.22	7.02	3.60	6.45	2.73	7.83	5.56
Needs Improvement	24.11	24.56	19.39	18.28	24.59	13.86	20.33
Available	14.89	23.68	18.28	22.58	22.95	13.25	19.11
Works Well	11.35	9.65	16.07	15.05	12.02	7.23	12.77
Don't Know	40.43	35.09	42.66	37.63	37.70	57.83	42.22
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 48.49 Prob = 0.0004

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Community Services

Medical

Comm-med	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	0.00	0.87	0.27	0.53	1.06	1.14	0.59
Needs Improvement	12.50	12.17	7.73	7.37	10.64	9.14	9.35
Available	25.69	29.57	27.47	26.84	24.47	22.86	26.20
Works Well	53.47	50.43	57.60	63.16	50.53	44.00	54.17
Don't Know	8.33	6.96	6.93	2.11	13.30	22.86	9.69
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 66.72 Prob = 0.0000

Dental

comm-dental	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	5.56	7.76	6.67	8.47	5.32	7.56	6.84
Needs Improvement	23.61	37.07	36.00	42.33	27.13	25.58	32.69
Available	26.39	29.31	25.07	28.57	23.40	22.09	25.51
Works Well	36.81	17.24	24.53	16.40	27.13	20.93	23.90
Don't Know	7.64	8.62	7.73	4.23	17.02	23.84	11.06
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 83.34 Prob = 0.0000

Transportation

comm-trans	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	6.29	3.45	2.42	0.00	1.08	2.31	2.37
Needs Improvement	26.57	43.97	33.87	28.95	42.47	32.37	34.32
Available	31.47	31.90	30.11	38.42	23.66	25.43	30.08
Works Well	22.38	14.66	27.69	30.53	22.04	23.12	24.66
Don't Know	13.29	6.03	5.91	2.11	10.75	16.76	8.56
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 76.39 Prob = 0.0000

Recreation

comm-rercreat	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	6.94	1.72	1.59	2.11	3.72	4.09	3.04
Needs Improvement	29.86	28.45	23.34	25.26	31.91	26.32	26.73
Available	31.94	31.03	33.95	36.84	22.34	19.88	30.02
Works Well	18.06	27.59	34.22	30.00	21.81	21.64	27.15
Don't Know	13.19	11.21	6.90	5.79	20.21	28.07	13.07
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 102.52 Prob = 0.0000

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Higher Education

comm-highered	Group						
	Fam/SA	Gov. Agency	IDD Provider	MCO/ Funder	MH Provider	Other	Total
No Access	4.86	2.61	2.97	3.21	4.81	4.73	3.75
Needs Improvement	27.78	30.43	21.62	22.99	25.67	18.93	23.72
Available	15.28	29.57	22.43	29.41	21.93	13.02	21.93
Works Well	14.58	16.52	14.32	19.25	16.58	13.02	15.53
Don't Know	37.50	20.87	38.65	25.13	31.02	50.30	35.07
Total	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 53.87 Prob = 0.0001

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Appendix C: Focus Group Participant Groups and Dates

Group	Date	Participants
Disability Rights WI	3/17/2022	6
Waisman Center - Community Ties	3/17/2022	7
Outpatient Psychiatry Providers	3/18/2022	8
IDD Residential Providers	3/25/2022	4
Dane County Collaborative Stabilization Coalition	3/25/2022	12
Family Members	4/7/2022	2
Winnebago Hospital	4/7/2022	3
MCO Staff	4/8/2022	11
Self-Advocates	4/11/2022	10
Intensive Treatment Providers	4/11/2022	10
ASD Community of Practice	4/12/2022	9
Madison Police	4/13/2022	2
MCO Staff	4/14/2022	8
Juvenile Justice Interview	4/14/2022	1
DHS Staff	4/15/2022	11
Law Enforcement	4/15/2022	5
MCO Staff	4/18/2022	9

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Appendix D: Respondent Comments

Survey Respondent Comments

Crisis respite is often unavailable or inadequate for family support. Lack of respite for families in crisis is leading to unnecessary interactions with law enforcement, significant family stress, and challenges keeping children in their family home. -IDD Practitioner
Police are a reactionary service when there is already an active crisis that is putting the person or others at imminent risk and is not a service that should be utilized often. Police interactions are often traumatizing for the person in crisis and lead to incarcerations or citations instead of supports. -MCO Staff
Individuals with ASD having a mental health crisis don't go to mental health care but rather are treated as criminals and detained by police. –Family Member
As a mental health provider, most my of training was learned through experience. MH providers could definitely use more supported training on supporting individuals with both IDD and MH. County crisis also does not receive much training or support in this area, which many times results in police getting involved, which is not trauma informed nor beneficial. -MH Practitioner
Many mental health professionals do not feel confident in their abilities to care for patients with IDD, even though the recommended treatment/modality might be the same (e.g., CBT for anxiety) just adapted for developmental level. –IDD Practitioner
Need better training on basics of mental health and behavioral health, triggers, interventions, and how different environments can impact conditions. –MCO Staff
There are few mental health professionals that are familiar with the unique world view and traits of autistics. Mental health issues are often confused with autism symptoms and vice-versa. –Family Member
Too many times we are trying to apply a behavior planning strategy where a MH treatment plan should be completed. -Mental Health Practitioner
Many of these services are denied and said to be LAST resorts in problem solving with families, even when there are clear indicators that treatment is needed. –Family Member
There are very few individuals trained to diagnose both IDD and mental health needs. As soon as autism is mentioned along with a mental health need the doors seem to close and they feel that someone with a diagnosis of autism can't participate in their recovery. -Gov't Agency Staff
There is such a shortage of trained providers in the area of mental health. Our students (with IDD) are told they can't get therapy for mental health. Where does that leave a student with trauma in terms of

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getting counseling? It is very sad our most vulnerable populations, students with IEPs, have the least access to the professional therapy services they need. -School Personnel
Lack of access to routine mental health services leads to more people in crisis and nothing in between the community and the hospital. -Disability Advocate
It is very difficult to find mental health providers right now and there are waitlists that are months long. -Family caregiver
I find it deplorable that a child of any age is admitted for inpatient treatment and no contact is made with an outside provider - no follow up for medications started in the hospital or guarantee of services/counseling after discharge. -Medical Provider
It's hard to find a provider who is comfortable. Many don't feel adequately trained and in combination with a lack of Medicaid providers, this creates a large hole in our system -Gov't Agency Staff
Our biggest issue is that we cannot find any caregivers. My two workers are completely exhausted. – Family Member
Families have case managers but there aren't enough agency providers to provide needed services such as respite, supportive home care, etc. Providers are overwhelmed with waiting lists and staffing shortages (wages through personal care agencies is not OK). -Gov't Agency Staff
With caregiver shortage and other services unavailable, families are taking on more responsibilities with little or no respite creating risk for burnout while behaviors increase in individuals who are spending all their time at home with little structure or outside activities. -MCO/Funder
Parents and their children feel lost in the wait lists and stressors of caring for their children with complex behavioral/medical/mental health needs. -MH Practitioner
If a service is good, it becomes impossible to get more people involved due to staffing. Low pay results in both staff minimally engaged and the strong staff burning out. -School Personnel.

Focus Group Respondent Comments

De-escalation and crisis intervention training is especially important for people with developmental disabilities. De-escalation addresses our population's need for support, calming our bodies and minds. (It) brings caring professionals rather than law enforcement. Caring professionals' job is to care for people. Law enforcement's job is to stop the threat. -Self-Advocate
Better training on the front end could prevent the escalation of a crisis and the need for police response. *–Law Enforcement*

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Staff get a bad reputation when they have no experience, training, or back-up and are expected to provide crisis support. -IDD Service Provider
There is a complete lack of education for providers at all levels on IDD. With no training, there is reluctance of accountability-whose job is it to do mental health for IDD. -MH Practitioner
Why do providers call 911? Because in that moment they can't keep everyone safe and there is no one else to call. A hospitalization may give them time to figure out what to do next, but it's rarely appropriate. –IDD Provider
Incredibly sad that families beg for an admission because they have nothing else. –Crisis Provider
Need to shift the thinking to how to support people in their home rather than removing them. –Gov't Agency Staff
Being restrained and guarded by law enforcement is terrible for people in crisis, but we get called because we respond quickly and there is no one else. -Law Enforcement Personnel
In my experience people who have IDD face even more stigma in the area of mental health. Our struggles are downplayed or thought to be behaviors/a part of our disability. Professionals can be quick to label/blame us rather than help us. -Self-Advocate
Hard to find counselors who want to talk to us- they just want to try every medication. Medication is not the solution. I don't want to be a walking zombie, I wasn't helped. -Self-Advocate
Better outpatient care would go a long way towards crisis prevention. -MH Practitioner
When we don't have anything else, we are left to try and manage people with medication. MH Practitioner
No one speaks the same language. Better communication between the systems, so we stop categorizing kids into either MH or IDD. We need a system that sees the child as a whole person and not a checkmark in a box. -Family Member
People get bounced between the two systems when no one can decide what is driving the train. It feels like they can't support MH and vice versa. Behaviors are used as an exclusionary criterion for MH treatment. People get sent home even with acute MH symptoms (like suicidality) and that leads to increased restrictive measures. -MCO Staff
Home is not the least restrictive environment if your mental health issues keep you from accessing the community. -Family Member

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We need better communication between the two systems so that plans can actually be implemented in the community. -Family Member
It would be a blessing if children and young adults (with IDD) could live a meaningful and happy life in a system that can support their needs with experienced and trained caregivers. -First Responder
More infrastructure would improve quality of life. Things like employment give people purpose and meaning which help mental health overall. _MCO Staff
Individuals with IDD-MH need to have meaningful activities to fill their days. More purpose leads to better mental health. -Gov't Agency Staff

Family Caregiver Interview Respondent Comments

Families shouldn't have to beg for services, and we shouldn't have to wait until there is a crisis before getting services that would help prevent the problem.
When someone is in crisis, they need trauma-informed support and de-escalation, not police intervention.
The system is doing a bad job being pro-active and preventive.
With all my knowledge, I struggle to navigate. If I'm struggling, how do other families without fewer resources or knowledge do it?
Everyday life takes so much bandwidth, and the services are so fractured. It's really hard to get the information in a cohesive and coherent way. The highway on-ramp to services is broken.
The programs are siloed, and parents need to do the heavy lifting to get anything. We need services to help navigate. Families don't know what they don't know.
I'm exhausted trying to figure it all out and I keep thinking that I'm not doing enough, and my daughter is not getting what she needs.
I think it would be nice to come to a new meeting and have someone say, 'what do you think I need to know?
The first thing is to formulate a team approach to include families. I think most families are pushed away. You can't do it, so step aside and let the professionals do it. I think it's more costly for the government. Providers should empower families to learn and let them do the things they are willing to do instead of blaming families.

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Just listen and understand what we're going through-what we as a family and the person with disabilities go through. Please just try to offer very clear and effective preventative measures and assistance. Just listen to us.
Increase understanding that the whole family needs support.
Just keep asking what people need, stay curious about the needs are.
Listen to the family member. Listen to client and to the parent. The person with diagnosis is the expert.
Listen to the parents because they know their child and their concerns and questions are valid.
To include families' opinions, ask for other professionals to offer recommendations for treatment, collaborate on treatment together for crisis plans.

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Appendix E: Psychiatric Diagnoses and Drug Lists for Medicaid Claims

Psychiatric Diagnostic Categories

=<17 0.R. Procedure W Principal Diagnoses of Mental Illness
=<17 Acute Adjustment Reaction and Psychosocial Dysfunction
=<17 Childhood Mental Disorders
=<17 Depressive Neuroses
=<17 Disorders of Personality & Impulse Control
=<17 Neuroses Except Depressive
=<17 O.R. Procedure W Principal Diagnoses of Mental Illness
=<17 Other Mental Disorder Diagnoses
=<17 Psychoses
>17 Acute Adjustment Reaction and Psychosocial Dysfunction
>17 Childhood Mental Disorders
>17 Depressive Neuroses
>17 Disorders of Personality & Impulse Control
>17 Neuroses Except Depressive
>17 O.R. Procedure W Principal Diagnoses of Mental Illness
>17 Other Mental Disorder Diagnoses
>17 Psychoses
Acute Adjustment Reaction & Psychosocial Dysfunction
Acute Anxiety and Delirium States

Adjustment Disorders and Neuroses Except Depressive Diagnoses
Alc/Drug Abuse or Depend W Rehabilitation Therapy W/O Cc
Alc/Drug Abuse or Depend W/O Rehabilitation Therapy W/O Cc
Alc/Drug Abuse or Depend, Detox or Oth Sympt Treat W Cc
Alc/Drug Abuse or Depend, Detox or Oth Sympt Treat W/O Cc
Alc/Drug Dependence W Rehabilitation Therapy
Alc/Drug Dependence, Combined Rehab & Detox Therapy
Alcohol & Drug Dependence W Rehab or Rehab/Detox Therapy
Alcohol Abuse & Dependence
Alcohol/Drug Abuse or Dependence W Cc
Alcohol/Drug Abuse or Dependence W Rehabilitation Therapy
Alcohol/Drug Abuse or Dependence W/O Rehabilitation Therapy W Mcc
Alcohol/Drug Abuse or Dependence W/O Rehabilitation Therapy W/O Mcc

Alcohol/Drug Abuse or Dependence, Left Ama
Behavioral & Developmental Disorders
Behavioral Disorders
Bipolar Disorders
Childhood Behavioral Disorders
Childhood Mental Disorders
Cocaine Abuse & Dependence
Depression Except Major Depressive Disorder
Depressive Neuroses
Depression Except Major Depressive Disorder
Disorders Of Personality & Impulse Control
Drug And Alcohol Abuse or Dependence, Left Against Medical Advice
Eating Disorders
Intentional Self-Harm and Attempted Suicide
Major Depressive Disorders & Other/Unspecified Psychoses
Mental Illness Diagnosis with O.R. Procedure
Neuroses Except Depressive
Opioid Abuse & Dependence
Organic Mental Health Disturbances
Other Drug Abuse & Dependence
Other Mental Health Disorders
Psychoses/Schizophrenia

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Psychotropic Drug Categories

Alcohol Deterrents
Antiparkinsonian Agents
Alpha-Adrenergic Agonists
Alpha-Adrenergic Blocking Agt. (Hypoten)
Central Alpha-Agonists
Alpha-Adrenergic Blocking Agents
Opiate Agonists
Opiate Partial Agonists
Anticonvulsants
Benzodiazepines (Anticonvulsants)
Anticonvulsants, Miscellaneous
Psychotherapeutic Agents
Antidepressants
Monoamine Oxidase Inhibitors
Sel.Serotonin,Norepi Reuptake Inhibitor
Selective-Serotonin Reuptake Inhibitors
Serotonin Modulators
Tricyclics, Other Norepi-Ru Inhibitors
Antidepressants, Miscellaneous
Antipsychotic Agents
Atypical Antipsychotics
Butyrophenones
Phenothiazines
Thioxanthenes
Antipsychotics, Miscellaneous
Psychotherapeutic Agents, Miscellaneous
Amphetamines
Amphetamine Derivatives
Selective Serotonin Receptor Agonists
Anorexigenic Agents And Stimulants, Misc
Anxiolytics, Sedatives, and Hypnotics
Barbiturates (Anxiolytic, Sedative/Hyp)
Benzodiazepines (Anxiolytic,Sedativ/Hyp)
Anxiolytics, Sedatives,And Hypnotics, Misc
Antimanic Agents

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Appendix F: START Program Description

The National Center for START Services

The National Center for START Services at the University of New Hampshire Institute on Disability/UCED is a national initiative that works to strengthen efficiencies and service outcomes for individuals with intellectual and developmental disabilities (IDD) and behavioral health needs in the community. The National Center was established in 2009 at the IOD to provide technical support, clinical expertise, and training and consultation services that support the development of:

- Comprehensive Evaluation of Services & Systems of Care (local and state)
- A Systems Linkage Approach to Service Provision
- Expert Assessment & Clinical Support
- Outcomes-Based Research & Evaluation
- Short-Term Therapeutic Resources & Opportunities
- Cross Systems Crisis Prevention & Intervention Planning
- Family Support, Education, & Outreach
- Interdisciplinary Collaboration

By supporting the development of the cornerstones of the START model as outlined, START programs and their participants experience an array of benefits including:

- Reduced use of emergency services and state facility/hospital stays
- High rates of satisfaction by families and care recipients
- Cost-effective service delivery
- Increased community involvement and crisis expertise in communities
- Strengthened linkages that enrich systems, increase resources, and fill in service gaps

The START Model

The START program model was implemented in 1988 by Dr. Joan Beasley and her team to provide community-based crisis intervention for individuals with IDD and mental health needs. The model is evidence-informed and utilizes a national database. It is a person-centered, solution-focused approach that employs positive psychology and other evidence-based practices.

START is a comprehensive model of service supports that optimizes independence, treatment, and community living for individuals with IDD and behavioral health needs. In the 2002 U.S. Surgeon General's Report on mental health disparities for persons with intellectual/developmental disabilities, START was cited as a model program (12). In 2016, the START model was identified as best practice by the National Academy of Sciences Institute of Medicine (13).

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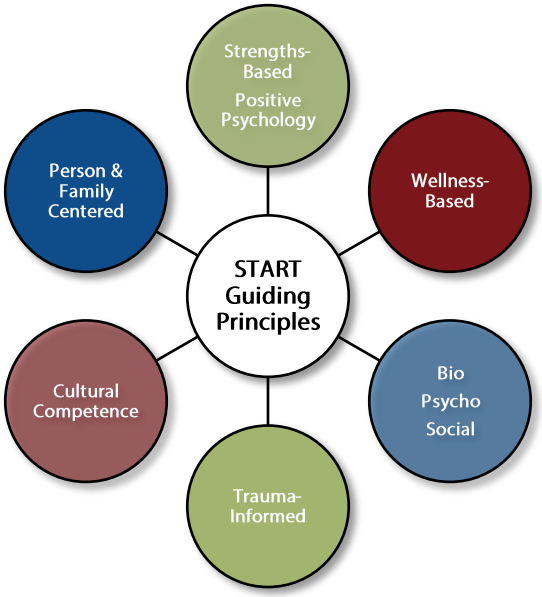
Guiding Principles

The guiding principles of START are identified in literature as best practices. The following descriptions provide a brief overview of each of these principles. Each service, tool, and intervention endorsed by START is designed with these concepts in mind. Endorsed approaches should be seen as touchstones for START team members and a clear reminder of the rationale and reason behind the work of the START community.



START Clinical Team Overview

Although START program development is tailored to meet regional needs, all programs must have a START clinical team. The START clinical team operates as system-linkage supports and provides 24-hour crisis response to those enrolled in START services.

A START clinical team does not replace any one member of an existing system of support. Rather, they collaborate and facilitate change through the way they understand, interact with, and respond to the people and systems they serve. Based on the premise that there is no value in expertise if it is not shared, START Clinical Teams continuously share knowledge with system partners to build capacity. The goal of START is to help the person and system achieve stability, eventually making START services unnecessary. This goal is accomplished through specialized support (ex: outreach), assessment, and intervention that build on the principles and practices of START. Services and supports offered by START Clinical Teams include:

- Training and expertise in the mental health aspects of IDD, including Clinical Education Teams
- Systems linkage supports
- Intake and assessment activities using standardized and validated assessment tools
- Comprehensive Service Evaluations: bio-psycho-social analysis of strengths and needs

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including trauma, developmental and communication-related psychological vulnerabilities, skills, natural supports, cultural considerations, etc.
- Eco-mapping, systemic analysis, and consultation
- Outreach to the person, their family, and support system to enhance team capacity
- Observation and coaching provided to teams using wellness and solution-focused approaches and the integration of positive psychology interventions in daily life
- Cross systems crisis prevention and intervention planning
- 24-hour in-person crisis response
- Medication consultation
- Facilitated team meetings and action planning
- Psychiatric hospitalization transition planning
- Access to innovative training and research initiatives led by the National Center for START Services

START Team Design

A START Clinical Team is made up of the following positions:

Program Director (Master's Degree): Provides full-time supervision and 24/7 support to the clinical team. Serves as a liaison to community providers, coordinates all training activities, develops community linkages, and chairs the Advisory Council.

Clinical Director (Ph.D.): Provides full-time clinical oversight to the clinical team and therapeutic support services, is responsible for Clinical Education Team Meetings, and provides consultation to community providers/psychologists.

Medical Director (MD): A licensed psychiatrist who provides part-time consultation and training to the clinical team, physicians treating individuals supported by START, and the START therapeutic supports staff as needed.

Assistant Director (Master's Degree; dependent on program size): Oversees operations of the clinical team and therapeutic supports operations, directly supervises team leaders, and assists the Program Director as needed with the development of community linkages.

Clinical Team Leaders (Master's Degree; number of team leaders depends on program size) Provides day-to-day administrative support and supervision to START Coordinators, may maintain a small caseload and fills in as needed, and provides backup on-call support and coaching to Coordinators.

START Coordinators (Master's Degree): Provides direct, community-based START clinical team services to individuals enrolled in the program, completes required assessments, evaluations, and plans, provides 24-hour on-call crisis support for enrolled individuals, and regularly enters data into SIRS.

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Therapeutic Coaching (STC) Overview

Therapeutic Coaching is designed to assess and stabilize a person in their community environment(s). START Therapeutic Coaching (STC) provides planned and emergency strengths-based, clinical coaching to primary caregivers and persons in their home setting to rethink presenting challenges. This service is part of the START crisis continuum and is only provided with the participation of the START clinical team. The START coordinator determines the need for coaching services in collaboration with the STC team leader, clinical director, the person, and their circle of support. In most cases, STC is planned in coordination with coaches that are familiar with the person and their setting. However, in some cases, the service may be provided in a more urgent capacity. The provision of supports may occur any day of the week and will depend on the needs identified in the cross-systems crisis plan.

The goal of STC is to assist the person's caregiver by offering observational assessment of the person and their circumstances and implementing planned and/or crisis intervention strategies. Reasons therapeutic coaching supports may be accessed include:

- To provide coaching and training to family and support staff on positive, effective support strategies
- To identify biopsychosocial factors that may contribute to crisis
- To increase the likelihood that the person can maintain their preferred community living situation
- To transition successful intervention strategies to the person's home
- To provide support if a person is unable to leave their home for therapeutic intervention (e.g., symptoms of ASD keep a person from feeling comfortable in new environments), or
- For additional support prior to or following emergency Resource Center admissions (in these circumstances, Resource Center staff will participate in admissions and transition planning)

Eligibility

1. All persons enrolled in START are eligible for planned and emergency therapeutic coaching services if the program is set up to provide STC. Admission to STC is based on the assessment of clinical need and appropriateness. As with other therapeutic support services, supporting families is a priority.
2. All persons must have an established Cross-Systems Crisis Prevention and Intervention Plan (CSCPIP) prior to beginning STC services (a Provisional Crisis Plan is acceptable if within the first 45 days of intake).
3. The person’s primary caregiver is interested in receiving the service and coordinating supports with the STC team.

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Appendix G: START Program Development Timeline

Start Up (Prior to START Operations): During this process, the National Center for START Services and identified stakeholders in the region and/or state follow research methodologies to assess the strengths and needs of the local system of support. A system analysis may occur at this point. Because START uses a systems linkage approach, it is important that the unique strengths and challenges in each region are considered when designing services.

Program Development (Year 1): Program design and action planning focus on building the START team, developing linkages and relationships with community stakeholders, developing policies and procedures, and training START staff. If a program also provides therapeutic supports (Resource Center or Therapeutic Coaching) these services are designed and built during this phase as well.

Program Implementation (Years 1 and 2): With continued guidance from NCSS, the program focuses on developing the skills of staff to meet fidelity and gain a level of confidence and expertise within the IDD and MH field. Ensuring that Coordinators are certified and focusing on preparation for program certification is ongoing and prioritized.

Certification Prep (Year 3): After all aspects of the START program are implemented, the team begins preparing for National START Program Certification. At this phase, at least half of START staff have achieved coordinator certification, the program is providing full on-call supports, and have internal QA procedures in place to monitor fidelity elements and mechanisms for evidence-informed decision making. The program works with their assigned NCSS project manager and the QA department to prepare for certification. This may include a “practice” certification review.

Certification (Year 3 and beyond): The program demonstrates mastery in established standards of START practices. More details on Program Certification can be found within the START Program Certification Manual in the Online Resource Area (subsection: Clinical Team Resources) of Moodlerooms. An ongoing network fee for certified programs is $50,000.00 per program.