

National Needs Assessment: Mental Health Services for People with Intellectual and Developmental Disabilities

National Summary of Results for States

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Executive Summary

The purpose of this needs assessment was to help identify current gaps and needs in mental health (MH) services for the intellectual and developmental disabilities (IDD) population in the U.S., particularly to inform training efforts to increase capacity in the workforce to serve this population. An online survey was distributed through 29 national organizations representing disability and MH professionals, policymakers, and advocates. There were 877 responses from 48 states consisting of two respondent groups: *key informants* (501, 57%), and *experienced individuals* (376, 43%).

Experienced individuals indicated a person with IDD or a family will most likely go to a family doctor or health center to find out what to do about a first-time, non-emergency MH concern. This is one reason it is crucial that physicians are trained to recognize MH symptoms in people with IDD. Key informants indicated that community MH centers are the most likely places people with IDD will go for MH services, in part because these centers typically accept Medicaid. Strengthening these centers is crucial for serving people with IDD, but they should not be the only option for MH services.

Key informants indicated that while most types of general MH services and MH consultation services exist and are technically available to people with IDD, access to them is difficult or limited. Both groups of respondents frequently talked about shortages of MH providers and services within states to meet existing needs. This is a challenge for both urban and rural communities, but often there is little available beyond a state's largest urban centers. When there is not enough capacity to address overall MH needs of the general population, people with IDD tend to be severely underserved.

Respondents indicated the typical wait time for non-emergency MH services is roughly one to six months, but it can be years. When people with IDD do not access MH services in the community, they are more likely to end up in crisis centers or hospital emergency rooms. The least available type of MH service for people with IDD is emergency room expertise. Other types of MH services that are less available are inpatient or residential care, respite care, and community mental health teams.

The evidence from this survey suggests that the existing mental healthcare workforce is not prepared to serve people with IDD. There is little motivation for high demand professionals to seek additional training for that purpose. Respondents also noted a pervasive myth that people with IDD cannot benefit from therapy. People with IDD are left with very few options, much fewer than people without IDD. In some areas, people with IDD are limited to a single place where they are allowed to receive MH services. Many agencies and professionals offering services addressing the most common MH concerns will find reasons to turn people away if they have an IDD.

Some of the major barriers to mental healthcare are financial. There are a host of issues with Medicaid, insurance, and high out-of-pocket costs that systematically exclude people with IDD. Another major barrier is providers tending to rely heavily on verbal communication, and lacking skill with nonverbal and augmented communication. Existing MH services are somewhat accessible to people with milder forms of disability, but much less accessible to people with more severe disability. Services are even less accessible for those who speak a language other than English or use sign language.

To increase the capacity of the existing workforce to serve people with IDD, many professionals interacting with the IDD population were suggested for training, tailored as needed to their roles and responsibilities. The most often mentioned training theme was *a basic or foundational understanding of the IDD-MH population*. Related themes were working with families/caregivers, and using a whole-person approach. The second most popular theme was *recognizing and identifying MH symptoms in people with IDD*. Depending on the trainee, this ranged from screening/referring to making a differential diagnosis. *Strategies for engaging people with IDD in therapy* was a popular theme, along with *effective therapies or interventions*. Additional themes were managing and handling behaviors, medication management, and trauma-informed care. Each training theme encompassed a number of topics. There were also a number of suggestions beyond training to make MH practices accessible and inclusive.

Most suggestions to help individuals and families centered around some kind of local directory or an online resource that is more effective than the 211 system. Suggested content covered not only details people need to know about a practice, but also what they need to know for an initial evaluation of individual professionals' qualifications. There were many suggestions for other publications and information resources, not only to inform individuals and families, but also to help inform others. Needs to increase public awareness and reduce stigma were often mentioned. Respondents also used this space to talk about what individuals and families need to know to have hope, and to be part of the solution. A number of training topics were suggested for individuals and families, including some overlapping with training topics for professionals.

Many comments from respondents were about strategies to make long-term or systemic improvements. The most often mentioned was to incorporate IDD into graduate-level education programs. Similarly, a number of comments were about addressing shortages. Long waitlists for services were mentioned throughout the survey, most often related to shortages of qualified MH providers. Shortages of residential, inpatient, and psychiatric facilities as well as emergency room expertise were frequently mentioned.

The most often mentioned suggestions that might be for the policy or government level were about requiring levels of training, education, certification, and continuing education aimed at increasing the quality and professionalism of the MH workforce. A number of suggestions were aimed at Medicaid, particularly reducing barriers to care and increasing reimbursement for MH services. Needs for cross-system collaboration and coordination were often mentioned to address problems associated with siloed systems.

Introduction

The deinstitutionalization movement in the 1970s and 80s heralded the end of routinely institutionalizing people in the U.S. because they had intellectual and developmental disabilities (IDD). For years prior to this time, experts and advocates had been vocal across the country about the need for communities to take steps preparing to receive, serve, and include people with IDD in all aspects of community living.

Unfortunately, health professionals in general tended to harbor negative feelings and attitudes about people with IDD (Werner & Stawski, 2012). There was no foundation of research, training, or clinical experience to support community mental health services for this population (e.g., Hudson & Chan, 2002; Munir, 2009; Nezu & Nezu, 1994; Razza, Dayan, Tomasulo, & Ballan, 2014). For decades following deinstitutionalization, mental health service providers were more than reluctant to accept people with IDD into services (VanderSchie-Bezyak, 2003). Responsibility for mental health treatment fell to families, mostly using emergency rooms and residential facilities as primary resources (Venville, Sawyer, Long, Edwards, & Hair, 2015; Weiss, Slusarczyk, & Lunsky, 2011).

The purpose of this needs assessment was to help identify current gaps and needs in mental health (MH) services for the IDD population in the U.S., particularly to inform training efforts to increase capacity in the workforce to serve this population. This paper focuses on collective national-level results for states.

Note: *IDD* was defined as lifelong disabilities starting before age 22, resulting in significant limitations in several areas of major life activity and requiring lifelong services and supports. Examples: autism, brain injuries, cerebral palsy, hearing or vision disabilities, intellectual or cognitive disabilities, and physical or mobility disabilities.

Method

An online survey instrument was presented in English and Spanish. It had sections where respondents were directed based on responses. The first section determined eligibility for the survey and the second verified consent to participate. The third defined terms and collected demographics. From there the survey split depending on how a person chose to respond, as a key informant or as an experienced individual.

Key informants were defined as people with an overall view of mental health service systems. *Experienced individuals* were defined as people who know what it is like for someone with IDD to find and use services for mental health concerns. Key informant items were informed by results from a 2007 needs assessment in Canada (Lunsky, Garcin, Morin, Cobigo, & Bradley). The survey instrument was formally reviewed and revised three times by *Mental Health and Developmental Disabilities National Training Center* (MHDD NTC) staff and advisory board members, including adults with IDD.

Beginning September 3, 2019 an invitation introducing the survey was sent by email to 29 national-level organizations suggested by MHDD NTC staff and advisory board members along with a request to help distribute the survey through their networks. Contacted organizations represented disability and mental health professionals,

policymakers, and advocates. Individuals who received notice through an organizational listserv, e-newsletter, or social media posting could share it with other organizations, professionals, and friends. The survey deadline was November 15, 2019. Because there were still people entering the survey and almost a hundred responses in process on the 15th, the survey was kept open until the 26th.

Participants

There were 889 responses to the survey, including 12 from five U.S. territories. This paper focuses on the **877 responses from 48 states**: 501 from *key informants* (57%) and 376 from *experienced individuals* (43%). The following demographics are what was reported by this group of participants.

Respondents could choose more than one *race/ethnicity*. Of the 849 who provided this information, 15 (1.8%) indicated Alaska Native or American Indian, 21 (2.5%) Asian, 34 (4.0%) Black or African American, 4 (.5%) Pacific Islander, 787 (92.7%) White or Caucasian, and 3 added Caribbean, Mestiza, and Mixed. Fifteen respondents chose more than one race, and 773 (91.0%) indicated White or Caucasian as a single race. Of the 870 who provided data about ethnicity, 44 (5.1%) indicated they were Hispanic or Latino. Of the 866 respondents who provided data about *gender* 738 (85.2%) indicated female, 125 (14.4%) male, and 3 added agenderqueer, genderqueer, and non-binary.

Participant Roles

Respondents were asked to further describe themselves by choosing all roles that applied to them from a provided list. Figure 1 shows these results. Of the 871 people responding to this item, about 39% identified themselves as family members or caregivers, 25% disability service providers, and 23% administrators. About 12% identified as mental health providers in the public sector, and 11% in the private sector. About 10% identified as individuals with a disability, 8% as healthcare providers, 6% as policymakers, and 4% as university clinicians or researchers.

Figure 1: Professional and personal roles of respondents (n = 871)

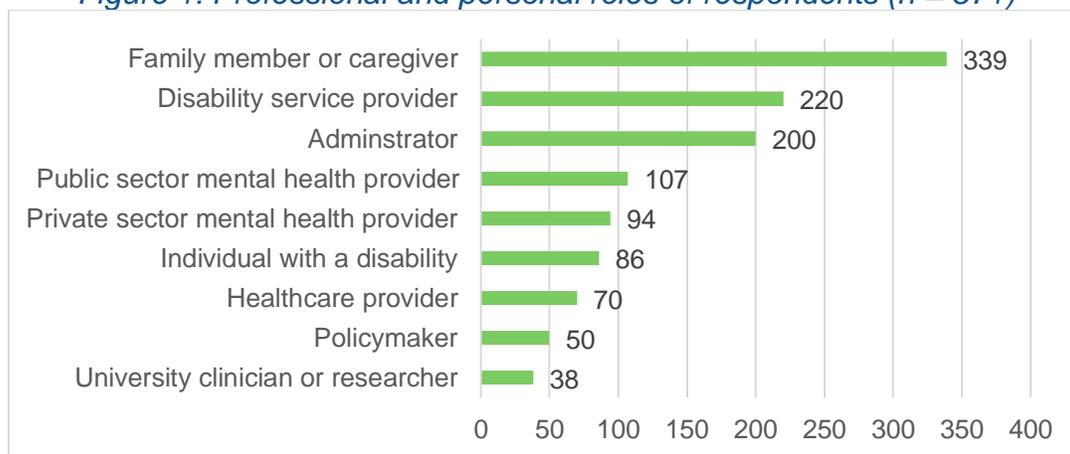


Figure Note: A respondent could choose more than one role.

Sixty-five respondents added roles. The most frequent was advocate or advocacy organization (28, 3%) followed by care coordinator, case manager, or navigator (13, 2%). Others roles: ICF surveyor for Medicaid, intake coordinator, legal guardian,

managed care organization (2), P&A or legal (4), rehabilitation counselor (2), research coordinator, school MH provider (4), social worker, state employee, teacher or educator (4), transition support team, and wraparound facilitator.

Factors Related to Experience

Experienced individuals were asked to indicate the types of disabilities that were related to their experience. Figure 2 shows those results. Of the 366 who responded to this item, most had experience related to intellectual or cognitive disabilities (75%), followed by autism (63%). Around a quarter each had experience related to physical disabilities (27%) or brain injuries (22%). Fewer had experience related to vision (11%) or hearing disabilities (10%). Nine respondents added a disability including Cerebral Palsy (2), chromosome duplication, dementia, dyslexia, epilepsy (2), learning disorders, pain disorders, and shunted hydrocephalus.

Figure 2: Experience by disability (n = 366)

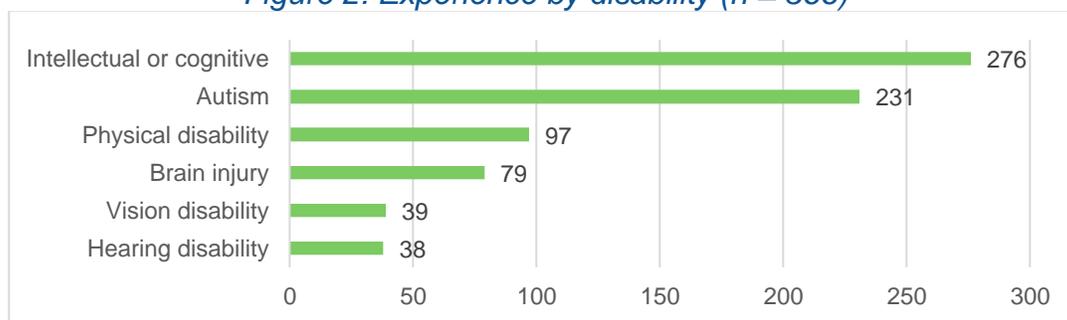


Figure Note: A respondent could choose more than one disability.

Experienced individuals were asked if their experience was mostly related to services in **rural or urban** places. Of the 369 who responded to this item, most indicated urban places (**224 or 61%**). About a third indicated rural places (**120 or 33%**). Twenty-five added the following: both (12) or suburban (13).

Results

Notes:

- The number of responses to items varies. Respondents could skip items, and responses such as “I don’t know” were excluded.
- For some items, the state was the unit of analysis. For a state to be included based on in-state agreement, it had to have at least 5 responses to that item. However, all comments from all states were addressed under themes.
- For this survey, *children* were defined as up to age 12, *adolescents* age 13 to 17, and *adults* age 18 and older.

Where People Go When They Have Mental Health Concerns

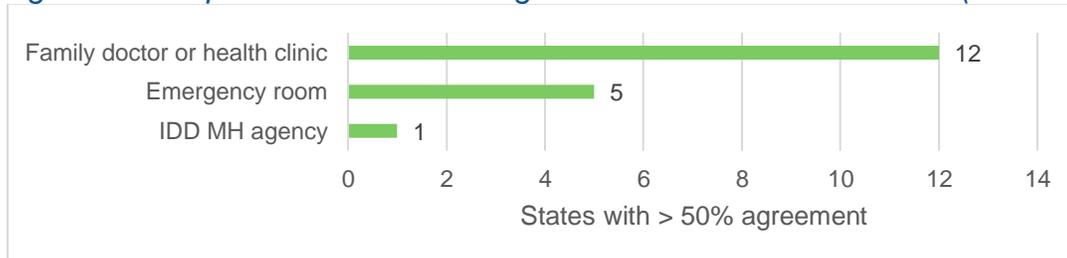
Where People Go First

Experienced individuals were asked where **adults** with IDD were likely to go for help the *first time* there was a mental health (MH) concern. Twenty states had enough responses (≥ 5) for assessing in-state agreement. In rank order from highest to lowest,

Figure 4 shows the number of states with over 50% agreement from experienced individuals for each place where adults with IDD might go.

The highest result was for **family doctors or health clinics** with agreement in 60% of 20 states. There was agreement on the emergency room in a quarter of states. Only one state had agreement on IDD MH agencies. No states had agreement on disability agencies, hospitals for mental illness, independent counselors or therapists, MH centers, religious leaders, or residential facilities.

Figure 4: First place adults with IDD go for MH services in 20 states (n = 312)

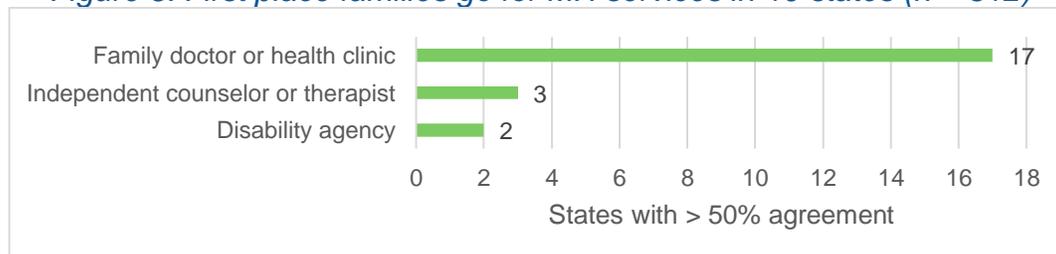


Resources added by individuals do not represent in-state agreement. They included Aging and Disability Resource Center, Article 16 clinic, case manager, crisis services, HCBS provider, online, parents, psychiatrists, schools, staff, and trusted adults.

Experienced individuals were also asked where **families** were likely to go for help the *first time* there was a MH concern for a child or adolescent with IDD. Nineteen states had enough responses (≥ 5) for assessing in-state agreement. In rank order from highest to lowest, Figure 5 shows the number of states where there was more than 50% agreement from experienced individuals for each place where families might go.

The highest result from experienced individuals was once again for **family doctors or health clinics** with agreement in 89% of 19 states. Results were much lower for independent counselors or therapists (16%), and disability agencies (11%). No states had agreement on emergency rooms, hospitals for mental illness, IDD MH agencies, MH centers, religious leaders, or residential facilities.

Figure 5: First place families go for MH services in 19 states (n = 312)



Resources added by individuals do not represent in-state agreement. They included Aging and Disability Resource Center, behavioral plan (HMO), case manager, government agency, Regional Center, schools, and Single-Entry Point for resources.

Comments added by experienced individuals from 16 states at this point in the survey helped explain why people go to doctors first. They noted that individuals and families don't know where to go for mental health concerns and doctors are a known professional resource. In five states it was noted that schools are also a resource.

Comments added by four experienced individuals described efforts toward meeting the unique needs of this population.

- A dual-diagnosis clinic for better and more timely evaluations
- DD agencies prepared to make appropriate MH referrals
- Personal care professionals prepared to make appropriate MH referrals
- Autism centers associated with universities across the state are appropriate first places to go for MH concerns

However, the vast majority of experienced individual comments about where people go when they have mental health concerns painted a more negative picture.

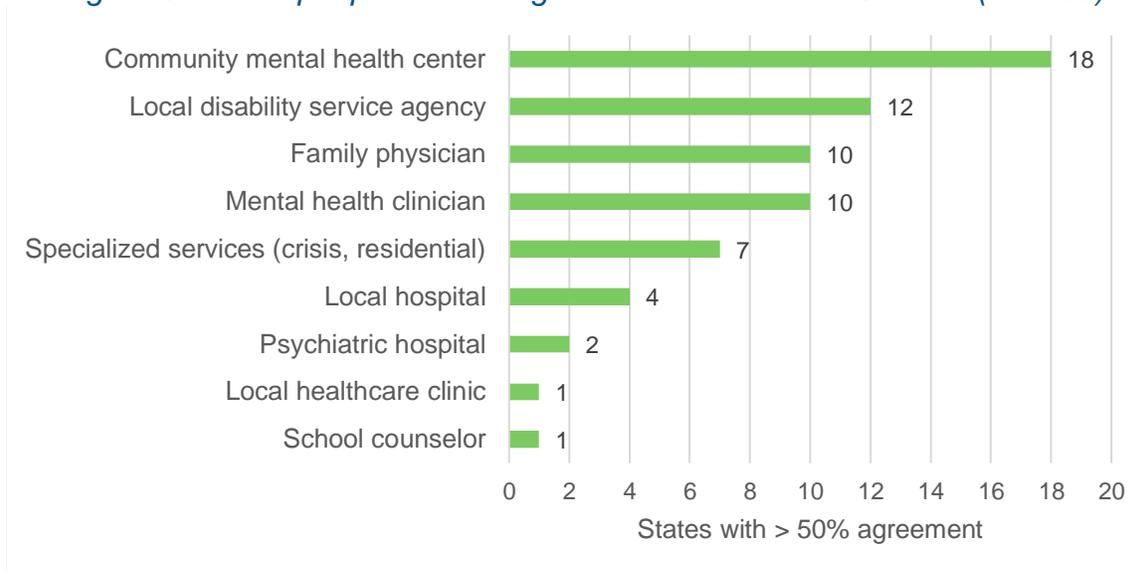
- In 18 states comments stated a general lack of providers or options for MH services to meet current needs.
- In 13 states issues with Medicaid or other insurance coverage were noted. The latter included providers not accepting Medicaid, services that are not covered, and other imposed limits on services. In 5 states it was also noted that family capacity or resources was a major factor in accessing services.
- In 10 states comments stated that people with IDD were often turned away from the places where they sought MH services.
- In 10 states comments noted long wait times for MH services. In 5 states it was noted that even when accepted, getting services was a long process.
- In 9 states comments noted use of the emergency room due to crises that could have been prevented if individuals or families either sought or received services sooner. In 6 states it was noted use of the ER was due to a lack of other options.
- In 6 states comments mentioned being treated disrespectfully. This included not believing people or not taking them seriously, being annoyed with them, and treating them as incompetent or as a burden.
- In 6 states comments noted an over-reliance on medications for MH concerns in this population.
- Comments from 18 states were directly relevant to training needs. Most noted that there were few MH providers or physicians who were adequately prepared to serve people with IDD. The specific issue mentioned most often was recognizing MH issues in people with IDD. Diagnosing was also mentioned, as well as being sensitive to difficulties faced by people with IDD.

Where People Go for Mental Health Services

Key informants were asked where people with IDD were likely to go for help when they have MH concerns. Twenty-eight states had enough responses (≥ 5) for assessing in-state agreement. In rank order from highest to lowest, Figure 3 shows the number of states where there was over 50% agreement for each place where people with IDD were likely to go.

The highest result from key informants was for **community mental health centers** with agreement in 64% of 28 states. Less than half had agreement on disability service agencies (43%), and just over a third for family physicians and MH clinicians (36% each). A quarter of states had agreement on crisis or residential services. There was much less agreement on local hospitals (14%) and psychiatric hospitals (7%). Local healthcare clinics and school counselors each had agreement in only one state. No states had agreement on university clinicians or researchers.

Figure 3: Where people with IDD go for MH services in 28 states (n = 469)



Resources added by individuals do not represent in-state agreement. They included case, service, or supports coordinators/managers; community DD organization; managed care organization; government agencies; regional centers or county services; religious social services; and specialized MH-IDD program.

Comments added by ten key informants described efforts toward meeting the unique needs of this population.

- Support for MH clinicians to provide services for the IDD population
- Training for DD staff to navigate the MH system
- MH services customized for the IDD population
- Community partnerships to address the MH needs of the IDD population
- School-based MH supports for students with IDD
- Peer supports for people with IDD and MH diagnoses
- Medicaid waiver that integrates DD and MH systems, along with training to successfully transfer people to waiver services
- Integration of behavioral healthcare with physical healthcare in healthcare plans, along with coverage by Medicaid
- Self-directed service options with flexibility for MH services
- All local MH centers serving the IDD population

However, like the previous comments from experienced individuals, the vast majority of key informant comments about where people go for MH services followed more negative themes.

- In 30 states comments noted a general lack of providers or capacity for MH services to meet current needs. Comments in five states added the need was particularly severe beyond urban centers.
- In 14 states comments stated that people with IDD were often turned away from places where they seek MH services.
- In 8 states, comments talked about financial issues, including the lack of affordable services and issues with Medicaid or other insurance coverage. The latter included low reimbursement rates, providers not accepting Medicaid, and services that are not covered.
- Comments from 20 states were directly relevant to training needs. Most noted there were few MH providers or physicians adequately prepared to serve people with IDD. Specific issues mentioned included recognizing MH issues in people with IDD, making appropriate diagnoses, and making appropriate referrals.

Choice in Mental Health Services

Comparison to People Without IDD

Experienced individuals were asked how much choice or options people with IDD had for where to go for MH services *compared to people without IDD*. Response options and their values: none (0), much fewer (1), somewhat fewer (2), the same (3). The midpoint of a 0-3 scale is a mean of 1.50. Results above the midpoint are more positive, and results below it are more negative. Mean results for both adults and families shown in Table 1 fell below the midpoint, with a lower result for adults.

Table 1: Choice in MH services compared to people without IDD (scale 0-3)

Group	<i>n</i>	Mean	Standard Deviation
Adults age 18 and older	348	1.25	.71571
Families	347	1.37	.72630

Experienced individuals were further asked if they were aware of any community mental health **places that would not serve people** if they had an IDD. Of 350 responders to this item, **135 (39%)** said yes. Out of 41 states with responses to this item, **31 (76%)** had one or more responders who said yes.

Comments added by experienced individuals in this section of the survey on choice or options tended to continue with more negative themes.

- In 21 states comments noted a lack of MH services or providers. In 11 states comments mentioned that people with IDD were limited to one particular place or provider for MH services, and in 8 states it was noted that allowed services were poor quality. In 9 states it was noted that services and providers are particularly lacking outside large urban centers.
- In 17 states comments stated that people were turned away from places. Most of these comments were about MH provider agencies finding reasons to turn people away even if they could not legally deny services to people with IDD.

Agency-based reasons included lack of provider experience or capacity, and belief that DD agencies should bear responsibility for MH needs. Individual-based reasons included IQ level cutoffs, nonverbal status, and financial or insurance issues. In a few states respondents mentioned conflicts between MH and DD systems.

- In 17 states financial issues were mentioned, mostly related to limited individual resources or places not accepting Medicaid or insurance. Also mentioned were services that are not covered or other limits imposed by Medicaid or insurance.
- In 5 states issues of disrespect were noted, including dismissing people and making families feel inadequate when they need help. It was mentioned that people with IDD received lower quality services than people without IDD, and people with IDD were waitlisted longer than people without IDD.
- Comments from 19 states were directly relevant to training needs. Most of these were about preparing MH providers and physicians to effectively work with people who have IDDs, particularly autism.

Mental Health Service Systems

Key informants were asked a series of questions about general MH services for children, adolescents, and adults with IDD. *General mental health services* were defined as serving a range of people with a range of concerns, or not specialized in one type of condition, service, or client. These are services that tend to be most available to the general population for the most common MH concerns.

Availability of General Mental Health Services

Three items asked key informants if providers of general MH services tended to serve children, adolescents, and adults with IDD. Response options and their values: no (0), some do (1), most do (2), they all do (3). Mean results shown in Table 2 fell well below the 1.50 midpoint of the scale for all age groups, the lowest for adolescents.

Table 2: Availability of general MH services for people with IDD (scale 0-3)

Age Group	<i>n</i>	Mean	Standard Deviation
Children up to age 12	469	1.16	.86187
Adolescents age 13-17	467	1.10	.57163
Adults age 18 and older	468	1.21	.70795

Key informants were asked how available general MH services were at the local level **outside the largest population centers**. Response options and their values: not at all available (0), slightly available (1), moderately available (2), very available (3). The mean response ($M = 1.03$, $n = 469$, $SD = .65783$) was well below the 1.50 midpoint.

Three items asked key informants **how well MH providers were prepared** to meet the needs of children, adolescents, and adults with IDD. Response options and their values: not well at all (0), slightly well (1), moderately well (2), very well (3). Mean results shown in Table 3 were far below the 1.50 midpoint of the scale for all three age groups.

Table 3: Preparedness of MH providers to meet needs of people with IDD (scale 0-3)

Age Group	<i>n</i>	Mean	Standard Deviation
Children up to age 12	468	.82	.80101
Adolescents age 13-17	466	.83	.79822
Adults age 18 and older	466	.87	.83926

Comments added by six key informants at this point in the survey described more efforts toward meeting unique needs of this population.

- An agency working to develop its own capacity to serve people with IDD
- Collaboration between regional DD centers and MH programs
- Funding streams for prevention and early intervention
- Using telehealth to increase access to MH services
- Developing a primary care consultation model
- State contracted MH providers required to serve people with IDD

However, most comments added by key informants about the availability of general MH services and the preparedness of providers to serve people with IDD continued to build on negative themes.

- In 21 states comments noted a lack of providers, services, or capacity to serve people with IDD. New issues mentioned were high turnover of MH providers, and barriers to services imposed by federal and state requirements.
- In 16 states comments were specifically about a severe lack of resources, services, or providers in rural areas. In six states, difficulties associated with travel to access services in larger population centers were noted.
- In 6 states comments mentioned siloed services or systems in conflict, preventing access to services.
- Comments from 15 states were directly relevant to training needs. Most of these were about MH providers and physicians learning how to work with people who have IDs.

Accessibility of General Mental Health Services

Key informants were asked how accessible general MH services were for children, adolescents, and adults based on severity of disability. Response options and their values: not at all accessible (0), slightly accessible (1), moderately accessible (2), very accessible (3). As shown in Table 4, mean results for all age groups with *milder* disabilities were higher than results for all age groups with *more severe* disabilities. For milder disabilities, means approached the 1.50 midpoint of the scale.

Table 4: Accessibility of general MH services by severity of disability (scale 0-3)

Age Group	Mean: Milder	Mean: More Severe
Children up to age 12	1.41 (<i>n</i> = 419, <i>SD</i> = .69381)	1.03 (<i>n</i> = 419, <i>SD</i> = .72665)
Adolescents age 13-17	1.45 (<i>n</i> = 419, <i>SD</i> = .67693)	1.04 (<i>n</i> = 418, <i>SD</i> = .72175)
Adults age 18 and older	1.45 (<i>n</i> = 422, <i>SD</i> = .73953)	1.05 (<i>n</i> = 421, <i>SD</i> = .76213)

Key informants were asked how accessible general MH services were for individuals with IDD and families who primarily **speak a language other than English**. Using the

same accessibility scale as above, the mean response ($M = .82$, $n = 417$, $SD = .66647$) was far below the 1.50 midpoint of the scale, and lower than all accessibility ratings based on severity of disability.

Comments added by key informants in this section of the survey on the accessibility of general MH services included similar negative themes described previously. However, language access was a new topic in this section of the survey.

- In 19 states comments mentioned issues related to language. Comments in 6 mentioned a lack of interpreters. It was mentioned in a few that it was impossible to access any MH services with the combination of IDD and speaking a language other than English. Comments in 5 states mentioned it is even more difficult to get sign language interpreters. Comments in a few states mentioned the only language used other than English is Spanish. It was also mentioned that there are little to no language resources outside the largest cities.
- In a couple of states, comments elaborated further on denying services and discriminating against people with IDD. In one it was mentioned that a “right of refusal” is an accepted standard operating procedure that allows MH providers to systematically exclude people with IDD. Similarly, in another state it was noted the accepted practice to deny services means that providers are typically not motivated to learn how to serve people with IDD.

Types of Mental Health Services

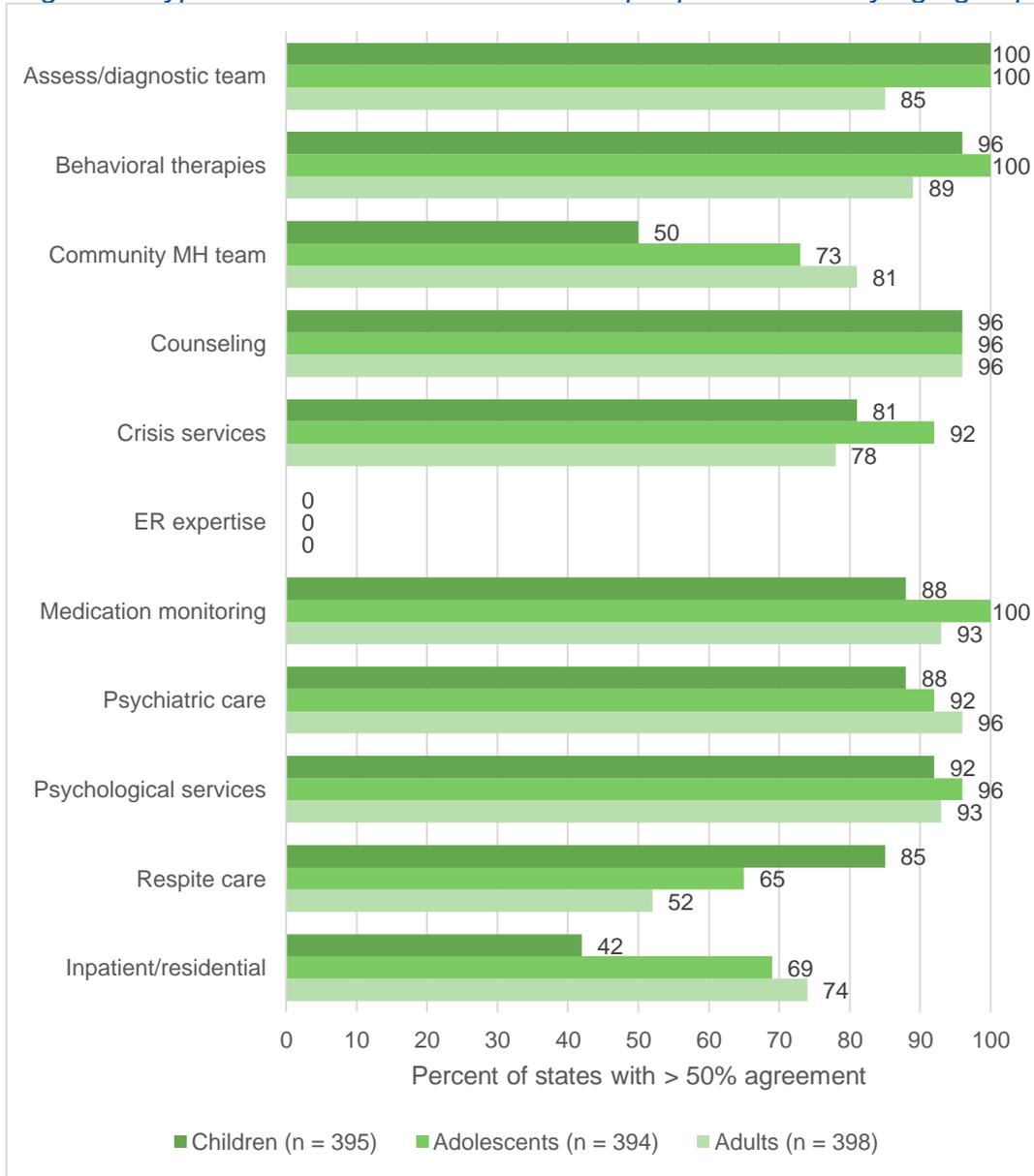
Key informants were asked about the availability of typical types of MH services for children, adolescents, and adults with IDD. Using in-state assessments of agreement, 26 states had enough responses (≥ 5) for children, 26 for adolescents, and 27 for adults. Because the number of states is not the same across age groups, the *percent of states* with agreement is used in Figure 6, rather than the number of states used in other figures. In this case, percent is better to visually compare age groups.

These results indicated that **assessment and diagnostic teams** were the most available service for both children and adolescents (100%), but less so for adults (85%). Medication monitoring and behavioral therapy were most available for adolescents (100%), and slightly less so for adults and children. Counseling, psychiatric care, and psychological services were all slightly less available overall. Crisis services were somewhat lesser available overall.

Community mental health teams and inpatient or residential care were less available for adults and adolescents, but especially for children (50% and 42% respectively). Respite care was somewhat less available for children (85%), decreased for adolescents (65%) and decreased more for adults living with family (52%). The biggest gap for all age groups was in emergency room expertise, which did not reach a level of agreement for any age group within any state.

Types of services added by respondents don't represent in-state agreement. They included Infant and early childhood mental health services, Regional Centers, schools, and addiction recovery services.

Figure 6: Types of MH services available for people with IDD by age group



Comments from seven key informants noted efforts to meet needs of this population.

- Group homes for children and adolescents funded by a Medicaid waiver
- Using cross-system partnerships to facilitate a continuum of services
- Community resources working together to increase services for children
- Behavior analysts available statewide
- State sponsored programs offering a variety of services for all age groups
- State programs available for non-traditional and community-based services
- New Crisis Services specializing in IDD
- Strong local systems of services
- Developing mental health extended services system in schools

However, comments in **29 states** stated that while MH services existed, *access to them was difficult or limited*. A number of respondents noted reasons:

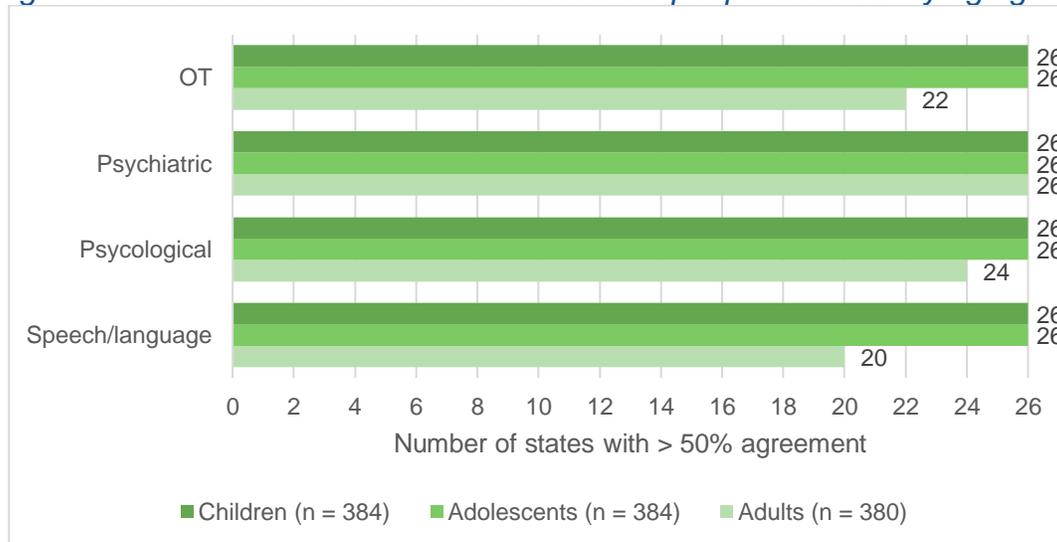
- 17 states – lack of providers, services, or capacity to address existing needs
- 17 states – varies by location, particularly lacking outside large urban centers
- 14 states – long waitlists
- 9 states – too few residential or inpatient facilities
- 5 states – available by private-pay or insurance only (not Medicaid)

Mental Health Consultation Services

Key informants were asked about the availability of typical MH *consultation* services for children, adolescents, and adults with IDD. Using in-state assessments of agreement, 26 states had enough responses (≥ 5) for children, adolescents, and adults. Figure 7 shows the number of states with more than 50% agreement that each type of consultation service is available within state for each age group.

For **children and adolescents**, there was agreement across all 26 states that occupational therapy, psychiatric, psychological, and speech/language consults were available. For **adults**, there was agreement across all states that psychiatric consults were available, but psychological consults (92%) were slightly less available, followed by occupational therapy (85%) and speech/language consults (77%). Types of consultation services added by respondents don't represent in-state agreement, but they included children's hospital, and behavioral therapy or specialists.

Figure 7: MH consultation services available for people with IDD by age group



Comments from nine key informants noted efforts to meet needs of this population.

- State autism insurance mandate ensures access to services up to age 17
- All consultation services are accessible through a State agency
- State agency recently added occupational therapy, physical therapy, and speech-language therapy for adults
- County Board of DD makes all consultation services available

- High quality psychiatric consult program is available to everyone of all ages
- Beginning to use intensive outpatient therapy in several areas of the state
- Working on getting occupational therapy consults for adults
- Community Services Boards working to get staff training in these services
- Two comprehensive centers providing an eclectic mix of evaluations

However, comments in **28 states** stated that while MH consultation services existed, *access to them was difficult or limited*. A number of respondents noted reasons:

- 15 states – lack of providers, services, or capacity to address existing needs
- 13 states – varies by location, particularly lacking outside large urban centers
- 13 states – long waitlists
- 10 states – eligibility issues such as program enrollment, diagnosis, provider limitations, required referrals
- 8 states – financial issues with insurance, Medicaid, and private-pay

While the comments about MH consultation services addressed all age groups, they were mostly about adults. Comments in 10 states noted that consultation services were available to children and adolescents through school systems. Comments in 15 states noted they were less available for adults.

Mental Health and IDD Specialists

Key informants were asked if there were any MH providers in their states who specialized in working with children, adolescents, and adults who have IDD. Table 5 shows the number and percent of each response (yes, no, or unknown) for each age group. Between 59% and 64% of responders indicated these resources were available across age groups, lowest for children and highest for adults.

Table 5: MH services that specialize in working with the IDD population

Response	Children (n = 421)	Adolescents (n = 421)	Adults (n = 423)
Yes	248 (58.9%)	260 (61.8%)	270 (63.8%)
No	48 (11.4%)	42 (10.0%)	51 (12.1%)
Unknown	125 (29.7%)	119 (28.3%)	102 (24.1%)

Key informants from 41 states responded to this item. There were 26 states with enough responses (≥ 5) for assessing in-state agreement. Those with agreement for the existence of mental health providers specialized in IDD for each age group were **19 (73%)** states for children, **20 (77%)** for adolescents, and **22 (85%)** for adults.

Comments added by six key informants described efforts with specialists or specialized programs to help meet the unique needs of this population.

- Complex Behavior Collaborative provides access to applied behavior analysis (ABA) services for people with the most severe behavioral issues
- Robust IDD provider community and a children’s hospital with a department dedicated to MH and IDD care
- MH provider contracted by a county to provide MH services for adults with IDD
- Boards of DD and MH providers in rural counties partner and cross-train

- State developed a MH wellness program for people with IDD, including training for healthcare professionals, support staff, and caregivers
- MH services are provided through the early intervention system

However, comments in **29 states** noted that while a responder may have answered “yes” to this item, the *number* of specialists or specialized programs was one to few, and **not enough to meet current needs**. In four states it was noted that even with services specialized for people with IDD, access was limited by providers not accepting Medicaid. Comments in seven states mentioned long wait times for specialized services, and in one state it was noted the waitlist for a waiver program to pay for these services was 10 years long.

Length of Wait for Services

Typical Wait Time for Non-Emergency Services

Key informants were asked to estimate the *typical* wait time for non-emergency MH services for children, adolescents, and adults with IDD. They were provided with five options for ranges of time listed in Table 6 with results. The most often chosen option was 3 to 6 months across all age groups, followed by less than 3 months.

Table 6: Key informant estimates of typical wait time for non-emergency MH services

Wait Time	Children (n = 386)	Adolescents (n = 386)	Adults (n = 390)
< 3 months	106 (27.5%)	104 (26.9%)	121 (31.0%)
3 to 6 months	164 (42.5%)	159 (41.2%)	134 (34.4%)
7 to 10 months	58 (15.0%)	60 (15.5%)	48 (12.3%)
11 to 15 months	31 (8.0%)	34 (8.8%)	39 (10.0%)
> 15 months	27 (7.0%)	29 (7.5%)	48 (12.3%)

Wait Time Based on Experience

Experienced Individuals were asked an open-ended question about how long someone had to wait for a *first-time* MH appointment if it was not an emergency. There were 330 responses that could be stated in weeks, with four weeks equal to one month. Vague quantities were coded if possible and coded conservatively. Examples: “immediately” = 0 weeks, “weeks” = 2 weeks, and “months” = 8 weeks (2 months). Because responses were most often expressed as a range, they were split into lowest and highest wait times. There was a great deal of diversity in responses as might be expected when based on individual experience.

The *lowest wait time* averaged 7.24 weeks (1.81 months), with a range in responses from 0 to 48 weeks (up to 1 year). The *highest wait time* averaged 11.54 weeks (2.89 months) with a range in responses from 0 to 144 weeks (up to 3 years). The most frequent responses ranged from 4 weeks (1 month) to 24 weeks (6 months), which somewhat resembles the most frequent estimates from key informants.

Fourteen experienced individuals used this space to add **comments** rather than time estimates. Typically, they noted that the wait time depended on certain factors. Those most often mentioned were insurance or ability to private-pay. The next most often mentioned were the type of MH service or the type of MH provider.

Quality of Mental Health Services

Grading How Well Places Serve People with IDD

Experienced Individuals were asked to give letter grades to types of organizations within their experience, indicating how well they served the MH needs of people with IDD. For analysis, grades were converted to a numerical scale: F (0), D (1), C (2), B (3), A (4). Mean results are shown in Table 7. The highest result was a C+ average for IDD MH agencies ($M = 2.30$). Disability agencies ($M = 2.07$) and independent counselors or therapists ($M = 2.06$) had C averages. All other types of organizations had between C and D averages. Emergency rooms ($M = 1.13$) and religious leaders ($M = 1.17$) received the lowest grades.

Table 7: How well places serve the MH needs of people with IDD (scale 0-4)

Type of Organization	<i>n</i>	Mean	Standard Deviation	Most Frequent
Disability agencies	282	2.07	1.073	C
Emergency rooms	303	1.13	1.021	D
Family doctors or health clinics	325	1.83	.971	C
Hospitals for mental illness	251	1.62	1.137	C
IDD mental health agencies	209	2.30	1.135	B
Independent counselors or therapists	304	2.06	.995	C
Mental health centers	264	1.72	1.060	C
Religious leaders	186	1.17	1.110	F
Residential facilities	226	1.55	1.193	D

Added options each represent only one or two individuals. C-grades were most frequent: law enforcement, personal support agencies/personnel, schools (2), and specific organizations (2). A-grades went to a government agency and a therapist trained to work with people with IDD. One B-grade went to friends and families for getting help for people. F-grades went to jails, prisons, and training facilities.

Comments added by experienced individuals about how well MH needs were served in different settings built on previous themes. For example, it was not surprising that many comments here were about needs for training.

- In 19 states comments stated needs for training. Most of these were about working effectively with people who have IDD. Comments in a few states reiterated that professionals don't recognize MH symptoms in people with IDD. Also mentioned were making appropriate referrals, and how to modify or adapt treatments. Potential trainees beyond MH providers included family doctors, first responders, medical personnel, and school personnel.
- In 5 states comments mentioned staff factors other than needs for training, mostly noting staff are underpaid and there is high turnover.
- In 17 states comments continued about inadequate services for people with IDD. In 13 states comments noted that people with IDD are simply not served, not served well, or not served fully. In 5 states comments stated there are few services available to people with IDD. In 7 states it was noted services that are available tend to be poor quality. In 3 states it was noted services cause harm.

Resources That Have Been Effective

Key informants were asked to identify what training, education, or resources have been most useful in the past for serving people with IDD and MH concerns in their states. Most responses focused on organizations that have provided effective training. In-state organizations frequently included those created under the DD Act (i.e., DD Councils, P&As, UCEDDs) and LEND programs. State departments or agencies were frequently mentioned including those addressing disability, education, health, mental health, and rehabilitation. Universities and their academic programs were also often mentioned. Project ECHO and START programs were each mentioned a handful of times. Other types of in-state organizations providing training included advocacy organizations, DD centers, hospitals, independent living centers, medical centers, MH centers, state Arcs, and training centers for specific disabilities. At the national level, NADD was frequently mentioned as a resource for useful training.

Conferences, webinars, and other online delivery were most frequently mentioned as ways training was accessed in the past. The trainings or topics most often mentioned as useful included applied behavior analysis (ABA), adverse childhood experiences (ACEs), best practices or evidence-based practices, crisis intervention, Skills System, person-centered planning, positive behavior supports, and trauma-informed care.

Next Steps for Professionals

Going forward, Key informants were asked what training or education topics would be most useful for professionals to better serve the needs of people with IDD and MH concerns. They were asked a separate question about what information resources would be most helpful for professionals. Experienced individuals were asked what MH providers could do to better serve people with IDD. Responses to these three items tended to overlap and they are summarized together by themes.

Training: Basic or Foundational Understanding of the Population

The most frequently mentioned theme for professional training was a basic or foundational understanding of the IDD-MH population. Suggested topics relevant to this theme included the following:

- Prevalence and increased risk for MH issues, and most common MH conditions
- Awareness of types of IDDs, but also a recognition of the diversity and uniqueness of individuals
- Awareness of different ways of thinking, learning, and communicating
- Social model of disability, including stigma, oppression, myths, misconceptions, and discrimination
- Awareness of limitations in housing, transportation, and employment; health disparities; and vulnerability to abuse, exploitation, and trauma
- Impacts on families, and sensitivity to their experience
- Demystify and humanize the population, particularly with real life experience
- Recognize one's own biases

While not mentioned quite as frequently, a training theme that perhaps goes along with an understanding of the population was *how to work with families and caregivers*. A

number of people mentioned respecting the perceptions of family members or caregivers, and engaging them in the therapeutic process. Examples of the latter included helping to generalize skills gained in therapy across different settings, or helping with medication management. It was noted that professionals working with families and caregivers should understand caregiver fatigue and secondary trauma, and it would be helpful if they knew what training and support resources were available for families and other caregivers.

Another related training theme was a *whole-person approach* and understanding the extended needs of the IDD population. These were things related to developing skills for taking care of oneself, getting along with others, and being productive in society. Specific things mentioned included coping skills, emotional regulation, self-management, social skills, relationship skills, sexuality, sex education, and vocational services. Respondents wanted professionals to know about available services and resources outside their practice, and to help people engage community, natural, and peer supports. They also wanted professionals to understand the increased risks and additional supports needed for major life transitions.

Training: Recognizing Mental Health Symptoms

The second most frequently mentioned training theme was recognizing and identifying MH symptoms in people with IDD. The level of this kind of training could vary depending on the professional role of trainees. For DD providers and personal care professionals, it might be *recognizing and/or screening for* potential symptoms of MH issues and *making appropriate referrals*. For physicians and MH professionals, it might extend to *making a differential diagnosis*. Trainings might also vary by types of IDDs. Suggested topics included the following:

- Tools and methods for screening, or assessing and diagnosing MH symptoms in people with IDD
- How to use multiple sources of information to inform assessments or diagnoses
- Potential diagnostic errors, including diagnostic overshadowing
- Behavioral presentations of MH issues
- A developmental perspective, root causes and changes in MH over the lifespan

Specific IDDs mentioned relevant to recognizing MH symptoms included autism spectrum disorders, brain injuries, Down syndrome, fetal alcohol spectrum disorders, and genetic disorders. A related issue was recognizing cognitive decline and signs of dementia in people with IDD.

Training: Engaging People in Therapy and Effective Therapies

Another training theme frequently mentioned was strategies for engaging people with IDD in therapy. By far the most often mentioned topics in this area were about *communication*, particularly with people who have limited or no verbal skills. Suggested topics included the following:

- Working with people who have more severe disability
- Interacting with respect, dignity, and empathy
- Using plain language and types of questions that are easier to answer

- Understanding nonverbal communication
- Working with people who use augmented communication
- Being creative and thinking outside the box
- Providing services in different settings (e.g., residences, day programs)
- Using motivational interviewing, person-centered approaches, and supported decision making

A related and frequently mentioned training theme was *effective and appropriate therapies or interventions*. Suggested topics included the following:

- Evidence-based practices, clinical strategies, and therapeutic models
- Adaptations to therapies and the most common adaptations across therapies
- Reasonable accommodations including flexibility and patience
- Benefits of therapies for people with IDD, and what to reasonably expect

Specific therapies mentioned included anger management, art therapy, cognitive-behavior therapy, client-centered counseling, dialectical behavior therapy, mindfulness, music therapy, and relaxation techniques. The most frequently mentioned MH symptoms/disorders for treatment were anxiety, depression, and post-traumatic stress disorder. Others were attachment disorder, bipolar disorder, psychotic episodes, schizophrenia, and speech and communication disorders.

Additional Training Themes

Managing and handling behavior was a training theme mentioned by many people. Suggested topics:

- Understanding the complexity of behavior, and the diversity of factors that can cause behavior
- Dealing with aggression, disruptive behavior, inappropriate sexual behavior, self-injury, and violence
- Dealing with behavior across a variety of settings
- Using applied behavior analysis (ABA) with functional analysis and behavior planning, and positive behavior supports

Medication management was mentioned by many people. Suggested topics:

- Avoiding common pitfalls and overuse of medication
- Understanding responses to medications, particularly in relation to particular disabilities and interactions with other medications
- Questioning efficacy or effectiveness of medications
- Understanding compliance issues, particularly what supports are needed
- Moving people off medications
- Recognizing substance use disorders and self-medicating

Trauma-informed care was also mentioned by many people. Suggested topics:

- Assessing for trauma
- Recognizing potential symptoms and behavior manifestations of trauma
- Understanding adverse childhood experiences and the impact of early trauma

- Understanding chronic trauma
- Understanding triggers and avoiding trauma from interventions

Though not mentioned as frequently as topics under themes previously described, other training themes included cultural and other diversity awareness, early childhood MH, legal issues, strategies relevant to developing and maintaining a professional practice, and strategies for systems improvement.

Training Logistics

The training *delivery methods* most often requested were conferences, webinars, and other online or distance resources. Also requested were one-day workshops and in-person events, as well as hands-on and real-life experiences. The *type of trainer* most often mentioned was an experienced mental health professional who has successfully accepted and served people with IDD in a MH practice.

There were a number of professionals mentioned as *targets for training*. Most often mentioned were physicians, law enforcement, school personnel, emergency room doctors, and other emergency room personnel. Specific types of physicians and medical personnel mentioned included general practitioners, nurse practitioners, physician assistants, primary care doctors, psychiatrists, and public health providers. Specific types of school personnel mentioned included teachers, special education teachers, and special education aides. Other professionals mentioned included DD providers, first responders, MH clinicians, psychologists, and social workers. Staff in inpatient programs and managed care organizations were also mentioned.

There were a number of suggestions for *cross-training and collaboration*. The most often mentioned were DD providers and MH providers. Other mentioned pairings were psychiatry and behavioral health, DD agencies and psychiatric hospitals, healthcare and behavioral healthcare professionals, and direct support professionals and psychologists or psychiatrists. Other collaborative efforts included collaborative care programs, working groups, consultation teams, integrated healthcare teams, and crisis teams. It was noted that systems coordination is particularly needed in the transition from child to adult services.

A number of suggestions addressed *ongoing professional support*. These were about forming networks of MH professionals working with the IDD population, including professionals that may be spread across great distances. Specific suggestions included accessing expert case consultation and clinical supervision, forming a coalition, and forming professional learning communities.

Making a Practice Accessible and Inclusive

A number of suggestions could be grouped together under a theme of improving existing MH practices to include people with IDD. A number of these suggestions could improve a practice for all people seeking services. In addition to the number one suggestion to *invest in a well-trained staff*, suggestions included:

- Create a welcoming environment that is pleasant and uplifting
- Reduce waiting room time

- Offer the same array of services to all people
- Adopt strategies to improve staff retention, including higher wages
- Have IDD peers on staff as first contacts in the office
- Welcome and value input from family members, caregivers, and other providers
- Work with DD system providers, and provider teams
- Accept Medicaid and insurance; offer payment plans and sliding scale fees
- Abandon the system of 15-minute visits and increments for billing
- Have tools and/or personnel that will facilitate communication
- Provide information in plain language and in visual formats
- Adopt a whole-person approach, and know what resources are available to address factors related to MH such as exercise, independent living, nutrition, recreation, and employment
- Have mechanisms for assisting people with accommodations, paperwork, compliance, follow-up, and transportation
- Avoid medication as a first option
- Be flexible to work in different environments or during non-traditional hours
- Take people seriously, treat them with respect, build trusting relationships
- Stay in touch with people, partner with them in walking a lifelong path
- Keep up to date with current developments addressing needs of this population

Next Steps for Individuals and Families

Key informants were asked questions about what training and information resources would help people better understand IDD and MH concerns, and help them to access MH services. Experienced individuals were asked questions about what adults with IDD and families needed to know so they could get MH services they wanted. Responses to these four questions tended to overlap and are summarized together by themes.

Resources for Finding Mental Health Services

The most comments with a lot of overlap among suggestions for professionals, individuals, and families were about finding MH services. Suggestions included up-to-date in-state directories of MH resources and service providers. It was noted information should be presented in plain language and in visual formats. A number of suggestions talked about having and widely promoting one place to start looking for information, a centralized repository or clearinghouse. It was noted that the current 211 system is inadequate. State agencies were suggested as a starting point for information. A help line was also suggested. A number of suggestions were about online tools or apps to find providers and resources, but it was also noted not everyone has access to the internet. Mental health fairs, social media, and outreach efforts to individuals, families, and to rural areas were mentioned.

Suggestions for *directory content* included contact information, transportation options, hours of operation, age groups served, types of services, eligibility requirements, typical costs and payment options, network participation, program requirements, and processes for appeals if services are denied. Respondents also wanted to see individual provider details such as expertise, credentials, training, and experience with

the IDD population. It was noted it would be helpful to list the best places to go first if one has an IDD, and where to go in a crisis or emergency.

Information Resources

Many overlapping suggestions focused on publications and information resources. These suggestions were not only aimed at informing individuals with IDD and families, but also helping to educate other people. Others mentioned included primary care providers, case managers, dentists, employers, first responders, law enforcement, school children, school personnel, service/support coordinators, and social workers.

Suggested *content* included basic information to increase awareness about the IDD-MI population and MH treatment. Other content included advocacy and resource organizations, funding application processes, legal rights, MH conditions, kinds of therapies and services, adapting therapies, and tools for screening and assessment. Suggested *formats* included booklets, FAQ sheets, handouts, journal articles, newsletters, pamphlets, tip sheets, webinars, websites, and white papers. Suggested *places* for resources included faith-based and community organizations, health courts, libraries, recreation centers, schools, service and support agencies, and waiting rooms in medical settings.

More specific to individuals and families, suggestions included *guides* about what to look for in a MH provider, what questions to ask to ensure a good fit, and how to disclose a disability. Tools and language to help people communicate with professionals and to make choices were also mentioned.

Increasing *public awareness* and reducing stigma was relevant to a number of comments. Public service announcements and social media were mentioned, as well as celebrity spokespersons. Beyond the general public, targets included businesses, churches, civic groups, employers, first responders, religious leaders, and schools.

Support, Advocacy, and Training

A number of suggestions for supporting individuals and families focused on *inspiring hope*. These included letting people know they are not alone, they matter, they are members of a community, their mental health is important, they deserve services, help is available, it is okay to talk about concerns and ask for help, and they can be helped. It was also noted that individuals and families need to know there is no quick fix. As one respondent said, it is a marathon not a sprint.

A number of suggestions focused on *assistance* individuals and families need. These included assistance with completing paperwork; obtaining resources for funding; as well as understanding information, informed consent, and release of information. Addressing housing, employment, and particularly transportation needs were often mentioned. It was noted a number of times that someone might need to have an advocate present. Having health or family navigators, or a point-of-entry liaison to help find services, deal with insurance, and navigate systems were mentioned. It was also noted that parents and caregivers can have their own developmental and mental health issues and may need additional assistance to address their own needs.

A number of suggestions were more about letting individuals and families know what they can do to *be part of the solution*. Most of these suggestions were about advocating for oneself or for a loved one. Specific things to advocate for were MH services, support services, insurance coverage, better quality of care, legal rights, safety and resources in schools, treatment options other than medication, and a team approach. Involving family and friends, seeking information and assistance, connecting with others for mutual support, and applying for waiver funding were mentioned. Suggestions that focused on working with providers included asking questions, keeping the focus on MH symptoms, getting information in writing, seeking second opinions, shopping around for providers, and changing providers if one is not working. Suggestions were often about being patient, persistent, and never giving up.

A number of suggestions were about ideas for *training topics* including not only advocacy, but also coping skills, self-care, legal rights, steps to obtain services, and types of MH treatment. Specific therapies mentioned included cognitive behavior therapy, dialectical behavior therapy, equine therapy, eye movement desensitization, music therapy, neurofeedback, and yoga. Trainings about accessing funding and managing finances, developing a life plan, navigating systems, and communicating with providers were suggested. It was noted families could benefit from training about the relationships among physical health, mental health, and behavioral issues, as well as what they can do to help themselves or a loved one reduce depression and anxiety. Understanding the difference between IDD and MH, recognizing potential MH symptoms, evidence-base or best practices, addressing behavior, and trauma were mentioned for individuals and families as well as for professionals. Suggested training *formats* included webinars, online courses, and panel discussions, as well as in-person local events. It was also noted trainings aimed at professionals can often be opened up to include nonprofessionals.

Long-Term Systemic Solutions

Beyond training and improving resources for the existing workforce, many comments were about strategies to make more long-term or systemic improvements. The most often mentioned was to incorporate IDD into *graduate education programs*. Suggestions included infusion in existing curriculum, offering elective specialty courses, and incorporating IDD in internships and supervision. It was also suggested there could be graduate MH education and certification programs focused on IDD.

Similarly, a number of respondents talked about *addressing shortages*. Long waitlists for services were frequently mentioned throughout the survey, most often related to shortages of MH providers including psychiatrists, psychologists, and those who specialize in working with the IDD population. Shortages of residential, inpatient, and psychiatric facilities as well as emergency room expertise were mentioned frequently, including specialization in different age groups. Other shortages included independent living services, forensic services, respite providers, school-based services, and substance abuse treatment options. Increasing interpreters for language access, and increasing high quality telehealth for rural access were mentioned.

The most often mentioned suggestions that might be addressed at the policy or government level were about requiring levels of training, education, certification, and continuing education aimed at *increasing the quality and professionalism* of the MH workforce. It was noted that working with the IDD population should eventually be a basic competency for all MH workers. Increasing access by making some training/education free of charge or at a low cost was mentioned. Offering incentives was also mentioned, particularly tied to increasing providers outside urban centers. Another suggestion aimed at professionalism was to have required core competencies for case managers and for direct support professionals. Consistency in the workforce was often mentioned as particularly important for people with IDD.

Increasing the number of MH providers who will accept *Medicaid and Medicare* was frequently mentioned. A number of suggestions were about improving Medicaid by reducing barriers to care and increasing reimbursement for mental health services. This was often connected with providers being willing to serve people with IDD, and reducing high turnover in settings that accept Medicaid. Insufficient insurance or Medicaid coverage and high out-of-pocket cost were frequently mentioned throughout the survey. As one respondent noted, mental healthcare is so expensive it is viewed as a luxury. A suggestion was to bring mental healthcare coverage up to the same levels as physical healthcare. Similarly, it was noted that funding streams need to be aimed at long-term MH supports and not just crisis-driven acute care. Autism-specific waivers were also suggested, which might help reduce waitlists for other waiver programs.

Fostering *cross-system training and collaboration* were often suggested to help address problems with siloed systems. Creating Medicaid billing codes for cross-system consultations was suggested. Increasing system-wide awareness of legal obligations, particularly those preventing discrimination were also mentioned. Starting early with MH screening in early intervention, Head Start, and well-child visits was suggested, along with assistance for those families to access MH services. Creating networks of providers who work with the IDD population was mentioned, as well as encouraging co-location of health and MH services.

Additional Comments

Experienced individuals were asked if there was anything more they would like us to know. Many respondents used this space to tell personal stories to illustrate the frustrations, problems, and issues related to previous responses. Some new issues were about abuses, fraud, politics, and corruption within systems. Many people remarked about professionals who continue to believe the myth that people with IDD cannot benefit from therapy. One story was a reminder that diagnostic overshadowing can go both ways. Professionals might not recognize an IDD because it is overshadowed by MH symptoms.

Limitations

Decisions to use an online survey and to distribute it through national organizations were driven by limited time and limited resources within the scope of a larger project. Though this survey was reviewed and approved by an Institutional Review Board, it was

not technically research. It did not employ all the standards expected in high quality research. While there was an attempt to reach appropriate respondents, it was not possible under these conditions to control who responded or to ensure a representative sample. The typical respondent was White, female, and most likely a family member, disability provider, and/or an administrator. States were not all represented and among those that were represented, there was not equal representation.

While the survey was technically accessible, a survey method itself is not accessible to many people with IDD. A potential respondent needed to have internet access and an email address. If someone could not read or use a screen reader, they needed personal assistance to respond. There was an attempt to use plain language, but words that greatly increase reading level were necessary (e.g., words with a lot of syllables like psychiatric and psychological).

While this effort was not perfect, it does contribute information to the collective evidence about gaps in mental health services for the IDD population. It provides many ideas for training topics, information resources, and long-term systemic solutions. The credit for that goes to the hundreds of people who generously shared their time and expertise.

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