National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

State of Louisiana IDD-MH Service System Evaluation

June 18, 2024

Joan B. Beasley, PhD
Research Professor, College of Health and Human Services, Institute on Disability, University of New Hampshire

Karen Weigle, PhD
Associate Director/Director of Program Development, National Center for START Services ®, Institute on Disability, University of New Hampshire

Ann Klein, MA
Director of Outcomes and Evaluations, National Center for START Services ®, Institute on Disability, University of New Hampshire

Luke Kalb, PhD
Assistant Professor in the Department of Neuropsychology and the Center for Autism and Related Disorders, Kennedy Krieger Institute, Johns Hopkins Bloomberg School of Public Health

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Table of Contents

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Executive Summary

This evaluation was conducted by members of the UNH Institute on Disability National Center for START Services ® (NCSS) and funded by the Louisiana Office of Citizens with Developmental Disabilities (OCDD) as part of their ongoing effort to improve services for individuals with intellectual/developmental disabilities (IDD) and mental health (MH) service needs (IDD-MH) in Louisiana. It was conducted with input from OCDD and citizen volunteers with the active support of statewide leadership. The evaluation process highlights the self-reported experiences of service users, families, and providers regarding the effectiveness of the existing service system. To learn about mental health and other service experiences of people with IDD-MH, five data collection methods were employed: (1) an online survey, (2) zoom based discussion groups, (3) phone-based family caregiver interviews, (4) a review of Medicaid claims data provided by OCDD, and (5) on-site meetings with mental health providers and self-advocates. The identities of all participants in this evaluation are confidential.

Like any form of healthcare, resources are needed in all elements of a person's life to fully address mental health conditions. In addition to mental health treatment, IDD providers, educators, and primary health providers should also be included in service delivery. A comprehensive and integrated approach is warranted to both prevent the exacerbation of acute mental health conditions and to provide ongoing care and treatment. This evaluation focused on the effectiveness of the overall service system to both treat mental health conditions and support well-being for people with IDD. While the treatment of mental health conditions is essential, other services are also important to address mental health needs of people with IDD.

Despite efforts and some progress, the results from this evaluation indicate that most services used by people with IDD-MH require improvement in both capacity and access. IDD services do not treat mental health conditions and cannot be the primary provider of mental health care for people with IDD-MH. However, IDD services that promote mental well-being and work in partnership with mental health providers are of equal importance. Findings indicate that mental health providers remain unclear as to their role and responsibility to treat people with IDD-MH. People with IDD-MH also report that they are socially isolated from community life and have limited access to education, vocational, and recreational services. IDD providers, educators, and other health providers report that they lack the capacity and expertise to actively promote the health, education, and emotional well-being of people with IDD, especially those with mental health needs. Experiences of stigma and marginalization were reported to occur throughout the lifespan.

All providers, including mental health treatment providers, should expect that people with IDD are part of their service recipient population and should be included in the planning and implementation of services. A formal statewide interagency agreement that outlines the infrastructure to allow for cross-systems collaboration is needed. Further recommendations include:

1. Expansion and enhancement of the Resource Center system to include local hubs to provide community-based services and supports to people with IDD-MH throughout their lifespan.
2. Ongoing data collection, reporting, evaluation, and review to ensure that services are evidence informed and to monitor their impact and cost effectiveness.
3. Incorporate best practice and evidence-based training and capacity building efforts across the system of care, including consideration of mental health coaching.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

4. Consider an expanded use of telehealth methods to ensure access and improve capacity.
5. Improve community information dissemination strategies to reduce stigma and improve community knowledge of available resources.
6. Inclusion and accommodation of people with IDD-MH must be incorporated into the planning and implementation of all services.
7. Improve crisis prevention and response for the IDD-MH population in Louisiana.
8. The START model may be considered to assist with linkages, cross training, coaching and crisis supports as part of the plan going forward.

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Introduction

The information in this report represents the findings from a statewide evaluation of mental health services and supports for individuals with intellectual/developmental disabilities (IDD) and mental health (MH) service needs (IDD-MH) in Louisiana. The evaluation was conducted by members of the UNH Institute on Disability National Center for START Services ® (NCSS) and funded by the Louisiana Office of Citizens with Developmental Disabilities (OCDD) as part of their ongoing effort to improve services for individuals with IDD-MH. It was conducted with input from OCDD and citizen volunteers with the active support of statewide leadership. The evaluation process highlights the self-reported experiences of service users, families, and providers regarding the effectiveness of the existing service system. Five data collection methods were employed: (1) an online survey, (2) zoom based discussion groups, (3) phone-based family caregiver interviews, (4) a review of Medicaid claims data provided by OCDD, and (5) on-site meetings with mental health providers and self-advocates. The identities of all participants in this evaluation are confidential. Findings, along with recommendations for follow-up, are included in this report. The National Center for START Services ® at the University of New Hampshire/Institute on Disability appreciates the opportunity to assist in this effort.

Background

Across the United States, approximately 1.5% to 2.5% of the population has an intellectual/developmental disorder. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM 5-TR), Intellectual Developmental Disorder impacts both "intellectual and adaptive functioning deficits with a failure to meet developmental and socio-cultural standards for personal independence and social responsibility."[1] However, while this is the current diagnostic category in the DSM, the term most commonly used in the field across the United States remains Intellectual/Developmental Disabilities (IDD), which will be used throughout this evaluation.

The 2022 census data estimates the population of Louisiana to be 4,590,241 people.[2] According to the Office of Citizens with Developmental Disabilities (OCDD), there are approximately 41,618 people identified as eligible for developmental disability services, and based on prevalence studies, it is estimated that about one-third of those individuals (13,873) in the OCDD service system may also have mental health needs at some point in their lifespan.[3]

Epidemiological studies have established that the incidence and prevalence of mental health (MH) conditions for people with IDD is typically 2 to 3 times that of the general population, and mental health conditions, including those associated with a high degree of trauma, often contribute to challenging behavior.[4] Challenging behavior and the stigma associated with challenging behavior often serve as barriers to community inclusion and active treatment of health and mental health needs for people with IDD. Perhaps as a result, aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services.[4.] Additionally, a significant percentage of people with IDD and mental health needs live with family caregivers who are relied upon to advocate for their services.[5]

OCDD provided comprehensive background information about the current system and recent efforts regarding services and service outcomes. To provide access to mental health expertise to assist people in MH crisis or in need of consultation or evaluation, Louisiana operates the Resource Center (RC) an integrated multimodal consultation and evaluation community-based service. The OCDD Resource

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Center provides urgent clinical support and services statewide in response to the needs of people with IDD.

Prior to budget cuts between 2010 and 2017, there were multiple separate Resource Centers and community support teams each tied to a state operated center. While valuable and effective, the OCDD Resource Center is a very lean division within the office – about 90% of the budget are the personnel costs, with few additional enhancements available. The RC functions using a combination of telehealth/virtual contacts and traveling to meet people where they are – their homes, work, community. Recruitment and retention are better in some parts of the state; therefore, the degree of impact varies across regional areas. The community largely relies upon the expertise within the RC team and has limited ability to build capacity due to lack of funds to make this possible.

Regarding community-based crisis beds, there is discussion/planning underway to address this gap in the current system. Louisiana is also reviewing its urgent triage and diversion process as it appears that people may be referred too late for effective and timely intervention resulting in becoming stuck in a hospital or in jail, having lost their home or residential provider. The OCDD is seeking a remedy to this important challenge.

OCDD reports several successes to build upon, including very strong working relationships with the local governing entities, the Arc of Louisiana, and with many service recipients/families. One product of this collaboration was the development of “Clinician’s Guide to Accessible Mental Health Treatment”. OCDD is also collaborating with state operated hospitals and all six Managed Care Organizations (MCOs), along with the LSU Health Sciences Center’s Center for Evidenced Based Practices to build and deliver training to the newly implemented crisis service providers, and they are very interested in more collaboration. OCDD requested the evaluation described in this report as they consider the START model as part of their planning process.

There was also a discussion with representatives of the state’s Department of Education (DOE). While they report that there are some resources and methods available to improve education for students with IDD and/or mental health needs, there are access and personnel issues that undermine success. In response, the DOE has initiated efforts to develop statewide training, to incentivize participation and to work more collaboratively with disability, vocational /rehab services, mental health, and others to implement a more comprehensive and integrated approach from early education to graduation. The DOE has recently been awarded a five-year multimillion dollar grant to develop and implement a strategic plan. The DOE acknowledged that at this time, student and family experiences largely depend on their local entity, undermining the ability to introduce best practices and to enhance capacity across the state. However, there has been noteworthy progress to incorporate a strength-based and trauma informed approach to classroom management in all school settings. There are no formal methods in place to accommodate students with IDD-MH although it is acknowledged that students with these needs are both in special education and general education settings across the state.

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Methods

The following section describes the methods used to collect data for this evaluation.

Aims

The aims of this inquiry were to evaluate the following:

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

Data Collection Methods

Five 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
Method 2: Zoom-based discussion groups
Method 3: Family caregiver structured interviews
Method 4: Medicaid claims review
Method 5: On-site discussion forums

Methods were reviewed and implemented in collaboration with OCDD, and the online survey was modified based on their feedback. OCDD played a key role in distributing the survey across Louisiana, and they also helped to identify potential volunteers to participate in discussion groups and family interviews.

Method 1: Online Survey of Stakeholders

The online survey link was sent 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 educators. The goal was to receive feedback from as many citizens across the state as possible.

The 3 A's Framework of Effective Services[6] was employed to examine mental health and related service experiences for people with IDD-MH. The 3 A's are Access (timeliness, location, availability), Appropriateness (services match needs/wants, choice in service options, expertise of service provider), and Accountability (individuals are satisfied with the services, services are helpful, responsive, cost effective and flexible to meet needs).

<u>Survey Respondents</u>

A total of 152 volunteers completed the survey between July and November 2023. Figure 1 shows the self-reported role of respondents. Providers of developmental disability (IDD) services (n=47) represented 31% of respondents. Family members (n=53) and individuals with lived experiences (n=7) represented 39% of respondents.

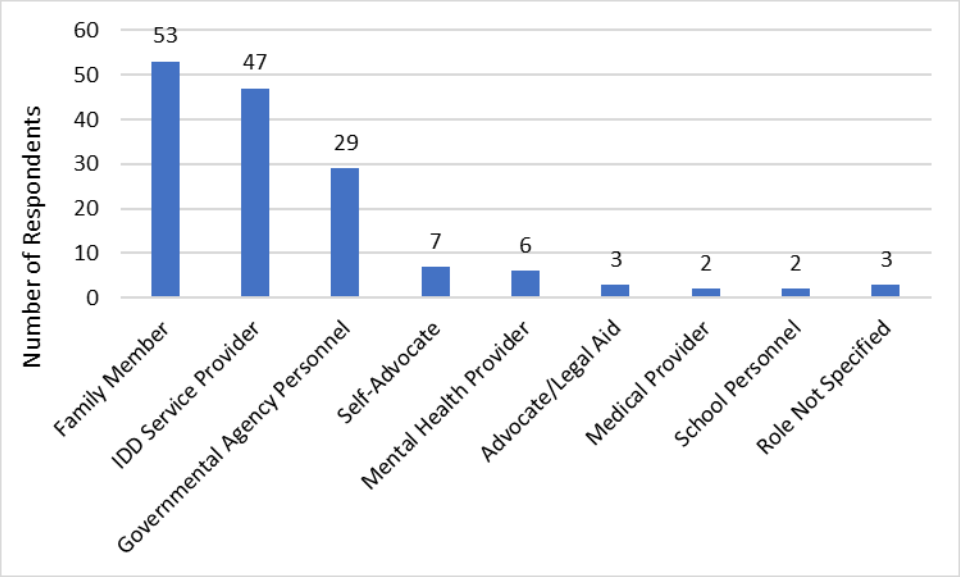
NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Figure 1: Number of Online Survey Respondents by Self-Reported Role (n=152)



Survey respondents represented all age groups, and 71% of provider respondents indicated that they had over 10 years of experience in their reported role.

Respondents were also asked to identify the parish from which they primarily provide or receive services. Twenty-six of Louisiana's parishes had at least one respondent. Of the 108 respondents who specified a parish, 88% (n=95) reported that they were from metropolitan parishes, while only 12% (n=13) represented more rural parishes. This division underrepresents rural areas in Louisiana, which make up approximately 28% of the population.[2] There were eight individuals who indicated they worked statewide and 36 respondents who did not specify a location. See Appendix A for a list of respondents by parish.

Every effort was made to include as many Louisiana citizens as possible to achieve representation in this process. To include more representative input, the in-person discussion groups focused on dialogue with under-represented groups. This includes some Parishes, mental health providers and people with IDD. Their feedback is also included in this report.

Online Survey Design and Analysis Methods

Survey participants responded to a series of questions about IDD, mental health, and related services for people with IDD-MH. For each service, a five-point Likert rating scale was used to rate effectiveness: available and works well; available, but not sufficient (service exists, but is difficult to access due to lack of providers, long wait lists, not accepting insurance, etc.); available, but needs improvement (service exists but does not meet the needs of individuals with IDD-MH [poor service, lack of expertise, lack of training, etc.]); not available; and do not know.

Analysis first consisted of identifying and clustering participants into three constituency groups based on self-reported role within the community system: 1) IDD service providers, n=47, 2) family members/self-advocates (people with lived experiences), n=60, 3) government agency personnel,

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

n=29, and 4) all other respondents, n= 47. 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. When differences were found to be significant, they are noted in the report. Due to the low number of respondents from rural parishes, a test of significance between rural and metropolitan respondents could not be conducted.

Second, each response category was recoded to a numerical value so that mean (average) scores could be calculated. 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 (0=do not have access, 1=available, but not sufficient (enough), 2=available, but needs improvement, 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 information on each question and corresponding statistical analysis tables, see Appendix B.

Method 2: Discussion Groups

A total of seven discussion groups and one law enforcement officer interviews were conducted via Zoom with a total of 80 volunteer participants (see Appendix C for a list of discussion groups). Each focus group began with an introduction to the purpose of the forum, followed by facilitated discussions in response to two questions:

1. “How well is the current service system meeting the needs of individuals with IDD who need mental health services?”
2. “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 evaluation team. This method allowed for major themes to emerge that help to guide the findings, discussion, and recommendations identified in this report.[7] Discussion groups provided greater depth and context to understanding survey results and were consistent with needs identified in the survey.

Method 3: Family Caregiver Experiences Interviews (FEIS)

This evaluation included a voluntary, structured telephone interview of family caregivers about their recent experiences with mental health services for their family members with IDD-MH. The Family Experiences Interview Schedule (FEIS), a survey developed by Tessler and Gamache,[8] was used to conduct 8 interviews. The FEIS is a 28-question, validated, family caregiver survey that has been used in other studies.[9,10] Informants were asked to use a four-point Likert scale to rate their experiences with mental health service providers with a recall period of one year. The options for each question were: *All that was wanted/needed*; *Some but not as much as I wanted/needed*; *Very little*; or *Not at all*. While

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Did not answer/do not know was not a choice presented, if an informant could not 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: (1) to assess whether their family member with IDD-MH experienced unmet service needs, and (2) to give advice to service planners about the mental health needs of individuals with IDD.

The FEIS interviews were designed to receive direct input from family caregivers, and their feedback is integrated into the summary of findings that follows. Family caregiver responses were consistent with survey data and feedback from discussion group participants. The identity of participants is confidential and not part of this report.

Method 4: Medical Claims Data Review

A total of 41,618 individuals were identified by the Louisiana office of Citizens with Developmental Disabilities (OCDD) as eligible for IDD services and were included in this review of Medicaid claims between 2021-2022. Three outcomes were evaluated: 1) psychiatric emergency department visits, 2) inpatient psychiatric hospitalizations, and 3) psychotropic drug prescriptions.

OCDD provided a de-identified summary of Medicaid mental health claims data for individuals eligible to receive developmental disability services in the calendar years 2021 and 2022. For 2022, about 18% (n=7642) received psychiatric medication prescriptions. As this is commonly used treatment in crisis services as well, we assumed that amongst those identified as receiving psychiatric medication some individuals also received crisis mental health services. Of the 7642 individuals, 8% (n=622) accessed emergency room treatment, and 9% (n=661) received psychiatric inpatient services. Cost data for emergency department visits was not available, but annual costs for inpatient and medication claims was approximately $229 million dollars in CY 2022. While limited in scope, the claims data provides an important snapshot for consideration in the context of the feedback from citizens of Louisiana.

According to the National Institutes of Health data, it can be estimated that for Louisiana, the average cost for an emergency room visit in 2022 was $623.00, for a total estimated additional cost of $387,500. Overall, emergency and inpatient mental health services are the costliest form of mental health care provided. In Louisiana, the length of in-patient stays far exceeded the national average, and many people were admitted more than once in 2022. While only a small percentage received emergency mental health services, considering the prevalence of mental health needs in the population, a significant amount of emergency mental health resources was expended.

Method 5: On-site Discussion Forums

To increase participation by several groups underrepresented in the initial data collection efforts, a fifth method was added to this evaluation. The analysis team conducted four on-site discussion forums with mental health providers (inpatient (n=8), outpatient (n=5), a group of persons with lived experiences of MH-IDD (self-advocates (n=9), and staff at one outpatient mental health clinic. Participants were invited by OCDD staff with an emphasis on including the input of rural parishes in Louisiana (see Appendix C for a list of forums). These forums focused on, “What are the services and supports needed in your community for people with IDD who have mental health experiences and/or challenging behavior? Group participants were given several scenarios related to mental health services and were asked to provide feedback about services based on the 3 A’s as described above.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Responses were recorded, scored, and compiled. The feedback provided enhanced the analysis of findings that emerged throughout the evaluation.

Note: when referring to “behavior support services”, these are not mental health services, respondents are referring to ABA-based Behavior Support Plans.

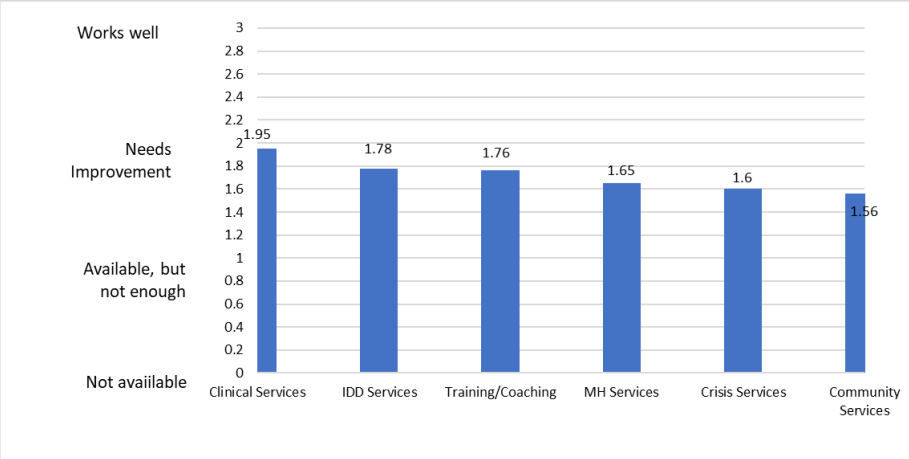
Mental health services include those that help contribute to the person’s emotional/ mental well-being and those designed to treat diagnosed mental health conditions.

Results

Approximately 260 citizens from across Louisiana participated in this evaluation of services for individuals with IDD-MH and their families.

A total of 152 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 be available in Louisiana, but either not enough to meet the need or required improvement to meet the needs of individuals with IDD. The greatest service gaps reported pertained to community services that promote inclusion (transportation, recreational and employment opportunities) and crisis prevention and intervention services, followed by mental health outpatient services. Clinical services (medical, dental, OT, PT, etc.) were the most highly rated services. None of the services were rated as working well (Figure 2). The feedback from the data collection portion of the study is consistent with reports from the in-person discussions. While Louisiana has made strides to improve access to mental health services, the lack of expertise and resources within these services was reported to be a major obstacle. **This indicates that both the capacity to provide some services and the quality of services may need to be addressed.**

Figure 2: Mean Scores for Each Service Category



Overall, participants identified the need to improve services across the spectrum for people with IDD-MH, with the most frequent discussions centered on crisis and mental health services.

This section of the report provides a description of each area of service and associated findings from community surveys, family interviews, and stakeholder discussion groups, along with relevant claims data.

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Outpatient Mental Health Services for People with IDD-MH

Findings suggest that there is a need to increase capacity to provide effective community-based outpatient mental health services for people with IDD in Louisiana. While most survey respondents (88%) reported access to some mental health services, only 21% reported services worked well for people with IDD and service users (family members and self-advocates) were much less likely to report that services worked well for them (4%). Participants noted that mental health services are in high demand across the state and that people with IDD are under-represented as a patient population receiving mental health care. Participants described an overall lack of providers resulting in long waitlists **and that many mental health providers were reluctant to serve individuals with IDD, citing lack of training and expertise**. Mental health providers report a lack of qualified mental health practitioners to provide effective mental health care, and while some training has been made available there is a lack of resources to allow people to receive the training. Furthermore, providers repeatedly stated that they needed clinical supervision and coaching not just didactic training to be more effective.

Participants and family caregivers also reported that there was often an assumption on the part of mental health providers that challenging presentations were “part of the IDD” and should be addressed within the IDD service system, often through behavioral supports such as ABA, rather than through mental health treatment. Study participants noted that medication management is often the only service provided. However, claims data provided by the Louisiana Office of Citizens with Developmental Disabilities (OCDD) indicates that only about 18% of the DD eligible population in 2022 had claims for psychiatric medications. Given the overall prevalence of mental health conditions for individuals with IDD[3], these data support the overall finding that individuals with IDD are being underserved in the mental health system. Participants reported that lack of effective mental health care often leads to loss of placement, long emergency department stays, and incarceration. According to in person discussion participants, while mental health providers will accept people with IDD for outpatient care, there are long waits for services, and there is little to no adaptation of practices or assessment methods to provide inclusive care.

Findings Within Evaluation Methods

Survey

The online survey consisted of seven questions to evaluate participant’s views about outpatient mental health care. As shown in Table 1, for those respondents with knowledge of services, outpatient services were widely reported to be available in Louisiana with over a fifth of respondents (21%) reporting that outpatient services worked well for individuals with IDD. However, it is noteworthy that services users (families and self-advocates) were more than three times less likely to report that services work well than all other respondents and more likely to report no access to outpatient services (Figure 3). This suggests that while services are available, system partners may be overestimating how well services are working for those that use them.

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

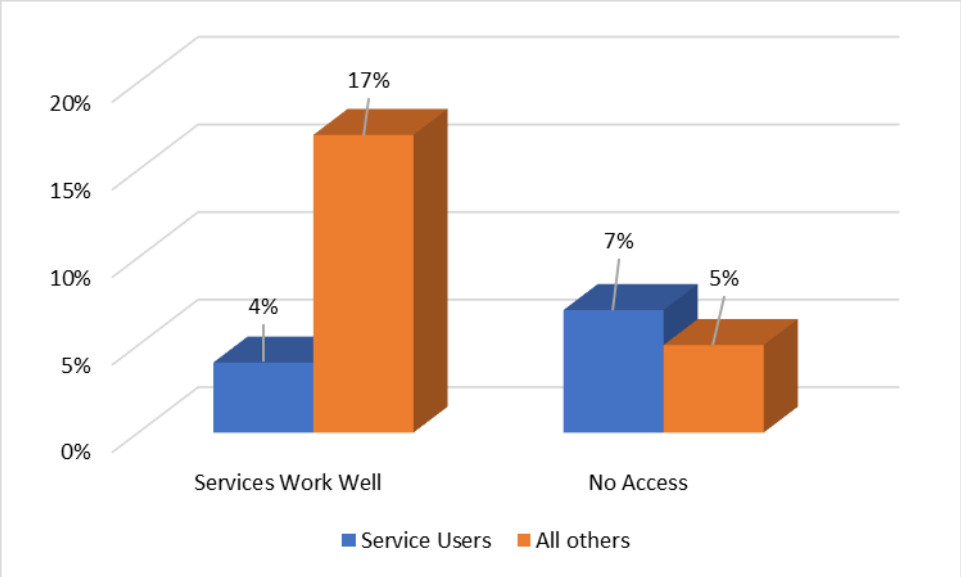
Table 1: Survey Results of Reported Effectiveness of Outpatient Mental Health Services

Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
Outpatient MH Therapy	21%	31%	34%	14%
Psychiatry	22%	36%	32%	10%
Diagnostic Assessment	19%	45%	25%	10%
Substance Abuse Treatment	29%	30%	32%	9%
Intensive Outpatient MH Therapy	20%	33%	29%	18%
Mental Health Rehab	17%	36%	33%	14%
Wrap	20%	38%	33%	9%
MH Services (average)	**21%**	**36%**	**31%**	**12%**

Figure 3 provides a breakdown of outpatient services reported as working well and lacking access by respondent groups (providers or service users). Service users (families/self-advocates) were more than likely to rate outpatient mental health services as unavailable when compared to providers and much less likely to report that services worked well for them. These findings were statistically significant (F=8.03, p=.01).

Respondents emphasized the need to build capacity within existing mental health services, with 36% on average stating that there are available services, but that they need improvement.

Figure 3: Survey Results of Works Well and No Access by Respondent Groups (service users/providers)



National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Survey respondents who rated the availability of mental health services as '*not available'* or *'needs improvement'* were asked to provide their thoughts on the perceived service gaps across Louisiana. Of those that commented (n=32), **half (50%) reported that services were not available in their area, 10% specifically cited access issues due to being in rural locations. An overall lack of available providers (18%), long wait lists (9%), and insurance or cost (13%) were reported as the biggest obstacles to access when services were available. More than a third (37%) reported that providers lacked training and expertise in IDD or were reluctant to accept patients with IDD.** Lack of training was a big issue presented by the mental health providers interviewed. In addition, in some communities in-person discussion group participants reported having to travel long distances to access mental health services. When asked about the use of telehealth, this appears to be underdeveloped and underutilized.

In both the survey and interviews, family caregivers were asked to rate their overall satisfaction with mental health services for their family members (n=58), most (78%) were less than satisfied.

Access to Qualified Prescribers/Psychiatrists in IDD-MH

Survey

An overwhelming number of survey participants reported that access to qualified psychiatrists is a challenge, and when they can access services, they may have to pay out of pocket for treatment. Two survey questions related to the availability of qualified psychiatrists and medications to treat mental health needs were:

1) *In your community, who primarily prescribes medications to individuals with IDD and MH needs?*
2) *Are there barriers to accessing prescribed mental health medication? If so, what are the barriers?*

For family respondents (n=56), half (50%) reported that psychiatric medications were prescribed by someone other than a psychiatrist or mental health practitioner, and 78% of those family respondents reported that lack of providers was a barrier to accessing medication overall.

Family Caregiver Interviews

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 1 caregiver responded that everything they needed was available. When asked about service and provider choice, no families reported having all needed service options or the opportunity to choose a provider. When asked, *"Was there any particular service that your family member needed that was not available?"* five of the seven who reported yes stated that they needed better access to outpatient mental health therapy, particularly prior to crisis events.

Discussion Groups and On-Site Forums

The lack of capacity throughout the state was reported among discussion group participants. Participants reported a lack of training, coaching, education, and confidence to work with individuals

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

with IDD-MH as the biggest barrier to services in the community. Providers noted that IDD is often absent from the school/training curricula for mental health and medical practitioners and that those with expertise developed it in the field and often have very long wait lists. Across discussion groups, there was a collective sense (40%) that increased education and training would help to address the low levels of confidence among providers and allow for more acceptance of clients with IDD-MH.

When asked to identify needs in the community, 25% of discussion group participants cited access to outpatient services as the greatest need and an additional 15% noted that better access to outpatient services with a focus on prevention would likely diminish the need for more costly crisis services. While behavior support services were acknowledged to be beneficial within the system, only 1% thought an increase in behavioral support was the greatest need.

Within on-site forums, participants rated three mental health outpatient services for individuals with IDD. Responses for the participants are summarized in Table 2 below. Participants overall reported that the lack of outpatient providers for this population creates more demand on the inpatient service providers who are often the ones that are used to provide mental health care.

Table 2: On-Site Forum Results of Reported Effectiveness of Outpatient Mental Health Services

Outpatient Services	**Access** (timely, nearby, enough to provide for needs)	**Appropriateness** (matches what is needed, options)	**Accountability** (acceptability change when needed, choice)
Wrap around	Does work with children with IDD-MH in some locations	Does not always have the expertise needed	Teams that offer expertise and support are not always welcomed in school setting
Mental health outpatient therapy (other than behavioral services)	Very hard to get • Long waitlists • Not enough • Far away (3-hour drive) Lack of services leads to inpatient and crisis service use	Does not have training Does not adapt to the IDD population	Long waits for services Lack of expertise Lack of providers
Psychiatry/prescriber	Hard to get	Mostly provided by PCP	Not sure that meds are working

Implications of Findings

Many participants within discussion groups and survey respondents indicated that Louisiana has a strong commitment to behavioral health services and a robust network of providers in the community,

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

especially in population centers. The quality of providers, access to Assertive Community Treatment (ACT) teams and wrap-around services for some children were all highlighted as strengths within the existing system. However, one-third of all discussion group participants reported that increased collaboration between the mental health and IDD systems was the greatest need to ensure that these services are available to people with IDD when needed. Evaluation participants reported that for people with IDD, treatment is often limited to medication to treat mental health conditions and that services such as ACT often exclude people with IDD. As mentioned earlier, the claims data indicate that about 18% of the OCDD eligible service population were prescribed medications in 2022. This reflects a lower rate of mental health service use than would be expected. Participants also reported concerns about psychiatry and the quality of psychiatric services along with a lack of access to other forms of mental health treatment for people with IDD. **Despite recent efforts there may be a significant underserved IDD-MH population within the state of Louisiana.**

Crisis Prevention and Intervention Services

Across all data collection methods was the reported need for crisis prevention and intervention services. Participants reported a lack of resources and capacity to prevent crises. Discussion groups highlighted the need for crisis prevention education, reporting that there is very little formal training for caregivers to address a situation so that it does not become a crisis, and while they largely rely on personal experience to assist in responding to crisis, there is mixed success. While the on-site discussion groups included the knowledge of some participants of the newly developed mobile crisis teams, many were unaware and did not know how to access. In addition, crisis team providers stated that didactic training as to how to evaluate and support people with IDD in crisis was not enough. Many wanted on-site coaching to be included in the training to build capacity, and this included consultants available at the time of crisis to assist interventions and decision-making. One team reported that they had access to expertise, and this was very helpful.

Findings Within Evaluation Methods

Survey

The online survey contained three questions designed to assess access to crisis prevention and family education.

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

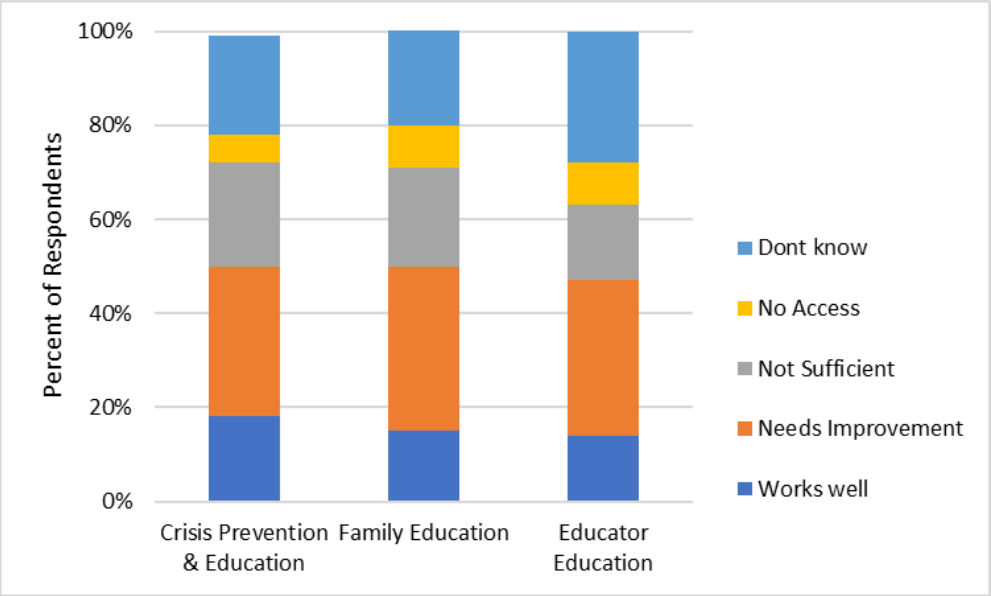
As seen in Figure 4 below, about 30% of survey respondents reported that they had no access or did not know about crisis prevention and family education services.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Figure 4: Crisis Prevention and Education



Family Caregiver Feedback

In both interviews and the survey, family caregivers responded to the question, "*How much information did you receive from your family member's mental health professional regarding his/her illness?"* Only 27% reported that they got all the information that they needed. Across the board, participants reported that crisis prevention, education, and planning all need improvement.

Discussion Groups and On-Site Forums

In alignment with survey responses, zoom-based discussion group participants reported the need for crisis intervention and response training, including preventative training on de-escalation for providers and caregivers. Overall, there is a reported lack of providers who are qualified to offer support in times of crisis for individuals with IDD-MH, leading to dangerous situations for the individual, caregivers, and direct support staff. Additional training on crisis prevention and intervention was suggested to bolster community-based support for individuals with IDD-MH in times of difficulty and avoid the need for use of law enforcement and emergency departments. Furthermore, many reported the need for additional training to address the needs of individuals with IDD-MH, as current mental health treatment approaches are reported to be ineffective because they are not adapted and modified for individuals with IDD. It is important to note that trauma-informed care was not mentioned by participants and may need to be addressed going forward.

When asked to rate overall capacity and expertise of the system to support individuals with IDD, discussion forum participants stressed the need for coaching so that providers across the service spectrum understand the needs of people with IDD-MH. Participants stressed that the lack of proactive support and prevention likely increased the need for more acute services. Participants cited work force

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

issues (staff shortages) as well as a lack of funding to compensate providers for additional training as barriers to more proactive training.

Table 3: On-Site Forum Reported Effectiveness of Training

Training and Coaching	**Access** (timely, nearby, enough to provide for needs)	**Appropriateness** (matches what is needed, options)	**Accountability (**acceptability change when needed, choice)
Expertise/ knowledge to serve people with MH-IDD All need training and competency in serving people with IDD	The Resource Center team provides some of these services	Not enough and people need to develop skills/capacity	This is a big issue that needs to be addressed in order to improve ability to provide services

Implications of Findings

Greater capacity to understand and support individuals who may be experiencing a mental health crisis is indicated. This includes the development of training and capacity building approaches to effectively intervene in times of difficulty, including evaluation, intervention and stabilization approaches used in the person's ordinary settings. Creating opportunities to avoid emergency room visits, police involvement, hospitalizations, and institutionalizations should be explored. Trauma-informed care should be emphasized.

Mental Health Crisis Intervention and In-patient Services

A concern identified by participants is that people with IDD over-rely on police and emergency departments to assist in times of mental health crisis. According to participants, there is a lack of community-based crisis evaluation and intervention services in the state, resulting in an overreliance on local police departments, emergency departments, and hospital admissions. While the majority (78%) of survey respondents with knowledge of services reported some availability, only 18% reported that they worked well and 22 % reported no availability for individuals with IDD.

Of concern was the large number of survey respondents (43%) who reported that they did not know if crisis services were available in their community. This is noteworthy as Louisiana has implemented a statewide mobile crisis response system that includes mobile crisis intervention as well as short-term stabilization services. While these services have been rolled out in many parts of the state, both survey and discussion group data suggest that many people across the state are not aware of these services.

Both survey and discussion group respondents expressed the need for community-based crisis services (crisis response, evaluation, and stabilization outside of the hospital) and a need to proactively address issues as they occur (crisis prevention) rather than relying on reactive (crisis

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

intervention) services. Respondents further emphasized that improved capacity through training and better access to outpatient mental health and related services would promote well-being. This was described as essential to reduce acute and restrictive intervention.

When crises occur and other alternatives are not available, there is an increased likelihood of emergency department visits. Medicaid claims data indicates that 7642 people with IDD received mental health services in the form of medication in CY 2022. Approximately 8% (n=622) of those people also used emergency department services, with a recidivism rate of 37% during the year.

In addition to emergency department visits, 661 persons with IDD had at least one psychiatric admission in CY 2022. The average length of each admission was 63 days and nearly half (43%) had more than one admission. The expected length of an inpatient mental health admission is 7-10 days so that the average length of admissions is six times that of what is expected. This can be due to several factors including lack of inclusionary accessible in-patient care, and lack of follow up care. The overall cost of these admissions in CY 2022 was over $215,000,000 with Medicaid payments of just under $79,000,000.

Table 4: Psychiatric In-Patient Claims for Mental Health 2022

Psychiatric Hospitalizations	CY 2022
# of Individuals	661
Average Recidivism Rate (repeat admissions)	43%
Average LOS	63 days
Total Cost	$215,298,523
Amount Reimbursed by Medicaid	$78,881, 675
Average Cost /Person	$325,716
Average Paid/Person	$119, 337

Findings Within Evaluation Methods

Survey

The online survey contained five questions regarding crisis intervention services. Table 5 provides a summary of responses for these services by those with knowledge. On average, overall crisis services were reported to work well (all that was wanted/needed) less than 20% of the time, with responses for specific services ranging from 10% (PRTF) to 23% (police response. While 22% of respondents reported no access, nearly half (43%) of respondents reported not knowing of crisis services were available in their area. This is very reflective of discussion group feedback in which most respondents reported being unaware of the availability of crisis services in their areas. This lack of knowledge was consistent across all respondent groups and there were no significant differences in how groups reported availability.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Table 5: Survey of Reported Effectiveness of Crisis Services

Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
Mobile Crisis	21%	24%	21%	35%
Crisis Stabilization	19%	25%	20%	36%
Community-Based Psychiatric Inpatient Beds	15%	49%	24%	12%
Psychiatric Residential for Children	10%	42%	23%	25%
Police Response	23%	51%	22%	4%
Crisis Services (average)	**18%**	**38%**	**22%**	**22%**

When online survey respondents rated the availability of crisis service options as '*do not have access'* or *'needs improvement,'* they were asked to provide an explanation for their response (n=35). **Over half of respondents (57%) reported that there was a lack of capacity both in resources and expertise and that community crisis resources beyond the police were not available.** An unwillingness to admit people with IDD-MH into hospitals was the most frequently reported barrier to care and 11% of those who responded reported that crisis services lacked active treatment for mental health symptoms and was focused primarily on managing outward behaviors (aggression). **Over a third of respondents (37%) reported that crisis responders (police, medical personnel, mental health practitioners) did not have training or expertise to support people with IDD experiencing a mental health crisis.**

Within the community survey and interviews, family caregivers were asked to rate several additional questions based on their experiences with the mental health system for their family member with IDD. **When families were asked if they knew where to get help during a crisis, 82% reported that they did not have the information they needed to access crisis assistance.**

Discussion Groups and On-Site Forums

A lack of crisis response services and reliance on law enforcement and hospital admissions in times of crisis were prevalent themes across the community discussion groups. Participants expressed that there is no place for people to go and that individuals often experience multiple crisis events when no treatment is available to them. While law enforcement response is reported as being supportive during times of crisis, the limitations of utilizing law enforcement in crisis response was also emphasized. Limitations include a lack of appropriate training and consultation for law enforcement officers and the fact that jails are not appropriate holding spaces for individuals with IDD in times of mental health crisis. In addition, as reported earlier, the cost of psychiatric admissions is high.

Discussion group responses were consistent with survey data indicating an overall lack of knowledge about the crisis services currently available in Louisiana. Both service users and community provider participants described law enforcement as the only option available to them in times of crisis. While

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

other groups were aware of the crisis services being rolled out statewide, many expressed concerns that people with IDD might still be excluded from those services as first responder training and expertise in IDD-MH was not mandatory. The need for additional crisis response, especially in-person response and supports for crisis stabilization was emphasized. Furthermore, there was widespread agreement that there is a need for better crisis prevention planning and strategic interventions as people transition back into the community. The reported lack of crisis stabilization and response services was highlighted in connection to concerns around individuals receiving appropriate services post-crisis. Multiple participants expressed that without outpatient treatment and crisis intervention and prevention, there were often concerns about the safety of individuals returning to their homes and communities, and lack of capacity leads to fewer opportunities for community participation, and, in some cases, the result is termination of services. Participants emphasized the need for crisis intervention/stabilization services as part of the continuum of care to divert from the use of emergency department in times of crisis. When using emergency departments, several discussion group members recalled struggles in which individuals were either discharged too quickly without appropriate resources in place or mental health holds that were much too long, resulting in individuals being "stuck" with no place to go.

Table 6: On-Site Forum Results of Reported Effectiveness of Crisis Services

Crisis Services	**Access** (timely, nearby, enough to provide for needs)	**Appropriateness** (matches what is needed, options)	**Accountability (**acceptability change when needed, choice)
Expertise/ knowledge to serve people with MH-IDD There is a lack of providers on the outpatient side who provide mental health services to the population. This creates more demand on the inpatient service providers who are often the ones that are used to provide mental health care	There are not enough beds No sub-acute care services LSU offered to develop sub-acute care beds for IDD-MH children	The milieu does not fit the needs of the population	While some use these services, they often get stuck or have to be discharged due to aggression.
Police/first responder training	Not enough are trained some stop responding	Some get tired of being called and do not come	Some police are trained
IDD-MH crisis Respite Not available and PRTF is not always appropriate for the IDD population. There is a plan to develop IDD PRTF	Difficult to access	May not be a good fit	Placement issues when ready for discharge kids with IDD MH get stuck

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Crisis stabilization beds		May not match the needs of the IDD population	
Alternatives to in-patient acute mental health care	Does not exist	Big gap in the system	This is greatly needed
Crisis response (in person) There are crisis response teams with staff trained in IDD-MH but this is very new	People are not clear about how to access	People are not clearly capable of providing	Community is not confident that people with IDD will get what they need
Hospitalization (acute care)	Had unit for people with ASD but was changed and now they do not fit into the milieu, also the stay is 5 days, and this does not work with the IDD population	Want to develop unit that is sub-acute for longer stays People get stuck in hospital	Stays do not meet the needs of the IDD population No accommodation of the population Not clear that they are treated for their mental health needs, mostly behavior control

Implications of Findings

The crisis prevention and response system has been expanded to include mobile mental health crisis response. Enhancement and access to that service, along with crisis stabilization and transitional services that can adapt to include people with IDD and be accessible as part of the safety net is warranted. This would both reduce the trauma and cost of hospital emergency service use and increase the capacity and efficiency in the community system.

IDD Services

An integrated whole person approach to community service systems of care requires that all providers can adapt to include and accommodate people with IDD and mental health service needs. While mental health providers and others have been described in this report, IDD services also need modification and consideration of changes in order to be more inclusive and effective. The final theme

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

to emerge from this part of the analysis is the **need for greater access to all IDD services for people with IDD-MH.**

Respondents reported the negative impact of exclusion from employment and social/recreational opportunities on quality of life and emotional well-being. Access to community services is reportedly difficult, particularly for individuals with IDD-MH. While there was some praise from participants for the OCDD service system, accommodation for the needs of people with IDD and mental health service needs was reportedly lagging. Stigma and refusal to serve the IDD-MH population were identified as predominant issues of concern along with lack of qualified and trained providers.

Findings within Evaluation Methods

Survey

The online survey asked respondents about the effectiveness of IDD services. As shown in Table 7, IDD services were reported as available by 86% of respondents, and a third (32%) reported that the services worked well for individuals with IDD-MH. Support coordination and self-directed supports were rated most effective by respondents, while out of home respite and supported employment were rated as least effective. However, there were statistically significant differences between respondent groups, with services users reporting services to be less effective than other respondents (F=11.10, p=.00, Figure 5). At the service level, statistically significant differences were reported for all IDD services except support coordination, which had similar responses across groups (Figure 5).

Table 7: Survey Results of Reported Effectiveness of IDD Services

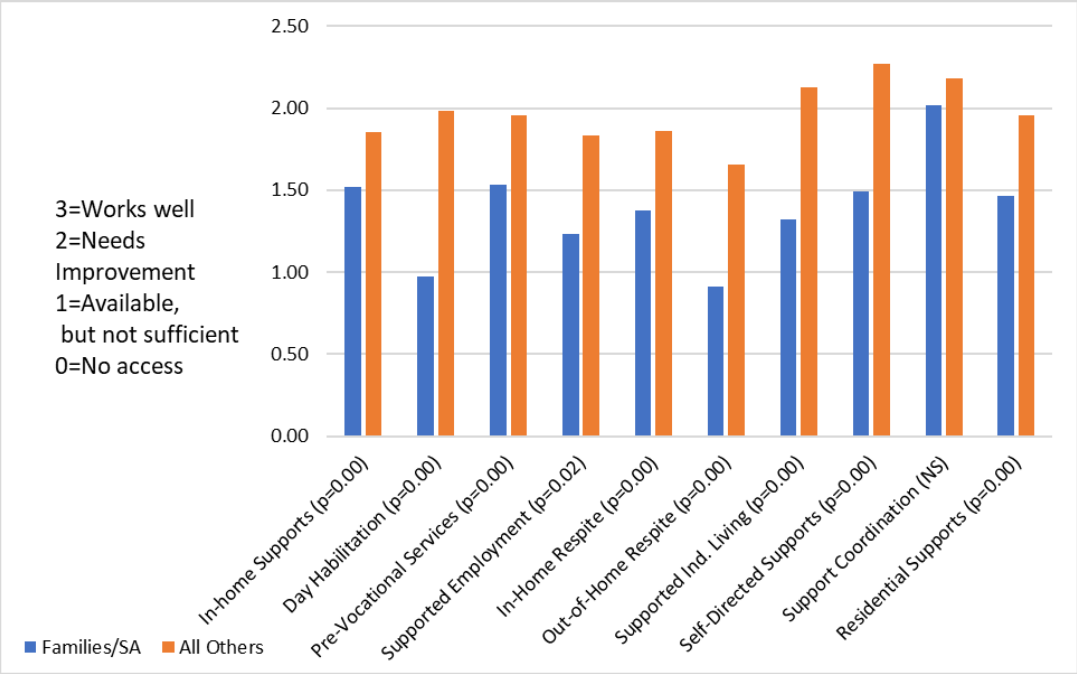
Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
In-home Supports	30%	23%	35%	11%
Day Habilitation	30%	24%	28%	18%
Pre-Vocational Services	29%	34%	29%	9%
Supported Employment	23%	32%	30%	14%
In-Home Respite	29%	27%	26%	18%
Out-of-Home Respite	16%	36%	21%	27%
Supported Independent Living	40%	19%	29%	11%
Self-Directed Supports	45%	18%	24%	13%
Case Management/Support Coordination	46%	27%	22%	6%
Residential Supports (ICF/DD)	31%	31%	27%	11%
IDD Services (average)	**32%**	**27%**	**27%**	**14%**

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Figure 5: Survey Results of Overall Effectiveness of IDD Services by Respondent Group



When online survey respondents rated the availability of service options as '*not available'* or *'insufficient,'* they were asked to provide an explanation for their response. Of the 32 respondents who provided an explanation for a lack of IDD services, 41% cited staffing shortages as the biggest barrier to access. An additional 9% reported that even when staff were available, they often did not receive adequate training and support to support individuals with IDD-MH. Over one quarter (28%) of respondents reported that people with IDD-MH were less likely to have access to needed IDD services, such as employment and housing, limiting their opportunities for community inclusion. Lack of respite care was reported by 19% as a need in the system.

Discussion Groups and On-Site Forums

Discussion group participants further emphasized issues related to limited access to appropriate services for individuals with IDD-MH. There was a reported lack of qualified and specially trained providers to meet the needs of individuals with IDD-MH. Parents and caregivers reported the challenge of finding appropriate services and the lack of easy access to information on where and how to access them. Service providers and case managers spoke about their struggles to find providers, specifically in rural areas, citing long wait lists and long distances to receive in-person evaluations and services. Self-advocates further spoke to transportation and distance to travel as concerns to accessing important supports, such as enjoyable activities in the community that promote mental wellbeing. Survey results supported these findings, with community services such as transportation, recreation and employment opportunities rated the lowest of all services, only 13% of survey respondents reporting that these services worked well for people, with IDD-MH.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

When asked to report about other community services**, transportation was cited as a barrier to employment opportunities, recreational activities, and medical care, including mental health care access, by 30% of respondents who reported it as a need (n=58).**

Participants in the on-site forums stressed the need for an improved understanding of the population. Self-advocates expressed that the lack of understanding leads to people with IDD-MH being misunderstood and underserved with access to the community limited because of stigma. Participants reported that people with IDD are often isolated in their homes with very little community integration.

Table 8: On-Site Forum Results of Reported Effectiveness of Community Services the Promote Inclusion

Community Services	**Access** (timely, nearby, enough to provide for needs)	**Appropriateness** (matches what is needed, options)	**Accountability (**acceptability change when needed, choice)
Community inclusion IDD (recreation/employment training/ employment)	Need more opportunities Very few employment opportunities	Trained support personnel and accommodations needed	Discharge from programs or lack of opportunity prevail

Implication of Findings

There was an expressed need for inclusion and capacity to provide community and social activities and meaningful employment. The lack of IDD and related services was identified as a contributing factor to the need for mental health services. The despair people feel when excluded was described as a trigger for mental health concerns for many individuals. People with IDD-MH are reported to be the last and least served by the IDD service providers in Louisiana regarding services that promote community inclusion.

Medical and Clinical Services

Medical and clinical services were reported to be widely available in Louisiana with over 93% of respondents reporting some access (Table 9). Like OCDD services, family members (along with some service users) were less likely to report services as effective than other respondents (F=5.08, p=.03, Figure 6). At the item level, there were statistically significant differences between service users and other responders for all clinical services. However, there were no significant differences for medical and dental care (Figure 6).

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

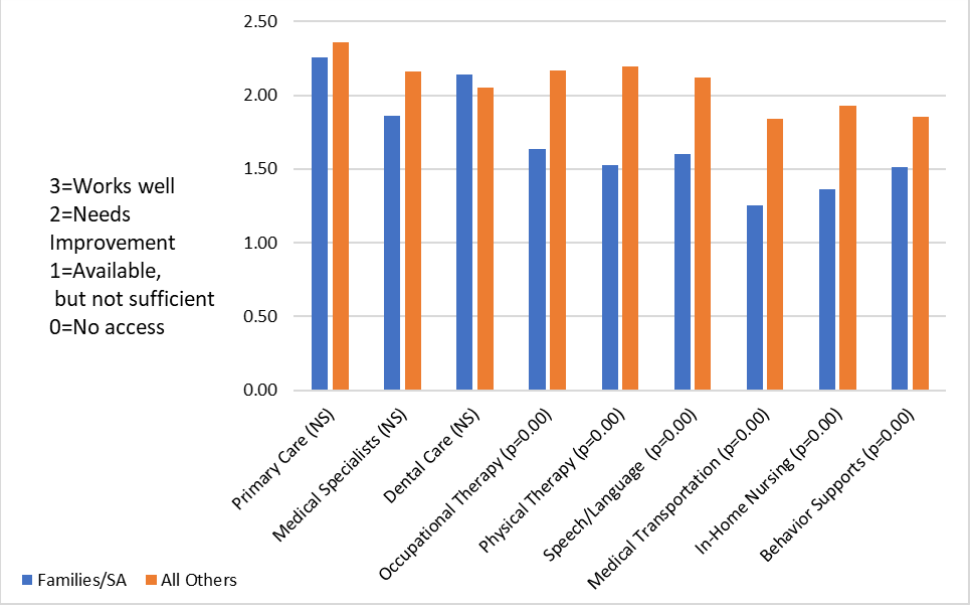
start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Table 9: Survey Results: Effectiveness of Medical/Clinical Services

Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
Primary Care	59%	14%	27%	0%
Medical Specialists	40%	24%	35%	1%
Dental Care	41%	31%	24%	4%
Occupational Therapy	42%	23%	29%	6%
Physical Therapy	42%	20%	30%	7%
Speech/Language Therapy	40%	23%	28%	8%
Medical Transportation	23%	35%	28%	14%
In-Home Nursing	26%	38%	27%	10%
Behavior Supports	23%	38%	30%	10%
Medical/Clinical Services (average)	**37%**	**27%**	**29%**	**7%**

Figure 6: Survey Results Effectiveness of Medical/Clinical Services by Respondent Group



National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Implications of Findings

While medical, dental, and other clinical services are reported to be far more available than mental health services, the need to improve their capacity and impact was identified by participants. In addition, gaps in access to care were reported to be far greater in some parishes than others, where there may be long distance travel required to access most services after long waits on waitlists. When asked about telehealth to help close this gap, there was a reported lack of access to equipment, Wi-Fi and resources to make this possible.

Evaluation Limitations

The Louisiana service system evaluation provides valuable feedback regarding service experiences of many community members across the state regarding the mental health service experiences of people with intellectual and developmental disabilities. While the brief time of the evaluation, number of participants, and the use of volunteer respondents limit the generalizability of findings, they are important to consider in service planning and policymaking going forward. Although this evaluation is limited in scope, participants across representative groups provided consistent feedback. The analysis is limited to evaluation of services for people with IDD and mental health needs. In addition, there were fewer participants with lived experiences of IDD-MH who participated in this evaluation than we had sought to engage. Their input is essential to successful planning going forward.

Conclusions

To learn about mental health and other service experiences of people with IDD-MH, five primary data collection methods were employed: (1) an online survey, (2) discussion groups, (3) family caregiver interviews, (4) a review of Medicaid claims data provided by the Office of Citizens with Developmental Disabilities, and (5) on-site discussion forums. The identities of all participants in this evaluation are confidential. Findings, along with recommendations for follow-up, are included in this report. The research team from the National Center for START Services® at the University of New Hampshire/Institute on Disability appreciates the opportunity to assist in this effort.

There were several positive findings to report. Many years of effort to develop collaborative relationships and include people with IDD in the delivery of mental health services is apparent. Family/parent advocacy is clearly a part of this effort. The result is that overall access to services across the state is noteworthy. Many participants also reported positive experiences with law enforcement officers and cited training initiatives within the state to better educate police officers in responding to mental health crises, including how to assist individuals with IDD. Respondents also cited the roll out of new behavioral health services for de-escalation and stabilization as a positive trend in the state, especially some that include training on IDD for responders. These initiatives reportedly show promise for increased capacity to respond to crisis in an informed and supportive manner. The Resource Center team is reported to be very helpful when people are in serious need and under severe conditions. Evaluation participants acknowledged the commitment and talent of partners across the state as well as the willingness of OCDD to acknowledge issues and invite feedback. In addition, there are mental health providers who are willing to provide step down and sub-acute care services especially for children and youth with IDD-MH.

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Despite efforts and some movement forward, most services require improvement in capacity and access. People with IDD-MH are still considered by some mental health providers to be too difficult to serve and unable to benefit from services and mental health care. People with IDD-MH report that they are socially isolated from community life and have limited access to community based mental health services. Participants noted that mental health services are in high demand across the state and that individuals with IDD are under-represented as a patient population receiving mental health care. Participants reported that lack of effective mental health care often leads to loss of home or placement, long emergency department stays, and incarceration.

According to evaluation participants, there is a lack of community crisis intervention evaluations to actively address the needs of people with IDD-MH across the state. Outpatient Medicaid claims data for people with IDD was unavailable but based on respondent reports and the available medication claims data reviewed, it is likely that while there an overall dearth of community mental health services, this problem may have a greater impact on people with IDD than other mental health service users.

IDD providers, educators and other health providers are not consistently trained to actively promote the health, education, and emotional well-being of the IDD population, especially in those with mental health needs. This has resulted in isolation, stigma, and marginalization occurring throughout the lifespan. There was little discussion of trauma informed care or approaches while families and people with lived experiences reported trauma inducing life experiences in the discussion groups.

It is important to note that access to mental health services goes beyond the availability of services. Inclusion of people with IDD in outpatient mental health settings requires accommodation and inclusive practices. Access has improved but has not led to service effectiveness. There is a reported need for training, expertise, and accommodations that welcome participation.

While the development of innovative resources is underway, there are also best practices and tools available to improve the abilities of mental health providers. For example, there continues to be reports of aggression and the need to manage behavior from some inpatient settings, attributing the lack of ability to “comply with the milieu” as a major obstacle.

Regarding child mental health services, there is a robust system of care initiative for children; however, not all include people with IDD and those who do may not have the needed expertise. It is reported that some school districts do not want wraparound services in their schools because they do not have the resources needed to respond to requests by the care teams.

Regarding resource allocation currently under way, a review of the limited claims data available indicates that when people with IDD-MH access inpatient care, they remain for far longer stays than typical patients, sometimes 3 to 4 times longer. In addition, many return to the hospital within a short period of time following discharge. This is both costly and difficult for the person and their family.

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Recommendations

Leaders, families, self-advocates, and community partners in Louisiana have moved the system forward to improve access to mental health care, support, and education for children and adults with IDD and mental healthcare needs. The innovative use of resources with the downsizing of state operated facilities created a foundation to build best practices in the community. The use of best practices and evidence-informed services like wraparound and other communities of practice methods in children's mental health, strengths-based approaches to education, trauma informed care, mobile crisis teams, mental health crisis stabilization services, IDD person centered approaches to vocational supports and job coaching, community support and other initiatives are under way. Despite these efforts, many remain unaware of available resources or report they do not exist in their local communities. While collaboration between state agencies occurs to trouble shoot around specific people with complex needs, there is little formalized ongoing collaboration that takes place on the individual, community, and statewide level, with reports of obstacles and barriers to access across the board.

Regarding in-patient and outpatient mental health services, they are reported to be lagging in both resources and expertise. While some are admitted to in-patient care, the stay usually exceeds what would be considered beneficial with few options for discharge and transition back to the community. However, there is a commitment to do more expressed by representatives from LSU medical school, and community mental health providers across the state. This would require resources to improve the capacity and availability of services provided and adaptations to create a more inclusive mental health system overall.

Below are recommendations to consider:

1. **While there is some structural development in place, it will not succeed without strategic partnerships.** A formal statewide interagency agreement that outlines the infrastructure to allow for cross system collaboration is needed. Agencies would include DD, MH, education, and health care providers who would work collaboratively to engage in improved outcomes for the population. Clarification of roles and responsibilities is needed including how to address emergency needs. Like any form of health care, no single entity can address the mental health care needs of all people with IDD. It requires a coordinated effort between all parties. Treatment of mental health conditions is only one part of addressing mental health needs. In response, providers across the state should develop linkage agreements within local communities to improve access and effectiveness of their individual service systems. The emphasis should include access and dissemination of information to improve capacity and attainment of needed services and supports.
2. **It is recommended that the state consider expansion and enhancement of the Resource Center system to include local hubs to provide community-based services and supports to people with IDD-MH throughout their lifespan.** Enhanced capacity is needed across the state delivery system to better serve the IDD-MH population. The Resource Center/linkage team could include staff trained as therapeutic coaches, and consultants trained with interdisciplinary approaches to diagnosis and treatment of people with IDD-MH. The Resource Center would have knowledge of community resources and help to provide linkages and referrals across the state. The goal would be to improve the capacity of the system as a whole. In addition, individuals would have cross systems crisis prevention and intervention plans developed by their support team under the leadership of the Resource Center linkage

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

coordinators. START is an evidenced based an evidence informed program that could be employed of adopted to meet this need. It is widely used across the U.S. so that collaboration between Louisiana and other partners allows for greater capacity building and cost effective strategies.

3. **Data collection, reporting and ongoing analysis mechanisms to ensure that the care provided is effective (including cost effective) is needed. Data collection, reporting and review is needed to evaluate the impact and cost effectiveness of efforts underway.** We know from prior studies that the most cost-effective care is provided using proactive strategies that build capacity, while the most costly and ineffective services are more often reactive and limited in scope.
4. **Didactic and participatory training of all stakeholders and providers in mental health, education and IDD across the spectrum is needed.** It is essential that capacity building is a targeted goal across the state especially in more remote locations where access to services and supports is complicated by distance. There are many resources available to provide training needed including trainings from the Link Center, The Tennessee network and NADD. Should START be adopted in the state, training for trainers and continuous access to evidence based training is part of what is offered by the National Center for START services. START programs offer Clinical Education Team meetings designed to train stakeholders from across the service delivery system and provide technical support for follow up. There is a prescribers' guide and training for physicians that is also widely used.
   https://centerforstartservices.org/research-evaluation/idd-mh-prescriber-guidelines
5. **Review of telehealth and other methods to improve access.** Access issues can be improved and addressed for some with telehealth. Telehealth for coaching, outreach and other services has been expanded to increase access to mental health supports for people with IDD.
   https://iod.unh.edu/evaluation-telehealth-services-mental-health-outcomes-people-intellectual-disabilities
   https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-023-09663-6
6. **Improve dissemination strategies so that those who may need the services being developed are aware of them and can access them.** Address the gap in knowledge that undermines timely access.
7. **While plans to increase opportunities for stepdown and mental health respite services are underway, it is essential that consideration of best practices, inclusion, and accommodation of people with IDD occur.** This may include access to information and methods regarding best practices from a national and international scope.
   https://centerforstartservices.org/start-model/start-therapeutic-supports-overview

As mentioned earlier, we suggest you consider the START model. Many of the resources needed can be addressed with the implementation of START as part of the Resource Center model already in place in Louisiana. While investment of funds would be needed to accomplish these goals, it is important to note that many more people would have access to services they need in their local communities. For example, the New Hampshire START services in 2022 cost $6028.55 per person per year and included cross systems crisis prevention and intervention planning, coaching and outreach visits, and 24-hour mobile crisis response (that works in conjunction with the mobile mental health crisis teams). Also, consider the development of one 6-bed statewide therapeutic respite program centrally located for diversion, crisis prevention, community transition, and crisis intervention services.

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

References

(1) American Psychiatric Association. (2022). Neurodevelopmental disorders. In Diagnostic and statistical manual of mental disorders (5th ed., text rev.).
(2) https://www.census.gov/quickfacts/fact/table/LA
(3) Fletcher, R. (2004). Information on dual diagnosis. Retrieved November 18, 2006, from http://www.thenadd.org/content/aboutnadd/ddinfo.html
(4) Beasley, J., (1998); "Long term co-resident caregiving in families and persons with a dual Diagnosis; (Mental Illness & Mental Retardation)." Mental Health Aspects of Developmental Disabilities, Vol.1 (1), (10-16)
(5) Beasley, JB & Kroll, J. (1999); "Family caregiving part II: Family caregiver-professional collaboration in crisis prevention and intervention." Mental Health Aspects of Developmental Disabilities Vol. 2(1), 22-26.
(6) Beasley, JB & duPree, K. (2003); "A systematic strategy to improve services to individuals with coexisting developmental disabilities and mental illness: National trends and the 'Connecticut blueprint' The Mental Health Aspects of Developmental Disabilities" (pp. 50-59).
(7) Vaismoradi, M., Jones, J., Turunen, H. & Snelgrove, S. (2016). Theme Development in Qualitative Content Analysis and Thematic Analysis. Journal of Nursing Education and Practice, Vol. 6 (5), 100-110.
(8) Tessler, R. and Gamache, G. (1995). Toolkit for Evaluating Family Experiences with Severe Mental Illness. Cambridge MA. Human Services Research Institute.
(9) Kalb, L. G., Beasley, J., Caoili, A., & Klein, A. (2019). Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program. American journal on intellectual and developmental disabilities, 124(1), 25-34.
(10) Holingue, C., Kalb, L., Klein, A., Beasley, K. (2020). 'Experiences with the Mental Health Service System of Family Caregivers of Individuals with an Intellectual/Developmental Disability referred to START.' Intellectual and Developmental Disabilities.
(11) US Department of Health and Human Services, Public Health Office, National Institute of Child Health and Human Development, Office of the Surgeon General. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Washington (DC): DHHS; 2002.
(12) National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Roundtable on Health Literacy; Roundtable on the Promotion of Health Equity. People Living with Disabilities: Health Equity, Health Disparities, and Health Literacy: Proceedings of a Workshop. Washington (DC): National Academies Press (US); 2017 Nov 28. Accessed September 1, 2020. https://www.ncbi.nlm.nih.gov/books/NBK526286/ doi: 10.17226/24741

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix A: Parish Breakdown of Respondents

Parish	Number of Respondents
Acadia Parish	
Allen Parish	
Ascension Parish	1
Assumption Parish	
Avoyelles Parish	
Beauregard Parish	
Bienville Parish	
Bossier Parish	2
Caddo Parish	4
Calcasieu Parish	3
Caldwell Parish	
Cameron Parish	
Catahoula Parish	
Claiborne Parish	
Concordia Parish	
DeSoto Parish	
East Baton Rouge Parish	19
East Carroll Parish	
East Feliciana Parish	
Evangeline Parish	
Franklin Parish	
Grant Parish	
Iberia Parish	2
Iberville Parish	
Jackson Parish	
Jefferson Parish	8
Jefferson Davis Parish	
LaSalle Parish	
Lafayette Parish	2
Lafourche Parish	1
Lincoln Parish	
Livingston Parish	4
Madison Parish	
Morehouse Parish	
Natchitoches Parish	
Orleans Parish	6
Ouachita Parish	
Plaquemines Parish	
Pointe Coupee Parish	1
Rapides Parish	4
Red River Parish	
Richland Parish	2
Sabine Parish	
St. Bernard Parish	1
St. Charles Parish	3
St. Helena Parish	
St. James Parish	
St. John The Baptist Parish	1
St. Landry Parish	3
St. Martin Parish	
St. Mary Parish	1
St. Tammany Parish	16
Tangipahoa Parish	13
Tensas Parish	
Terrebonne Parish	5
Union Parish	
Vermilion Parish	1
Vernon Parish	
Washington Parish	2
Webster Parish	2
West Baton Rouge Parish	1
West Carroll Parish	
West Feliciana Parish	
Winn Parish	
Statewide	8
Unspecified	36
Total	**152**

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix B: Pearson Chi-Squared Tables

Outpatient MH Services

OP_Therapy

	Group for tables				
OP_GROUP	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	6.90	0.00	21.82	2.38	10.71
Not Sufficient	27.59	35.71	18.18	33.33	26.43
Needs Improvement	27.59	28.57	20.00	23.81	23.57
Works well	17.24	7.14	10.91	26.19	16.43
Don't know	20.69	28.57	29.09	14.29	22.86
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 18.11 Prob = 0.0339

OP_Psychiatry

	Group for tables				
OP_PSYCH	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	0.00	14.29	4.76	7.80
Not Sufficient	20.69	21.43	23.21	30.95	24.82
Needs Improvement	34.48	28.57	28.57	21.43	27.66
Works well	17.24	7.14	8.93	30.95	17.02
Don't know	24.14	42.86	25.00	11.90	22.70
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 13.60 Prob = 0.1372

OP_Assessment

	Group for tables				
OP_EVAL	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	6.90	0.00	12.73	4.76	7.86
Not Sufficient	34.48	21.43	12.73	19.05	20.00
Needs Improvement	27.59	35.71	43.64	30.95	35.71
Works well	13.79	14.29	5.45	28.57	15.00
Don't know	17.24	28.57	25.45	16.67	21.43
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 17.73 Prob = 0.0384

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

OP_Substance Use Treatment

	Group for tables				
OP_SUB	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	6.90	7.14	5.66	2.38	5.07
Not Sufficient	27.59	14.29	9.43	21.43	17.39
Needs Improvement	17.24	21.43	11.32	21.43	16.67
Works well	27.59	21.43	3.77	21.43	15.94
Don't know	20.69	35.71	69.81	33.33	44.93
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.73 Prob = 0.7665

OP_Intensive Out-patient

	Group for tables				
OP_IOP	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	10.71	0.00	16.36	7.14	10.79
Not Sufficient	25.00	21.43	7.27	23.81	17.27
Needs Improvement	21.43	21.43	14.55	23.81	19.42
Works well	14.29	14.29	7.27	16.67	12.23
Don't know	28.57	42.86	54.55	28.57	40.29
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.74 Prob = 0.3722

OP_MH Rehabilitation

	Group for tables				
OP_MHREHAB	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	10.34	14.29	9.26	4.76	8.63
Not Sufficient	34.48	42.86	9.26	19.05	20.86
Needs Improvement	13.79	7.14	27.78	28.57	23.02
Works well	13.79	14.29	3.70	16.67	10.79
Don't know	27.59	21.43	50.00	30.95	36.69
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 15.80 Prob = 0.0712

OP_Wrap Around

	Group for tables				
OP_WRAP	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	0.00	10.91	2.38	5.71
Not Sufficient	37.93	28.57	12.73	16.67	20.71
Needs Improvement	24.14	21.43	21.82	28.57	24.29
Works well	13.79	14.29	9.09	16.67	12.86
Don't know	20.69	35.71	45.45	35.71	36.43
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.88 Prob = 0.2840

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Coaching and Training

TR_Crisis Prevention

TR_CSCP	Group for tables				
	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	14.29	7.02	4.76	6.34
Not Sufficient	34.48	21.43	12.28	26.19	21.83
Needs Improvement	34.48	21.43	31.58	35.71	32.39
Works well	24.14	14.29	15.79	19.05	18.31
Don't know	3.45	28.57	33.33	14.29	21.13
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.97 Prob = 0.7432

TR_Family Education

TR_FE	Group for tables				
	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	35.71	7.14	4.76	8.51
Not Sufficient	27.59	28.57	17.86	19.05	21.28
Needs Improvement	41.38	0.00	35.71	40.48	34.75
Works well	24.14	14.29	5.36	21.43	14.89
Don't know	3.45	21.43	33.93	14.29	20.57
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 24.69 Prob = 0.0033

TR_Educator Education

TR_EDC	Group for tables				
	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	35.71	7.27	4.76	8.57
Not Sufficient	20.69	28.57	14.55	11.90	16.43
Needs Improvement	37.93	7.14	32.73	38.10	32.86
Works well	20.69	14.29	7.27	19.05	14.29
Don't know	17.24	14.29	38.18	26.19	27.86
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 18.55 Prob = 0.0293

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

MH Crisis Services

CRIS_Mobile Crisis

	Group for tables				
CRIS_MC	Agency/ Depart	All other	Family/S A	IDD Service provider	Total
No Access	10.34	14.29	21.43	19.51	17.86
Not Sufficient	13.79	28.57	5.36	9.76	10.71
Needs Improvement	13.79	7.14	8.93	17.07	12.14
Works well	13.79	7.14	8.93	12.20	10.71
Don't know	48.28	42.86	55.36	41.46	48.57
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 8.53 Prob = 0.4813

CRIS_CSU

	Group for tables				
CRIS_CSU	Agency/ Depart	All other	Family/S A	IDD Service provider	Total
No Access	6.90	28.57	20.00	23.81	19.29
Not Sufficient	20.69	14.29	3.64	11.90	10.71
Needs Improvement	24.14	14.29	9.09	11.90	13.57
Works well	13.79	14.29	7.27	9.52	10.00
Don't know	34.48	28.57	60.00	42.86	46.43
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 8.95 Prob = 0.4419

CRIS_Psychiatric In-Patient

	Group for tables				
CRIS_PSYCHIP	Agency/ Depart	All other	Family/S A	IDD Service provider	Total
No Access	3.45	0.00	14.55	4.76	7.86
Not Sufficient	13.79	35.71	9.09	16.67	15.00
Needs Improvement	37.93	28.57	23.64	38.10	31.43
Works well	20.69	0.00	5.45	9.52	9.29
Don't know	24.14	35.71	47.27	30.95	36.43
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 17.48 Prob = 0.0417

CRIS_PRTF

	Group for tables				
CRIS_PRTF	Agency/ Depart	All other	Family/S A	IDD Service provider	Total
No Access	10.34	7.14	18.52	11.90	13.67
Not Sufficient	13.79	21.43	9.26	14.29	12.95
Needs Improvement	37.93	21.43	14.81	23.81	23.02
Works well	6.90	0.00	5.56	7.14	5.76
Don't know	31.03	50.00	51.85	42.86	44.60
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 7.13 Prob = 0.6236

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

CRIS_Police Response

	Group for tables				
CRIS_POL	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	0.00	1.89	2.38	2.17
Not Sufficient	20.69	7.14	3.77	21.43	13.04
Needs Improvement	24.14	21.43	33.96	30.95	29.71
Works well	13.79	7.14	9.43	21.43	13.77
Don't know	37.93	64.29	50.94	23.81	41.30
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 7.88 Prob = 0.5458

IDD Services

IDD_In-home Supports

	Group for tables				
IDD_IHS	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	6.25	22.03	2.13	9.93
Not Sufficient	31.03	25.00	22.03	44.68	31.13
Needs Improvement	34.48	25.00	20.34	10.64	20.53
Works well	31.03	6.25	23.73	34.04	26.49
Don't know	3.45	37.50	11.86	8.51	11.92
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 26.68 Prob = 0.0016

IDD_Day Habilitation

	Group for tables				
IDD_DHAB	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	6.25	31.03	2.17	13.51
Not Sufficient	39.29	6.25	8.62	30.43	20.95
Needs Improvement	21.43	31.25	12.07	19.57	18.24
Works well	35.71	6.25	8.62	39.13	22.97
Don't know	3.57	50.00	39.66	8.70	24.32
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 49.44 Prob = 0.0000

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

IDD_Pre-Voc

	Group for tables				
IDD_PVOC	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	6.25	14.04	0.00	6.08
Not Sufficient	37.93	12.50	7.02	28.26	20.27
Needs Improvement	27.59	18.75	26.32	21.74	24.32
Works well	31.03	6.25	8.77	32.61	20.27
Don't know	3.45	56.25	43.86	17.39	29.05
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 27.12 Prob = 0.0013

IDD_Supported Employment

	Group for tables				
IDD_SE	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	12.50	19.30	6.38	10.88
Not Sufficient	37.04	25.00	14.04	23.40	22.45
Needs Improvement	33.33	18.75	19.30	27.66	24.49
Works well	25.93	6.25	7.02	29.79	17.69
Don't know	3.70	37.50	40.35	12.77	24.49
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 19.52 Prob = 0.0211

IDD_In-home Respite

	Group for tables				
IDD_ IHR	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	6.25	27.59	8.51	14.00
Not Sufficient	24.14	0.00	12.07	34.04	20.00
Needs Improvement	31.03	37.50	18.97	12.77	21.33
Works well	41.38	6.25	18.97	21.28	22.67
Don't know	3.45	50.00	22.41	23.40	22.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 34.13 Prob = 0.0001

IDD_Out of Home Respite

	Group for tables				
IDD_ OHR	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.57	12.50	32.73	14.89	19.18
Not Sufficient	32.14	0.00	9.09	14.89	14.38
Needs Improvement	35.71	31.25	16.36	27.66	25.34
Works well	17.86	6.25	5.45	14.89	10.96
Don't know	10.71	50.00	36.36	27.66	30.14
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 22.87 Prob = 0.0065

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

IDD_Supported Independent Living

	Group for tables				
IDD_SIL	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	18.75	16.95	0.00	8.61
Not Sufficient	17.24	6.25	18.64	34.04	21.85
Needs Improvement	27.59	31.25	8.47	8.51	14.57
Works well	51.72	6.25	13.56	46.81	30.46
Don't know	3.45	37.50	42.37	10.64	24.50
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 40.43 Prob = 0.0000

IDD_Self-Directed Supports

	Group for tables				
IDD_SDS	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	18.75	20.69	0.00	10.07
Not Sufficient	14.29	6.25	22.41	21.28	18.79
Needs Improvement	25.00	25.00	15.52	2.13	14.09
Works well	53.57	12.50	22.41	48.94	35.57
Don't know	7.14	37.50	18.97	27.66	21.48
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 35.67 Prob = 0.0000

IDD_Service Coordination

	Group for tables				
IDD _ SC	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	12.50	10.17	0.00	5.30
Not Sufficient	27.59	25.00	11.86	21.28	19.21
Needs Improvement	27.59	12.50	32.20	14.89	23.84
Works well	41.38	25.00	33.90	53.19	40.40
Don't know	3.45	25.00	11.86	10.64	11.26
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 19.00 Prob = 0.0252

IDD_Residential Supports

	Group for tables				
IDD_RES	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	6.25	15.52	2.13	7.33
Not Sufficient	27.59	6.25	5.17	31.91	18.00
Needs Improvement	27.59	43.75	17.24	12.77	20.67
Works well	20.69	6.25	10.34	38.30	20.67
Don't know	24.14	37.50	51.72	14.89	33.33
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 36.10 Prob = 0.0000

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Community and Clinical Services

CS_Medical care

	Group for tables				
CS_MED	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
Not Sufficient	27.59	25.00	30.00	17.02	25.00
Needs Improvement	13.79	25.00	13.33	6.38	12.50
Works well	44.83	25.00	55.00	68.09	53.95
Don't know	13.79	25.00	1.67	8.51	8.55
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.05 Prob = 0.1225

CS_Medical Specialists

	Group for tables				
CS_SPEC	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	0.00	1.69	0.00	0.66
Not Sufficient	27.59	31.25	38.98	25.53	31.79
Needs Improvement	20.69	31.25	27.12	10.64	21.19
Works well	34.48	12.50	28.81	55.32	36.42
Don't know	17.24	25.00	3.39	8.51	9.93
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.95 Prob = 0.0922

CS_Dental Care

	Group for tables				
CS_DC	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	6.90	0.00	0.00	6.38	3.31
Not Sufficient	24.14	6.25	28.81	14.89	21.19
Needs Improvement	31.03	31.25	23.73	27.66	27.15
Works well	27.59	12.50	42.37	40.43	35.76
Don't know	10.34	50.00	5.08	10.64	12.58
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 11.95 Prob = 0.2159

CS_OT

	Group for tables				
CS_OT	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	0.00	12.07	0.00	4.67
Not Sufficient	31.03	6.25	17.24	27.66	22.00
Needs Improvement	20.69	31.25	13.79	14.89	17.33
Works well	37.93	25.00	18.97	44.68	31.33
Don't know	10.34	37.50	37.93	12.77	24.67
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 22.39 Prob = 0.0077

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

CS_PT

	Group for tables				
CS_PT	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	0.00	13.56	0.00	5.30
Not Sufficient	34.48	12.50	18.64	23.40	22.52
Needs Improvement	17.24	25.00	11.86	14.89	15.23
Works well	37.93	18.75	16.95	51.06	31.79
Don't know	10.34	43.75	38.98	10.64	25.17
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 25.13 Prob = 0.0028

CS_SLP

	Group for tables				
CS_SLP	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	0.00	13.79	2.17	6.04
Not Sufficient	27.59	12.50	13.79	28.26	20.81
Needs Improvement	20.69	31.25	15.52	10.87	16.78
Works well	37.93	18.75	17.24	43.48	29.53
Don't know	13.79	37.50	39.66	15.22	26.85
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 22.30 Prob = 0.0080

CS_Medical Transportation

	Group for tables				
CS-MTRAN	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.45	6.25	22.03	2.13	10.60
Not Sufficient	48.28	18.75	6.78	21.28	20.53
Needs Improvement	24.14	43.75	15.25	34.04	25.83
Works well	17.24	0.00	10.17	31.91	17.22
Don't know	6.90	31.25	45.76	10.64	25.83
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 40.31 Prob = 0.0000

CS_Nursing

	Group for tables				
CS_NUR	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	3.57	0.00	12.28	2.17	6.12
Not Sufficient	25.00	12.50	8.77	23.91	17.01
Needs Improvement	46.43	43.75	8.77	21.74	23.81
Works well	14.29	6.25	8.77	30.43	16.33
Don't know	10.71	37.50	61.40	21.74	36.73
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 25.98 Prob = 0.0021

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

CS_Behavior Supports

CS_ABA	Group for tables				
	Agency/ Depart	All other	Family/SA	IDD Service provider	Total
No Access	0.00	0.00	20.00	2.17	8.61
Not Sufficient	31.03	18.75	15.00	36.96	25.17
Needs Improvement	34.48	56.25	26.67	28.26	31.79
Works well	27.59	0.00	16.67	23.91	19.21
Don’t know	6.90	25.00	21.67	8.70	15.23
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 29.72 Prob = 0.0005

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix C: Discussion Group Participants and Dates

Group	Date	Participants
Community Providers	8/28/2023	17
LSU- center for evidence to practice	9/11/2023	3
LA Hospital Association	9/13/2023	23
Disability Rights	9/19/2023	13
Self-advocates	10/2/2023	4
Hospital Staff	10/3/2023	7
Police Interview	10/5/2023	1
Support Coordinators	11/16/2023	12

On-site Forums	Date	Participants
Self-advocates	4/12/2024	9
Psychiatric In-Patient/PRTF Providers	4/12/2024	8
Outpatient MH Providers	4/13 & 4/14/2024	6

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix D: START Program Description

The National Center for START Services®

The National Center for START Services® at the University of New Hampshire Institute on Disability 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 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.[11] In 2016, the START model was identified as best practice by the National Academy of Sciences Institute of Medicine.[12]

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

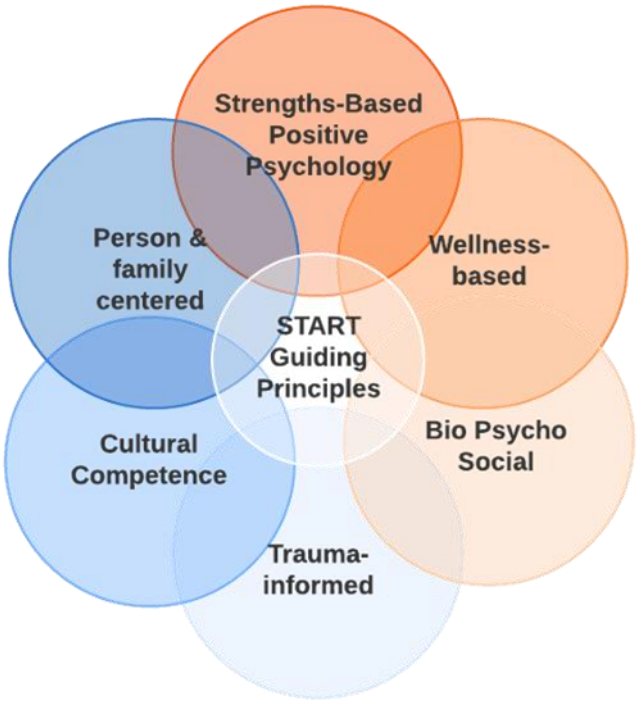
National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

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 continually 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 (e.g., 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

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

- Systems linkage supports
- Intake and assessment activities using standardized and validated assessment tools
- Comprehensive Service Evaluations: bio-psycho-social analysis of strengths and needs 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

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

plans, provides 24-hour on-call crisis support for enrolled individuals, and regularly enters data into SIRS.

Therapeutic Coaching (STC) Overview

Therapeutic Coaching is designed to assess and stabilize a person in their community environment(s). Using planned and emergency services, START Therapeutic Coaching (STC) provides strengths-based, clinical coaching to primary caregivers and persons in their home setting to help 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.

NATIONAL CENTER for START SERVICES®
Institute on Disability
University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix E: 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.

Program Certification Prep (Year 3): After all aspects of the START program are implemented, the team begins preparing for the National START Program Certification. At this phase, at least half of START staff have achieved coordinator certification, the program provides full on-call supports, and has 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.

Program 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.

NATIONAL CENTER for START SERVICES® Institute on Disability University of New Hampshire

National Center for START Services®
Institute on Disability
University of New Hampshire
5 Chenell Drive, Suite 301
Concord, NH 03301

start.iod@unh.edu
centerforstartservices.org

Phone: (603) 228-2084
Fax: (603) 228-3270

Appendix F: Acknowledgement and Supporting Literature

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the Systemic, Therapeutic, Assessment, Resources, and Treatment (START)/Sovner Center Model.

The National Center for START Services® (NCSS) was founded in 2011 at the University of New Hampshire's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services®, provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model which strives to build capacity across systems to meet the needs of individuals with IDD-MH.

Dr. Beasley is a Research Professor at the University of New Hampshire where she conducts research on the mental health aspects of intellectual and developmental disabilities. She currently leads the National Research Consortium in IDD-MH at NCSS.

The following publications provide additional information and context about the development and refinement of the START model by Joan Beasley, PhD, and colleagues.

- Beasley, J., Kroll, J., & Sovner, R. (1992). Community-based crisis mental health services for persons with developmental disabilities: The START model. The Habilitative Mental Healthcare Newsletter, 11(9), 55-58.
- Beasley, J. (1997). The three A's in policy development to promote effective mental healthcare for people with developmental disabilities. The Habilitative Mental Healthcare Newsletter, 16 (2), 31-33
- Beasley, J. B., Kroll, J. (1999). Family caregiving part II: Family caregiver professional collaboration in crisis prevention and intervention planning. Mental Health Aspects of Developmental Disabilities, 2(1), 1-5.
- Beasley, J. B. (2000). Family caregiving part III: Family assessments of mental health service experiences of individuals with mental retardation in the northeast region of Massachusetts from 1994 to 1998. Mental Health Aspects of Developmental Disabilities, 3(3), 105-113.
- Beasley, J. B. (2001). Collaborative services in Massachusetts: The START/Sovner Center Program. Impact, 14(3), 16-17.
- Beasley, J. B., & duPree, K. (2003). A systematic strategy to improve services to individuals with coexisting developmental disabilities and mental illness: National trends and the 'Connecticut blueprint'. Mental Health Aspects of Developmental Disabilities, 6(2), 50-58.
- Beasley, J. B. (2003). The START/Sovner Center Program in Massachusetts. The NADD Bulletin, 6(3), 57-59.