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# State of South Dakota IDD-MH Service System Evaluation

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## Executive Summary

The information in this report presents 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 South Dakota. The evaluation was funded by the South Dakota Council on Developmental Disabilities and conducted in partnership with the University of South Dakota's Center for Disabilities, Department of Human Services/Division of Developmental Disabilities, the Council on Developmental Disabilities, and the Department of Social Services/Division of Behavioral Health as part of an ongoing effort to improve services for individuals with IDD-MH. Four primary data collection methods were employed: (1) an online survey, (2) discussion groups, (3) family caregiver interviews, and (4) a review of Medicaid claims data provided by the Department of Human Services to evaluate costs associated with IDD-MH. The identities of all participants in this evaluation are confidential. Approximately 250 citizens from across South Dakota participated in this evaluation to learn about service experiences of individuals with IDD-MH and their families.

There were several positive findings. The use of holistic supports for individuals with IDD-MH with a well-rounded and comprehensive approach to care is noteworthy. Evaluation participants emphasized the positive experiences with law enforcement officers and the new 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 reported the increased use of telehealth in some rural communities to allow first responders real-time access to mental health professionals to assist in both de-escalation and evaluation. These initiatives reportedly show promise for increased capacity to respond to crisis in an informed and supportive manner. Evaluation participants acknowledged the commitment and talent of partners across the state as well as the willingness of the Department of Human Services to acknowledge issues and invite feedback.

While many services were reported to be available in South Dakota, they were also reported as inadequate to meet the needs of the IDD-MH population. The greatest service gaps reported included mental health crisis prevention and intervention services and mental health outpatient 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. All participants in the study expressed the need for community-based crisis services (crisis response, evaluation, and stabilization outside of the hospital) and a need for greater knowledge and capacity to proactively address issues as they occur (crisis prevention) rather than relying on reactive (crisis intervention) services. Given the collaborative and innovative efforts already under way, the START Model may be a good fit for South Dakota. START is an evidence-based, comprehensive cross-systems crisis prevention and intervention model (see Appendix D). START is targeted to address many of the concerns about services reported and may have both a service outcome and financial impact in South Dakota. For example, according to South Dakota Medicaid claims data reviewed, the average annual per person cost for MH emergency department visits was \$54,947. By comparison, New Hampshire START statewide services replace the use of emergency departments while providing training, outreach, linkages, crisis prevention and response services across the state for an annual per person cost of \$6028.55.

# South Dakota IDD-MH Service System Evaluation

## 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 South Dakota. The evaluation was conducted by members of the UNH Institute on Disability National Center for START Services™ (NCSS) and funded by the South Dakota Council on Developmental Disabilities. The evaluation was conducted in partnership with the University of South Dakota's Center for Disabilities, Department of Human Services/Division of Developmental Disabilities, the Council on Developmental Disabilities, and the Department of Social Services/Division of Behavioral Health as part of an ongoing effort to improve services for individuals with IDD-MH. It was conducted with the input of citizen volunteers from across the state with the active support of state partners. The evaluation focused on the self-reported experiences of service users, families, and providers regarding the effectiveness of the existing service system. Four primary data collection methods were employed: (1) an online survey, (2) discussion groups, (3) family caregiver interviews, and (4) a review of Medicaid claims data provided by the Department of Human Services to evaluate costs associated with IDD-MH. 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."<sup>1</sup> 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 is the term that will be used throughout this evaluation.

The 2020 census data estimates the population of South Dakota to be 913,797 people.<sup>2</sup> According to the Division of Developmental Disabilities (DDD), there are approximately 6000 people enrolled in services, and based on prevalence studies, we can estimate that about one-third of those individuals or 2000 adults in the DDS service system may also have mental health needs at some point in their lifespan.<sup>3</sup>

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.<sup>4</sup> 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.<sup>4</sup> Additionally, a significant percentage of people with IDD and mental health needs live with family caregivers who are relied upon to meet service needs.<sup>5</sup>

## Evaluation Methods

### Aims

The aims of this inquiry were to evaluate the following:

1. How effective is the current community system of care in South Dakota 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

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

Method 1: Online survey

Method 2: Discussion groups

Method 3: Family caregiver structured interviews

To explore resource allocation, we also conducted a 4<sup>th</sup> method:

Method 4: Medicaid claims review

Methods were reviewed with the South Dakota Council on Developmental Disabilities, and the online survey was modified based on feedback from South Dakota representatives. The Council of Developmental Disabilities and University of South Dakota's Center for Disabilities played a key role in distributing the survey across South Dakota. They also helped to identify potential volunteers to participate in discussion groups and family interviews.

### ***Method 1: Online Survey of Stakeholders***

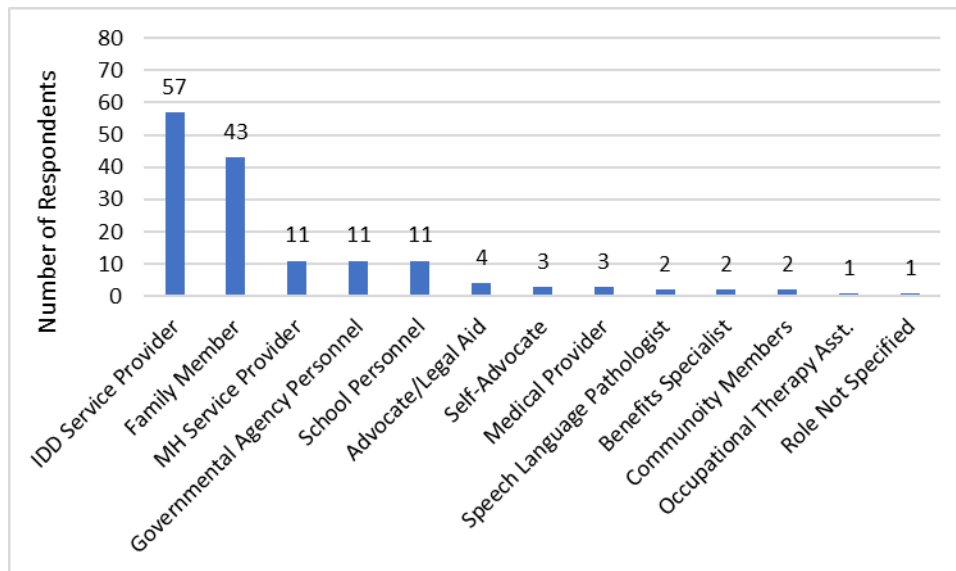
The online survey link was sent to constituents across the state including, but not limited to, IDD service providers, service users, mental health providers, family members, policy makers, medical personnel, juvenile justice personnel, advocates, funders, and educators. The goal was to receive feedback from as many citizens across the state as possible.

The 3 A's Framework of Effective Services<sup>6</sup> 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).

## Survey Respondents

A total of 151 volunteers completed the survey between May and July 2023. Figure 1 shows the self-reported role of respondents. Providers of developmental disability (IDD) services (n=57) represented 38% of respondents. Family members (n=43) and individuals with lived experiences (n=3) represented 30% of respondents.

**Figure 1: Number of Online Survey Respondents by Self-Reported Role (n=151)**



Survey respondents represented all age groups, and 65% of provider respondents indicated that they had over 10 years of experience in their reported role.

Respondents were also asked to identify the county from which they provide or receive services. Twenty-four of South Dakota's counties had at least one respondent. Of the 137 respondents who specified a county, 42% (n=58) reported that they were from counties within South Dakota's largest cities, Sioux Falls (Minnehaha and Lincoln counties) and Rapid City (Pennington and Meade counties). The remaining 58% of respondents (n=79) were from a more rural county. There were three individuals who indicated they worked statewide and eleven respondents who did not specify a location. See Appendix A for a list of respondents by county. Thirty percent of family caregiver responders were from Indigenous communities.

Every effort was made to include as many South Dakota citizens as possible to achieve representation in this process, including members of Indigenous communities in the state.

## Online Survey Design and Analysis Methods

Survey participants responded to a series of questions about mental health and related services for people with IDD-MH. For each service, to measure effectiveness there was a five-point Likert rating



scale: 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=57, 2) family members/self-advocates (people with lived experiences), n=46, and 3) all other respondents, n= 48. 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. A second chi-squared test was conducted for each question based on geographic location (metropolitan and rural) to determine if significant differences were present between respondents from Sioux Falls and Rapid City (the most populous areas of South Dakota) and the remaining counties. When differences were found to be significant, they are noted in the report.

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 with 0=not available, 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 presentation of each question and corresponding statistical analysis tables, see Appendix B.

## **Method 2: Discussion Groups**

A total of seven discussion groups and three law enforcement officer interviews were conducted via Zoom with a total of 81 volunteer participants (see Appendix C for a list of focus groups). Each focus group began with an introduction to the purpose of the forum, followed by 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.<sup>7</sup> 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 member with IDD-MH. The Family Experiences Interview Schedule (FEIS), a survey developed by Tessler and Gamache,<sup>8</sup> was used to conduct 20 interviews. The FEIS is a 28-question, validated, family caregiver survey that has been used in other studies.<sup>9,10</sup> Informants were asked to use a four-point Likert scale to rate their experiences with mental health service providers as: *All that was wanted/needed; Some but not as much as I wanted/needed; Very little; or Not at all.* While *Did not answer/do not know* was not a choice presented, if an informant could 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.

In addition, family caregivers provided basic demographic information for their family member with IDD as well as themselves. Data collected included family makeup, the family caregiver's age, educational level, and overall health. Information about day, home, and educational services that their family member with IDD receives was also gathered. The identity of participants is kept confidential and is not part of this report.

Twenty volunteer family caregivers participated in FEIS interviews. Family caregiver responses were consistent with survey data and feedback from discussion group participants. The FEIS interviews were designed to receive direct input from family caregivers, and their feedback is integrated into the summary of findings that follows.

### **Method 4: Medical Claims Data Review**

A total of 6000 individuals were identified by the South Dakota Division of Developmental Disabilities (DDD) as eligible for IDD services and were included in this analysis of Medicaid claims between 2021-2022. Three outcomes were evaluated: 1) psychiatric emergency department visits, 2) inpatient psychiatric hospitalizations, and 3) psychotropic drug prescriptions.

DDD provided a de-identified summary of Medicaid mental health claims data for individuals eligible to receive developmental disability services in fiscal years 2021 and 2022. For these years, about 24% (n=1423) 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. Therefore, of the 1423 individuals, 21% (n=303) accessed emergency room treatment, and 15% (n=219) received psychiatric inpatient services. The annual cost was approximately \$30 million dollars for a total of \$60 million dollars over the two-year period. While limited in scope, the claims data provides an important snapshot for consideration in the context of the feedback from citizens of South Dakota.

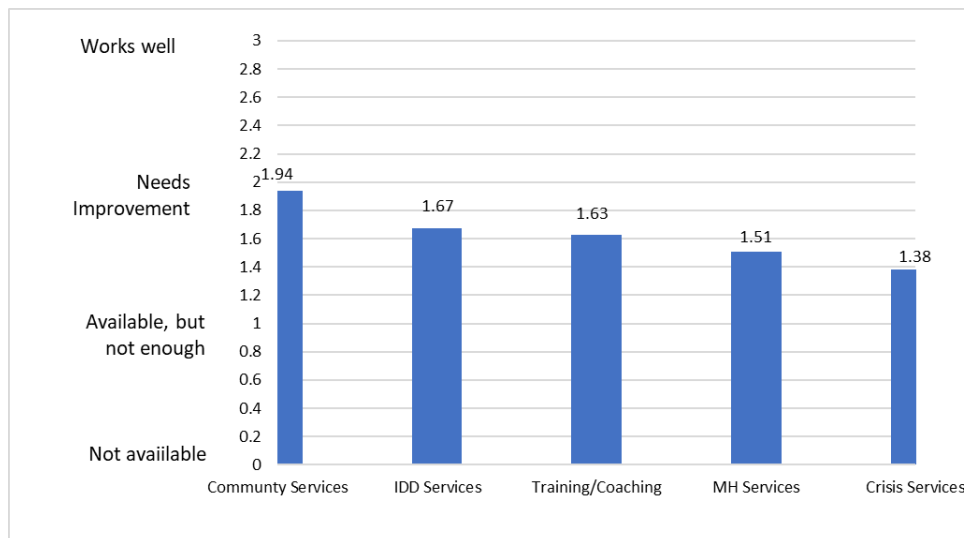


## Evaluation Results

Approximately 250 citizens from across South Dakota participated in this evaluation to learn about service experiences of individuals with IDD-MH and their families.

A total of 151 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 South Dakota, 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 crisis prevention and intervention services, followed by mental health outpatient services. Community services (medical, dental, transportation, recreation, etc.) were the most highly rated services. None of the services were rated as working well (Figure 2). **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.

The next sections of the report provide a description of each area of services and associated findings from community surveys, family interviews, and stakeholder discussion groups, along with relevant claims data.

## Evaluation of Outpatient Mental Health Services for People with IDD-MH

### Summary

**Findings suggest that there is a need to increase capacity to provide effective community-based outpatient mental health services for individuals with IDD in South Dakota.** While most survey respondents (86%) reported access to some mental health services, only 10% reported services worked well for individuals with IDD. 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 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.** 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, and that medication management is often the only service provided. Participants reported that lack of effective mental health care often leads to loss of placement, long emergency department stays, and incarceration.

The South Dakota Division of Developmental Disabilities (DDD) provided a summary of Medicaid mental health expenditures for individuals receiving developmental disability services in fiscal years 2021 and 2022. For these years, a total of 1423 individuals, representing 24% of the DDD eligible population for that period, were prescribed psychiatric medications with an incurred cost to the system of more than \$7 million a year. It is important to note that 80% of the costs were not covered by Medicaid. It is unclear how the costs were covered.

**Table 1: Prescription Drug Claims Mental Health Service Users FY20 and FY21**

Psychiatric Medication Claims	Total
# of Individuals (% of DDD eligible population)	1423 (24%)
Total Cost	\$14,269,225
Amount Reimbursed by Medicaid	\$3,048,731
Average Cost /Person	\$10,028

### Findings Within Evaluation Methods

#### Survey

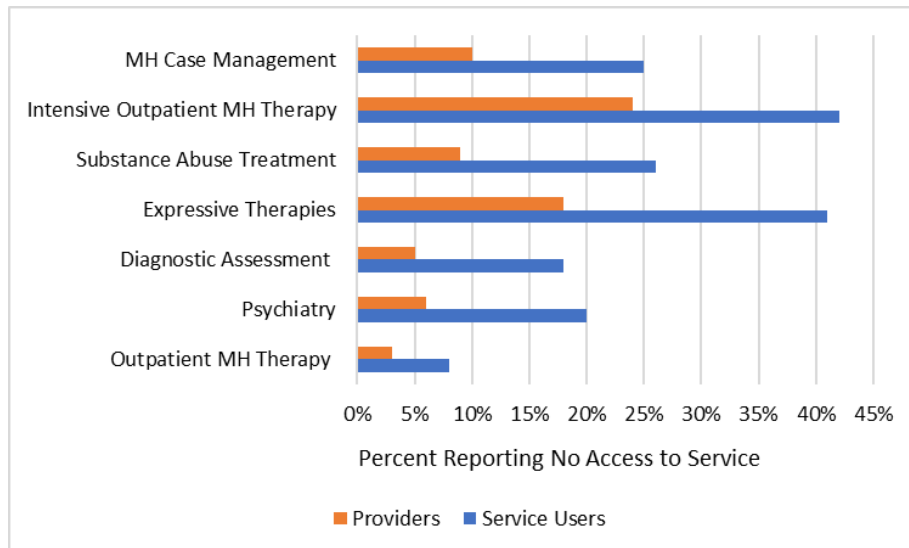
The online survey consisted of seven questions to evaluate participant’s views about outpatient mental health care. As shown in Table 2, only 10% of respondents overall reported that mental health services work well for individuals with IDD.

**Table 2: 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	14%	39%	43%	3%
Psychiatry	11%	45%	34%	10%
Diagnostic Assessment	11%	47%	34%	8%
Expressive Therapies	13%	33%	30%	24%
Substance Abuse Treatment	11%	40%	36%	13%
Intensive Outpatient MH Therapy	3%	35%	33%	28%
MH Case Management	9%	50%	27%	14%
<b>MH Services (average)</b>	<b>10%</b>	<b>41%</b>	<b>34%</b>	<b>14%</b>

Figure 3 provides a breakdown of reported lack of access to different MH services by respondent groups (either providers or service users). Service users (families/self-advocates) were more than twice as likely to rate outpatient mental health services as unavailable when compared to providers. When sub-analysis was conducted by geographic location, a very similar trend was reported in which rural respondents were much more likely to rate outpatient mental health service as unavailable compared to respondents from metropolitan counties. The biggest disparity observed was in access to psychiatry, reported as unavailable by 15% of rural respondents compared to just 2% of metropolitan respondents.

**Figure 3: Survey Results of No Access to MH Outpatient Services by Respondent Groups**



Respondents emphasized the need to build capacity within existing mental health providers, with 41% on average stating that there are available services, but that they need improvement.

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 South Dakota. Of those that commented (n=44), **more than a third (39%) reported that services were not available in their area, and nearly half of those specifically cited issues in rural areas. An overall lack of available providers (27%), long wait lists (18%), and insurance or cost (14%) were reported as the biggest obstacles to access when services were available. Nearly a quarter (23%) reported that providers lacked training and expertise in IDD or were reluctant to accept patients with IDD.**

For family caregivers who rated their overall satisfaction with mental health services for their family members (n=43), most (79%) 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=41), nearly half (46%) reported that psychiatric medications were prescribed by someone other than a psychiatrist or mental health practitioner, and 60% 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 15% responded that everything they needed was available, and another 15% reported that they did not have enough information on services that might benefit their family member to answer the question. When asked about service and provider choice, 30% of families reported as having some service options, and 50% reported the opportunity to choose a provider. When asked to report overall satisfaction with mental health services, 75% reported that they were less than satisfied, consistent with family respondents in the online survey (79% reporting they were not satisfied). When asked, “*Was there any particular service that your family member needed that was not available?*” 62% of caregiver respondents who reported yes (n=16) stated that they needed better access to outpatient mental health therapy, particularly with providers who understood IDD.

**Table 3: FEIS: Mental Health Service Availability (n=20)**

	All	Some	None/ Very Little	Did not know
Were the available mental health services for your family member the ones you thought were needed?	15%	25%	45%	15%
How much opportunity did you or your family member have to choose between different mental health service options?	15%	15%	70%	-
How much opportunity did you or your family member have to choose a particular therapist?	20%	30%	50%	-
How satisfied were you with the outpatient mental health services your family member received?	25%	35%	40%	-

### Discussion Groups

The lack of capacity throughout the state was reported among discussion group participants. Mental health providers reported a lack of training, education, and confidence to work with individuals with IDD-MH. This was a commonly reported barrier 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. Across discussion groups, there was a collective sense 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.

Concerns related to prescribing practices also arose as a theme within discussion groups. The lack of qualified providers to manage psychotropic prescriptions was reported by families and caregivers. Both within discussion groups and interviews, there were reports of caregivers unable to attain evaluation of medication effects and side effects. Family members reported concerning side effects and over-medication and being unable to find a provider to address these concerns. Providers echoed these concerns in reporting the lack of medication review and an overall reluctance to reduce medications. Discussion group participants reported that primary care physicians were managing medication who may not be qualified to do so, but there were no other options.

### **Implications of Findings**

For people with IDD, treatment most likely includes medication to treat mental health conditions. The claims data indicate that about 23% of the DDD eligible service population were prescribed medications in 2020 and 2021. This most likely reflects the prevalence of people with IDD who are identified as having mental health service experiences in South Dakota overall and is consistent with the reported lack of access to mental health services for the population. In addition, information attained from other evaluation methods identified concerns about medications prescribed, access to qualified prescribers and lack of access to other forms of mental health treatment for people with IDD. **Findings based on national trends also indicate that there may be a significant underserved population, perhaps as high as 10-15%, who do not receive any of the mental health services they may need.**



## Evaluation of Crisis Prevention Supports and Services

### Summary

Across all data collection methods was the reported need for crisis prevention and support services. Participants reported a lack of 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.

### Findings Within Evaluation Methods

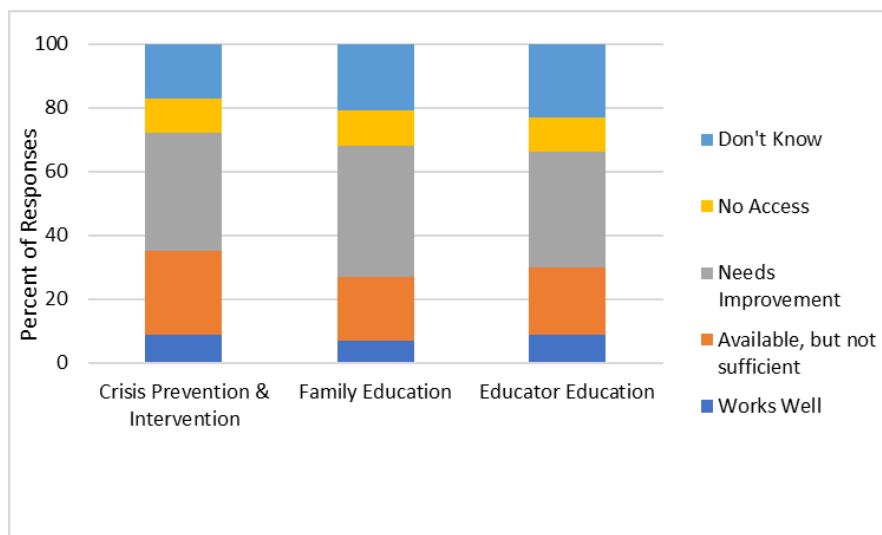
#### Survey

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.

**Figure 4: Crisis Prevention and Education**



#### Family Caregiver Interviews

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 25% 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

In alignment with survey responses, 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 jails and involuntary commitments at hospitals. 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.

### **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 stabilization and evaluation approaches that can be 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.

## **Evaluation of Mental Health Crisis Intervention and In-patient Services**

### **Summary**

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 crisis intervention evaluations and supports in the state, resulting in an overreliance on local police departments, emergency departments, and hospital admissions. While the majority (62%) of survey respondents with knowledge of services reported some availability, only 11% reported that they worked well. 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 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 indicate that 1423 people with IDD received mental

health services in the years 2020 and 2021. Approximately 21% (n=303) of those people used emergency department services, averaging 1.8 psychiatric emergency claims per individual. There was a recidivism rate of 56% during the two-year reporting period.

A total of \$16,648,940 was billed to Medicaid for psychiatric emergency department claims, of which, \$1,564,950 was paid by Medicaid. Over the two-year period, the average per person cost for emergency department visits to treat mental health crises was \$54,947. This far exceeds the cost of crisis response services outside the emergency department. For example, New Hampshire START services cost \$6028.55 per person per year and include cross systems crisis prevention and intervention planning, coaching and outreach visits, and 24-hour mobile crisis response.

**Table 4: Emergency Department Claims for Mental Health 2020-2021**

<b>Emergency Department Visits (Psychiatric/Behavioral)</b>	<b>Total</b>
# of Individuals (% of MH IDD population)	303 (21%)
# of Incidents	539
Recidivism Rate	1.8
Total Cost	\$16,648,940
Amount Reimbursed by Medicaid	\$1,564,950
Average Cost /Person	\$54,947
Average Reimbursed by Medicaid per Person	\$5,165

## Findings Within Evaluation Methods

### Survey

The online survey contained seven questions regarding crisis intervention services. Table 5 provides a summary of responses for these services. On average, overall crisis services were reported to work well (all that was wanted/needed) only 11% of the time, with responses for specific services ranging from 1% (crisis respite beds) to 31% (emergency departments). An average of 36% of respondents reported that when services were available, they needed improvement. **The greatest need for improvement cited was access to crisis stabilization services (44%) and inpatient units (41%).** Just over half of respondents reported that there were either not enough services or that they were not available at all (54%). Therapeutic respite services were rated as the least available (63%). Police response was rated as the most available.

**There was a statistically significant difference in the availability of psychiatric in-patient beds between rural and metropolitan respondents, with 65% of rural respondents reporting no access compared to 13% of metropolitan respondents (p=0.00).**

**Table 5: Survey of Reported Effectiveness of Crisis Services**

Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
Mobile Crisis	4%	34%	11%	51%
Crisis Stabilization	4%	44%	14%	39%
Community-Based Psychiatric Inpatient Beds	3%	41%	16%	40%
In-Home Crisis Respite	3%	29%	6%	62%
Out-of-Home Crisis Respite Services	1%	26%	9%	64%
Police Response	29%	39%	29%	3%
Emergency Departments	31%	36%	28%	5%
<b>Crisis Services (average)</b>	<b>11%</b>	<b>36%</b>	<b>16%</b>	<b>38%</b>

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=39). **Two-thirds of respondents (67%) 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 overall lack of crisis intervention services, especially of services other than the hospital (41%), along with an unwillingness to admit people with IDD-MH into hospitals (26%), were the most frequently reported barriers to care. **Nearly a third of respondents (31%) 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, 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, 79% reported that they did not have the information they needed to access crisis assistance.**

### ***Psychiatric Inpatient Services FY 2020-2021***

Review of the claims data includes number of individuals and admissions along with lengths of stay across the two-year period 2020-2021. Within the total number of individuals known to receive psychiatric medications (n=1423), a total of 219 individuals, representing 10%, were hospitalized. The average length of each admission was 8.8 days. This is lower than expected and may explain why many returned to the hospital for a second admission. Despite the relatively low number of people admitted and the brief length of stay, the cost exceeded 27 million dollars over the two-year period with Medicaid reimbursing 2.6 million dollars in billing.

**Table 6: Psychiatric In-Patient Claims for Mental Health 2020-2021**

<b>Psychiatric Hospitalizations</b>	<b>2 Year Total</b>
# of Individuals (% of population)	219 (10%)
# of Incidents (admissions)	356
Average Recidivism Rate (repeat admissions)	1.6
Average LOS (min-max)	8.8 (1-41)
Total Cost	\$27,706,387
Amount Reimbursed by Medicaid	\$2,620,631
Average Cost /Person	\$126,513

### Discussion Groups

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. Group 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 on IDD-MH among law enforcement officers and the fact that jails are not appropriate holding spaces for individuals with IDD-MH in times of crisis. In addition, as reported earlier, the cost of emergency department visits is high.

Discussion group participants suggested that mobile crisis response would be beneficial. Mobile crisis response and telehealth crisis response, where available, were reported as beneficial in helping to de-escalate crisis situations, and the need for additional crisis response and supports for de-escalation was emphasized. Furthermore, there was widespread agreement among discussion group participants that there is a need for better crisis stabilization and support as people transition back into the community. The reported lack of crisis stabilization services was highlighted in connection to concerns around individuals receiving appropriate services post-crisis. Multiple participants expressed that without treatment and stabilization, there were often concerns about the safety of individuals returning to their homes and communities and that unresolved issues often lead to fewer opportunities for community participation or, in some cases, the termination of services. This was further referenced regarding a need for a better continuum of care and the need for transitional places (outside of the emergency department) for people to go in times of crisis. Several discussion group members recalled struggles with discharge after crisis in which individuals were either discharged too quickly without appropriate supports in place or mental health holds became much too long, resulting in individuals being “stuck” with no place to go.

### Family Caregiver Interviews (FEIS)

While 35% of family caregiver respondents reported that they knew who to call in a crisis, very few reported that help was available at nights or on weekends or that there were options available outside



of the hospital for help. For the most part, families (60%) reported that they lacked information on what to do in a crisis.

## Implications of Findings

Crisis response and inpatient mental health service gaps may help to explain the claims data findings. The lack of a safety net and response structure to intervene, assess, and treat in times of difficulty should be addressed in planning.

## Evaluation of IDD and Community Services

### Summary

A whole person approach requires that all providers are able and willing to support people with IDD and mental health service needs. The final theme to emerge from this part of the analysis is the **need for greater access to all IDD and community services for people with IDD-MH**. Respondents reported exclusion from employment and social/recreational opportunities negatively impact quality of life and increase mental health needs. Access to community services is reportedly difficult, particularly for individuals with IDD-MH. While there was praise for the DDD service system, accommodation for the needs of people with IDD and mental health service needs was reportedly lacking. Stigma and refusal to serve the IDD-MH population were identified as major issues of concern along with lack of qualified and trained providers.

### Findings within Evaluation Methods

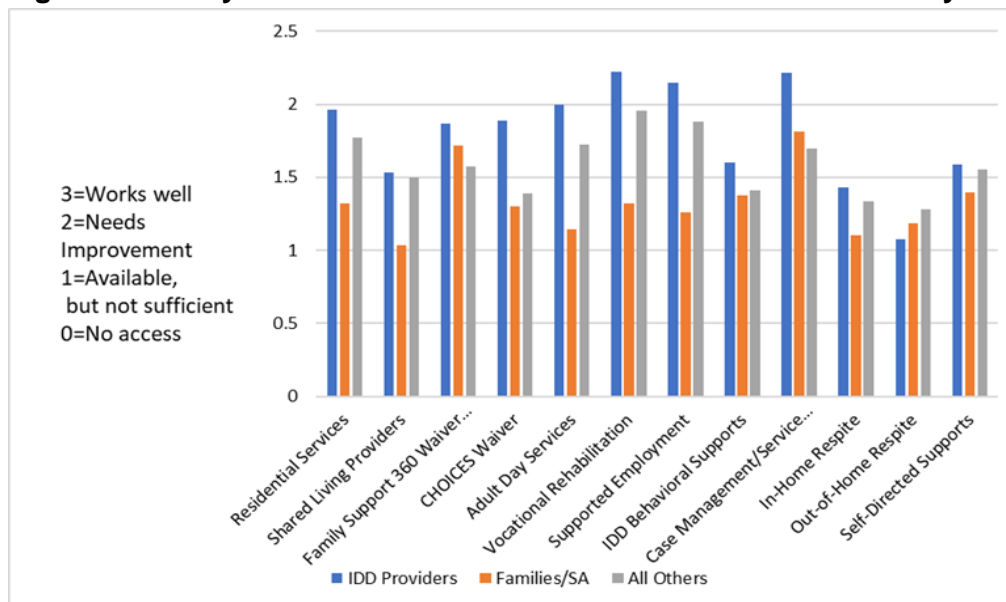
#### Survey

The online survey asked respondents about the effectiveness of IDD services. As shown in Table 7, IDD services were reported as available by 87% of respondents, but only 21% reported that the services worked well for individuals with IDD-MH. There were statistically significant differences between respondent groups, with IDD providers reporting overall services as most effective and families/service users reporting them the least effective ( $F=5.55$ ,  $p=.00$ , Figure 5). At the service level, statistically significant differences were reported for all IDD services except respite and behavioral supports, which had similar responses across groups (Table 8). IDD services were reported to be less available by rural respondents (vs metropolitan) with statistical significance observed for shared living providers ( $p=.01$ ), Family Support waiver services ( $p=.01$ ), adult day services ( $p=.03$ ), and case management ( $p=.04$ ).

**Table 7: Survey Results of Reported Effectiveness of IDD Services**

Services	Work well	Available, but needs improvement	Available, but not sufficient	Not available
Residential Services	25%	33%	35%	8%
Shared Living Providers	17%	27%	34%	22%
Family Support 360 Waiver Services	24%	33%	35%	9%
CHOICES Waiver	20%	28%	42%	10%
Adult Day Services	29%	25%	32%	13%
Vocational Rehabilitation	38%	24%	30%	8%
Supported Employment	34%	25%	34%	8%
IDD Behavioral Supports	7%	48%	31%	14%
Case Management/Service Coordination	34%	31%	32%	4%
In-Home Respite	7%	37%	34%	21%
Out-of-Home Respite	4%	39%	27%	30%
Self-Directed Supports	12%	39%	37%	12%
<b>IDD Services (average)</b>	<b>21%</b>	<b>32%</b>	<b>34%</b>	<b>13%</b>

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



**Table 8: Survey Results of Reported Effectiveness of IDD Services by Respondent Group**

Services Work Well	Families/ Self-Advocates	IDD Providers	All Others	p-value
Residential Services	13%	39%	16%	0.00
Shared Living Providers	15%	24%	11%	0.00
Family Support 360 Waiver Services	19%	43%	9%	0.00
CHOICES Waiver	13%	35%	4%	0.00
Adult Day Services	11%	44%	22%	0.00
Vocational Rehabilitation	16%	50%	37%	0.00
Supported Employment	13%	47%	31%	0.00
IDD Behavioral Supports	7%	11%	3%	0.08
Case Management/Service Coordination	26%	50%	19%	0.00
In-Home Respite	7%	11%	3%	0.34
Out-of-Home Respite	4%	5%	3%	0.79
Self-Directed Supports	3%	20%	10%	0.00

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 69 respondents who provided an explanation, 46% cited staffing shortages and waitlists as the biggest barriers to access. Over one quarter (29%) of respondents reported that people with IDD-MH were less likely to have access to needed IDD services, limiting their opportunities for community inclusion. Access was reportedly limited due to providers feeling a lack of appropriate training and resources to effectively include people with IDD-MH and meet their needs. **Of note, nearly one fifth (19%) of respondents overall and 40% of family respondents reported that they did not have enough information on the types of services available and how to access them.**

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 access, by 61% of respondents who reported it as a need (n=38).**

About 25% of families responding to the surveys were from Indigenous communities and, overall, their feedback regarding mental health services and crisis services were consistent with other respondents. However, only 3% of family members from those Indigenous communities reported that IDD services worked well for their family member.

#### Family Caregiver Interviews

Of those family caregivers interviewed, half (n=10) cited a lack of appropriate services for individuals with IDD-MH. Specifically mentioned were termination of services due to "behavioral" or mental health needs, a lack of providers with adequate training, and an overall lack of staff to provide authorized

services. One quarter of those interviewed also cited issues with information sharing and coordination of services and cited family advocate organizations as the only resources available to them.

### Discussion Groups

Discussion group participants further emphasized issues related to limited access to appropriate services for individuals with IDD-MH. Across discussion groups, 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.

**Table 9: Survey Results of Reported Effectiveness of Community Services by Respondent Group**

Services Work Well	Families/Self-Advocates	IDD Providers	All Others	p-value
Medical Care	45%	54%	50%	0.07
Dental Care	55%	43%	37%	0.11
Transportation	23%	30%	25%	0.00
Recreation	20%	39%	25%	0.00
Access to Higher Education	24%	35%	32%	0.00
<b>Community Services (average)</b>	<b>34%</b>	<b>39%</b>	<b>31%</b>	

Overall, community medical and dental services were the most highly rated with over 98% of respondents reporting access to medical care and 94% reporting access to dental care. There were no statistical differences between respondent groups or based on geography. There were differences in the reported effectiveness of transportation and recreational opportunities with 15% of family respondents reporting no access to transportation compared with 3% of all other respondents ( $p=0.00$ ). Additionally, 20% of families reported no access to recreational opportunities compared to less than 1% of all other respondents ( $p=0.00$ ).

Across groups, concerns were expressed regarding the ability of providers to terminate services for an individual, especially when individuals are facing mental health crisis. Discussion group participants reported causes of termination including lack of staffing, lack of appropriate mental health services to support the individual, and lack of transition support after mental health crisis. According to respondents, termination of services by service providers can happen without a discharge plan or alternative placement identified, leaving individuals in more restrictive settings or jeopardizing safety in the community. There was a widespread sense that there is a need for better continuity of care for individuals with IDD-MH and that more supportive systems linkages and collaboration would be of benefit. Participants reported the systems appear siloed and this disconnect causes families,

caregivers, and individuals with IDD-MH to struggle to access the resources that do exist in the state. Furthermore, the turnover and disconnect of care is reportedly “traumatizing” for individuals with IDD-MH navigating the systems. The need for better transition planning was highlighted not only for times of crisis, but also in the transition to adulthood, where many young adults experience a decrease in services and supports upon leaving the education system.

### Family Caregiver Interviews

When family caregivers were asked, “*What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?*” the majority of family caregivers expressed a need for increased support in navigating the service system.

Family respondents also reported a lack of good information on what services might be available and how to access them. When asked if there were services they wanted but could not access, five caregivers (25%) reported that they did not have the information they needed to know how to answer that question.

### **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. Improvement in quality of life would likely decrease the need for mental health and crisis services. People with IDD-MH are reported to be the last and least served by the IDD service providers in South Dakota regarding services that promote community inclusion. It is important to note that the gaps likely widen for rural communities in South Dakota. IDD services were reported to be less available by rural respondents (vs metropolitan) with statistical significance observed for shared living providers ( $p=.01$ ), family support waiver services ( $p=.01$ ), adult day services ( $p=.03$ ), and case management ( $p=.04$ ).

### **Evaluation Limitations**

The South Dakota 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 for consideration in service planning and policymaking going forward. While 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, and we did not examine the experiences of either the mental health population or the IDD population. In addition, there were few participants with lived experiences of IDD-MH who participated in this evaluation. Their input is essential to successful planning going forward.



## Conclusions

To learn about the services for people with IDD-MH, four primary data collection methods were employed: (1) an online survey, (2) discussion groups, (3) family caregiver interviews, and (4) a review of Medicaid claims data provided by the Department of Human Services. The identities of all participants in this evaluation are confidential. Findings, along with recommendations for follow-up, are included in this report. The 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. The use of holistic supports for individuals with IDD-MH with a well-rounded and comprehensive approach to care is noteworthy. Providers in South Dakota who use this form of team approach reported the importance this approach has for their ability to actively support and meet the needs of people with IDD-MH. Participants also reported positive collaboration with police departments across the state with law enforcement often cited as essential during times of mental health crisis. Evaluation participants emphasized the positive experiences with law enforcement officers and the new training initiatives within the state to better educate police officers in responding to mental health crises, including how to assist with individuals with IDD. Respondents also reported the increased use of telehealth in some rural communities to allow first responders real-time access to mental health professionals to assist in both de-escalation and evaluation. These initiatives reportedly show promise for increased capacity to respond to crisis in an informed and supportive manner. Evaluation participants acknowledged the commitment and talent of partners across the state as well as the willingness of the DHS system to acknowledge issues and invite feedback.

Regarding identification of service gaps, a total of 151 online surveys examined whether there were significant differences between specific service types. Most services require improvement in capacity and access. The greatest service gaps reported were crisis prevention and intervention services, followed by mental health outpatient services. Community services (medical, dental, transportation, recreation, etc.) were the most highly rated services. However, all reported ineffective community-based outpatient mental health services for individuals with IDD in South Dakota. 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 placement, long emergency department stays, and incarceration. According to evaluation participants, there is a lack of community crisis intervention evaluations and supports in the state, resulting in an overreliance on local police departments, emergency departments, and hospital admissions. Respondents emphasized that improved capacity in all mental health services across the state is needed to improve outcomes for people with IDD-MH. This was described as essential to reduce acute and restrictive intervention. The analysis found significant differences in rural and metropolitan experiences overall with rural communities having the greatest difficulties regarding effective care and treatment.

To improve service experiences, outcomes and cost effectiveness, resources will be needed to build an infrastructure and capacity to provide effective services for individuals with IDD-MH and their families. A system of care with clear linkages and enhanced capacity through implementation of best practices, cross training and collaboration is needed. South Dakota can develop such a plan given the clear commitment to people with IDD and to working together.

## Recommendations

There is commitment to improve services and supports to better assist people with IDD-MH across South Dakota. Trauma-informed care is important to this effort, along with creating a safety net across the system of care that allows for people to address issues as they arise. Of note is that rural communities and members of Indigenous communities may have the greatest needs.

The state of South Dakota may want to consider the START model to expand capacity and resources around best practice training, crisis prevention and response. START is an evidence-based, comprehensive cross-systems crisis prevention and intervention model. It is described in the addendum to this report. Greater capacity to understand and support individuals who may be experiencing a mental health crisis is indicated. This includes considering the development of training and capacity building approaches to effectively intervene in times of difficulty including approaches in the person's setting and locations for stabilization and evaluation. Creating opportunities to avoid emergency room usage, police involvement, hospitalization, and institutionalization should be explored. Many of the capacity issues could be improved through the implementation of a START program and the creation of a community network.

The use of a model like START may have both a service outcome and financial impact in South Dakota. As an example, the New Hampshire START statewide program is in its 10<sup>th</sup> year of operation. The program serves individuals with IDD-MH in both rural and metropolitan communities to provide training, consultation, linkages, and crisis prevention and response services across the state of New Hampshire. In South Dakota, for the years 2020-2021 the average per person cost for emergency department visits to treat mental health crises was \$54,947. This far exceeds the cost of annual enrollment in NHSTART services at a rate of \$6028.55 per person per year with services that include systems linkages, consultation, training, cross-systems crisis prevention and intervention planning, coaching, and outreach visits along with a 24-hour mobile crisis response. Other examples of START implementation to consider include Iowa START and the work currently being developed in Idaho and New Mexico.

Given the collaborative and innovative efforts already under way, we believe the START Model is a good fit for South Dakota.

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## Appendix A: County Breakdown of Respondents

<b>County</b>	<b>Number of Survey Respondents</b>
Beadle	1
Bon Homme	2
Brookings	18
Brown	5
Butte	2
Clay	2
Codington	1
Davison	2
Grant	1
Hughes	7
Jones	2
Lawrence	10
Lincoln	6
Meade	2
Minnehaha	40
Moody	1
Oglala Lakota	13
Pennington	10
Perkins	1
Spearfish	1
Spink	4
Tripp	1
Union	1
Yankton	4
Statewide	3
Unspecified	11
<b>Total</b>	<b>151</b>

## Appendix B: Pearson Chi-Squared Tables

### Crisis Services

#### CRIS\_Mobile Crisis

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_MC				
No access	42.86	52.94	54.76	51.25
Needs Improvement	38.10	29.41	33.33	33.75
Available	9.52	11.76	11.90	11.25
Works well	9.52	5.88	0.00	3.75
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 4.34 Prob = 0.6311

#### CRIS\_Crisis Stabilization/Hospital Diversion

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_CSU				
No access	29.63	35.29	46.34	38.82
Needs Improvement	40.74	52.94	41.46	43.53
Available	18.52	11.76	12.20	14.12
Works well	11.11	0.00	0.00	3.53
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 8.66 Prob = 0.1935

#### CRIS\_Psychiatric In-Patient

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_PSYCHIP				
No access	30.00	52.63	40.91	39.78
Needs Improvement	40.00	31.58	45.45	40.86
Available	23.33	15.79	11.36	16.13
Works well	6.67	0.00	2.27	3.23
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.58 Prob = 0.4717



**CRIS\_In Home Crisis Respite**

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_IHCR				
No access	47.62	72.22	65.79	62.34
Needs Improvement	33.33	27.78	26.32	28.57
Available	14.29	0.00	5.26	6.49
Works well	4.76	0.00	2.63	2.60
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.39 Prob = 0.4948

**CRIS\_Oou of Home Crisis Respite**

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_OHCR				
No access	50.00	73.68	65.79	63.64
Needs Improvement	30.00	21.05	26.32	25.97
Available	20.00	5.26	5.26	9.09
Works well	0.00	0.00	2.63	1.30
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.78 Prob = 0.4482

**CRIS\_Police Response**

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CRIS_POL				
No access	0.00	7.69	1.96	2.73
Needs Improvement	51.52	42.31	29.41	39.09
Available	24.24	23.08	35.29	29.09
Works well	24.24	26.92	33.33	29.09
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 7.84 Prob = 0.2498

### CRIS\_Emergency Departments

CRIS_ED	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	3.03	7.69	4.00	4.59
Needs Improvement	48.48	30.77	30.00	35.78
Available	24.24	30.77	30.00	28.44
Works well	24.24	30.77	36.00	31.19
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 4.08 Prob = 0.6664

### Outpatient Mental Health

#### OP\_Therapy

OP_Therapy	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	2.70	8.33	0.00	3.20
Needs Improvement	37.84	41.67	38.46	39.20
Available	43.24	38.89	46.15	43.20
Works well	16.22	11.11	15.38	14.40
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.39 Prob = 0.4951

#### OP\_Psychiatry

OP_PSYCH	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	5.56	20.00	5.77	9.76
Needs Improvement	52.78	40.00	42.31	44.72
Available	27.78	28.57	42.31	34.15
Works well	13.89	11.43	9.62	11.38
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 8.13 Prob = 0.2288

**OP\_Evaluation**

OP_EVAL	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	5.56	18.18	4.08	8.47
Needs Improvement	33.33	51.52	53.06	46.61
Available	47.22	24.24	30.61	33.90
Works well	13.89	6.06	12.24	11.02
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 11.14 Prob = 0.0842

**OP\_Expressive Therapies**

OP_EXP	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	20.69	40.62	15.22	24.30
Needs Improvement	41.38	21.88	34.78	32.71
Available	31.03	21.88	34.78	29.91
Works well	6.90	15.62	15.22	13.08
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.34 Prob = 0.1555

**OP\_Substance Use Treatment**

OP_SU	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	3.12	26.32	13.51	12.50
Needs Improvement	46.88	47.37	29.73	39.77
Available	40.62	21.05	40.54	36.36
Works well	9.38	5.26	16.22	11.36
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.86 Prob = 0.1305

### OP\_Intensive Out-Patient

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
OP_IOP				
No access	20.00	42.11	28.21	28.41
Needs Improvement	36.67	26.32	38.46	35.23
Available	40.00	31.58	28.21	32.95
Works well	3.33	0.00	5.13	3.41
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 4.28 Prob = 0.6389

### OP\_MH Case Management

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
OP_MHCM				
No access	9.68	25.00	10.53	13.98
Needs Improvement	54.84	50.00	47.37	50.54
Available	29.03	20.83	28.95	26.88
Works well	6.45	4.17	13.16	8.60
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.08 Prob = 0.5332

### Training and Coaching

#### TR\_Coaching

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
TR_COACH				
No access	5.88	18.75	6.00	9.48
Needs Improvement	44.12	43.75	50.00	46.55
Available	41.18	18.75	18.00	25.00
Works well	8.82	18.75	26.00	18.97
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 12.42 Prob = 0.0533

### TR\_Crisis Planning

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
TR_CSCP				
No access	8.57	22.58	10.00	12.93
Needs Improvement	42.86	45.16	46.00	44.83
Available	40.00	22.58	30.00	31.03
Works well	8.57	9.68	14.00	11.21
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 5.39 Prob = 0.4945

### TR\_Family Education

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
TR_FE				
No access	6.25	23.53	11.90	13.89
Needs Improvement	50.00	52.94	52.38	51.85
Available	40.62	17.65	21.43	25.93
Works well	3.12	5.88	14.29	8.33
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.74 Prob = 0.0969

### TR\_Educator Education

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
TR_EDC				
No access	5.56	30.00	9.76	14.02
Needs Improvement	50.00	43.33	46.34	46.73
Available	27.78	20.00	31.71	27.10
Works well	16.67	6.67	12.20	12.15
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.23 Prob = 0.1154



## IDD Services

### IDD\_Residential Services

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
IDD_RS				
No access	2.27	29.03	0.00	7.58
Needs Improvement	47.73	35.48	19.30	32.58
Available	34.09	22.58	42.11	34.85
Works well	15.91	12.90	38.60	25.00
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 40.75 Prob = 0.0000

### IDD\_Shared Living

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
IDD_SL				
No access	13.89	48.15	12.20	22.12
Needs Improvement	41.67	22.22	17.07	26.92
Available	33.33	14.81	46.34	33.65
Works well	11.11	14.81	24.39	17.31
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 22.70 Prob = 0.0009

### IDD\_Family Support Waiver Services

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
IDD_FSW				
No access	2.86	15.62	8.11	8.65
Needs Improvement	42.86	50.00	8.11	32.69
Available	45.71	15.62	40.54	34.62
Works well	8.57	18.75	43.24	24.04
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 28.53 Prob = 0.0001

### IDD\_Choices Waiver Services

IDD_CHOICE	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	0.00	33.33	0.00	9.62
Needs Improvement	32.14	36.67	19.57	27.88
Available	64.29	16.67	45.65	42.31
Works well	3.57	13.33	34.78	20.19
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 44.18 Prob = 0.0000

### IDD\_Adult Day

IDD_AD	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	5.56	39.29	4.00	13.16
Needs Improvement	33.33	32.14	16.00	25.44
Available	38.89	17.86	36.00	32.46
Works well	22.22	10.71	44.00	28.95
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 32.61 Prob = 0.0000

### IDD\_Vocational Rehabilitation

IDD_VR	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	0.00	32.26	0.00	7.81
Needs Improvement	20.93	32.26	22.22	24.22
Available	41.86	19.35	27.78	30.47
Works well	37.21	16.13	50.00	37.50
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 41.64 Prob = 0.0000

### IDD\_Supported Employment

	Cohort			Total
	All Other	Family/S A	IDD Service provider	
IDD_SE				
No access	0.00	32.26	0.00	7.81
Needs Improvement	26.19	32.26	20.00	25.00
Available	42.86	22.58	32.73	33.59
Works well	30.95	12.90	47.27	33.59
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 41.82 Prob = 0.0000

### IDD\_Behavioral Supports

	Cohort			Total
	All Other	Family/S A	IDD Service provider	
IDD_ABA				
No access	12.82	27.59	7.55	14.05
Needs Improvement	48.72	51.72	45.28	47.93
Available	35.90	13.79	35.85	30.58
Works well	2.56	6.90	11.32	7.44
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 11.43 Prob = 0.0758

### IDD\_Case Management

	Cohort			Total
	All Other	Family/S A	IDD Service provider	
IDD_CM				
No access	2.33	10.53	0.00	3.65
Needs Improvement	34.88	39.47	21.43	30.66
Available	44.19	23.68	28.57	32.12
Works well	18.60	26.32	50.00	33.58
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 20.92 Prob = 0.0019

### IDD\_In Home Respite

IDD_IHR	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	18.18	34.48	13.51	21.21
Needs Improvement	45.45	31.03	35.14	37.37
Available	33.33	27.59	40.54	34.34
Works well	3.03	6.90	10.81	7.07
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 6.83 Prob = 0.3372

### IDD\_Out of Home Respite

IDD_OHR	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	21.88	33.33	34.21	29.90
Needs Improvement	43.75	44.44	31.58	39.18
Available	31.25	18.52	28.95	26.80
Works well	3.12	3.70	5.26	4.12
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 3.16 Prob = 0.7891

### IDD\_Self-Directed Supports

IDD_SDS	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	6.90	23.33	6.52	11.43
Needs Improvement	41.38	56.67	26.09	39.05
Available	41.38	16.67	47.83	37.14
Works well	10.34	3.33	19.57	12.38
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 18.55 Prob = 0.0050

## Community Services

### CS\_Medical

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CS_MD				
No access	0.00	4.76	0.00	1.47
Needs Improvement	7.50	23.81	9.26	13.24
Available	42.50	26.19	37.04	35.29
Works well	50.00	45.24	53.70	50.00
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 11.62 Prob = 0.0709

### CS\_Dental

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CS_DC				
No access	10.00	4.76	3.70	5.88
Needs Improvement	15.00	28.57	24.07	22.79
Available	37.50	11.90	29.63	26.47
Works well	37.50	54.76	42.59	44.85
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.27 Prob = 0.1138

### CS\_Transporation

	Cohort			
	All Other	Family/S A	IDD Service provider	Total
CS_TRAN				
No access	2.27	15.00	3.77	6.57
Needs Improvement	38.64	52.50	26.42	37.96
Available	34.09	10.00	39.62	29.20
Works well	25.00	22.50	30.19	26.28
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 18.23 Prob = 0.0057



### CS\_Recreation

CS_REC	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	0.00	19.51	0.00	5.93
Needs Improvement	27.50	41.46	18.52	28.15
Available	47.50	19.51	42.59	37.04
Works well	25.00	19.51	38.89	28.89
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 31.07 Prob = 0.0000

### CS\_Education

CS_EDUC	Cohort			
	All Other	Family/S A	IDD Service provider	Total
No access	0.00	13.51	0.00	4.03
Needs Improvement	34.09	40.54	23.26	32.26
Available	34.09	21.62	41.86	33.06
Works well	31.82	24.32	34.88	30.65
Total	100.00	100.00	100.00	100.00

Pearson Chi2 = 16.91 Prob = 0.0096



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## Appendix C: Focus Group Participants and Dates

<b>Group</b>	<b>Date</b>	<b>Participants</b>
Community Support Providers	6/16/2023	19
Family Members	6/20/2023	17
Case Mangers	6/22/2023	13
Individuals with Lived Experience/Self-Advocates	6/27/2023	3
Mental Health Providers	6/27/2023	7
Disability Rights	6/28/2023	10
SD Developmental Center Staff	7/17/2023	9
Law Enforcement Interviews	7/11 and 7/27, 2023	3

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

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

By supporting the development of the 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

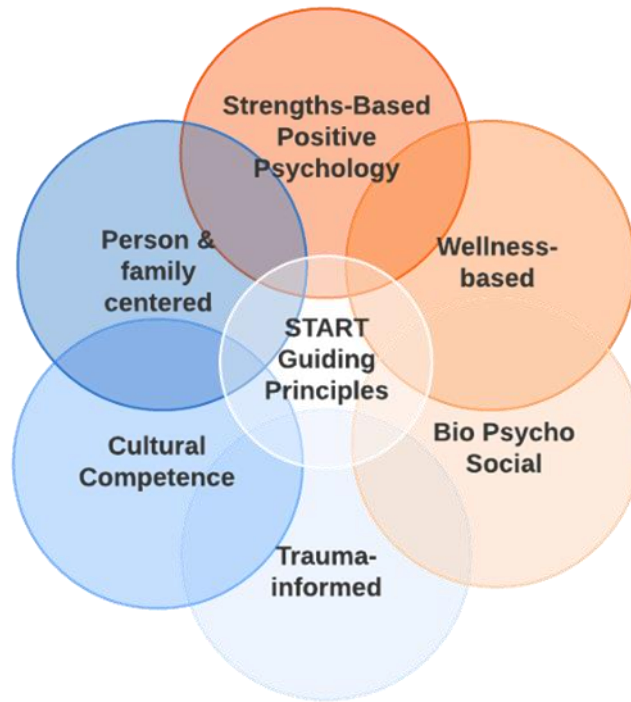
### **The START Model**

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.<sup>11</sup> In 2016, the START model was identified as best practice by the National Academy of Sciences Institute of Medicine.<sup>12</sup>

## 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

- 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



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

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

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

## **Eligibility**

1. All persons enrolled in START are eligible for planned and emergency therapeutic coaching services if the program is set up to provide STC. Admission to STC is based on the assessment of clinical need and appropriateness. As with other therapeutic support services, supporting families is a priority.
2. All persons must have an established Cross-Systems Crisis Prevention and Intervention Plan (CSCP/IP) 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.

## **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 National START Program Certification. At this phase, at least half of START staff have achieved coordinator certification, the program is providing full on-call supports, and have internal QA procedures in place to monitor fidelity elements and mechanisms for evidence-informed decision making. The program works with their assigned NCSS project manager and the QA department to prepare for certification. This may include a “practice” certification review.

**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.