Iowa START (I-START)

July 2020 – June 2021

Annual Report

Prepared for

Iowa START

Prepared by

The Center for START Services

THE CENTER FOR START SERVICES
Institute on Disability / UCED
University of New Hampshire

On August 3, 2021

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START, which stands for Systemic, Therapeutic, Assessment, Resources, & Treatment, is a comprehensive model of service supports that optimizes independence, treatment, and community living for individuals with intellectual/developmental disabilities (IDD) and mental health needs.

The Center for START Services, a program of the University of New Hampshire Institute on Disability/UCED, is a national initiative that strengthens efficiencies and service outcomes for individuals with IDD and behavioral health needs in the community.

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Introduction

This report offers a comprehensive summary of services provided by the I-START program for Fiscal Year 2021 (FY21), including I-START COVID-19 response. The analysis includes assessment of outcomes as well as fidelity measures for the START model. Recommendations reflect the results of the analysis and service provision to date.

Findings from this report are separated into f sections:

- FY21 program enrollment and census trends
- Characteristics of persons served (demographics and clinical trends)
- Emergency service trends
- START clinical team services

I-START will develop an action plan based on recommendations from the analysis in collaboration with the Center for START Services.

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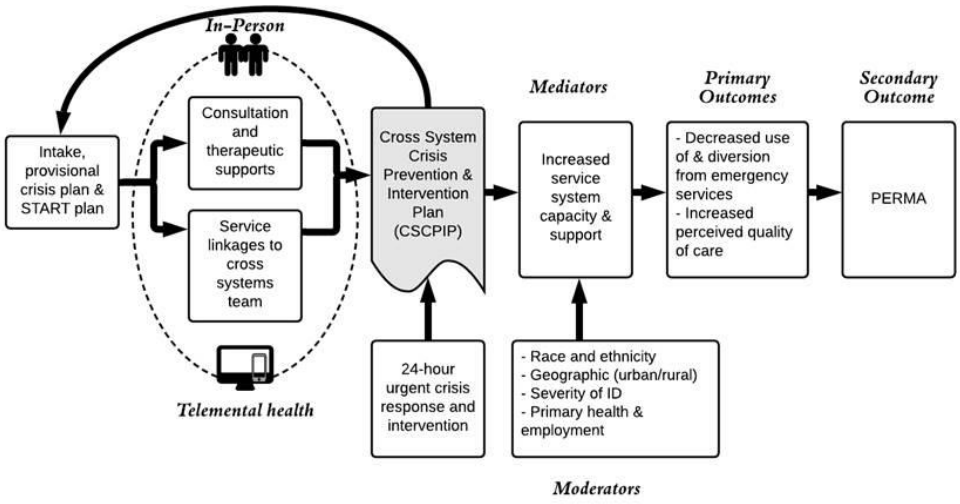
I-START Team

Section I. Background

First developed by Dr. Joan B. Beasley in 1988, START was cited as a best practice in the US Surgeon General's Report (2002) and more recently presented to the National Academy of Sciences, Engineering and Medicine (2016). Studies spanning over 30 years of START services have found significant reduction in crisis service use, emergency department visits, and psychiatric hospitalizations. [1,2]

As shown in the figure below, START programs provide mental health assessment and 24-hour crisis response, START coordination and coaching/support, along with training and systems linkages to address the mental health needs of people with IDD and their families. START crisis prevention and intervention services are patient-centered and engage service recipients with IDD-MH in treatment, including those with significant delays in cognitive, communication, and social functions. START services significantly reduce emergency mental health service use, and caregivers report high service satisfaction.



National START Program Certification

The Center for START Services (CSS) provides in-person and web-based training, technical assistance, planning, and case consultation to implement the START model. Ongoing technical assistance includes close collaboration with stakeholders, quality reviews of START methods, and evaluation through data entered into the START Information Reporting System (SIRS). The goal of CSS is to foster the successful development and implementation of the START model and to assess efficacy and goodness of fit in each location in which the model is implemented. The goal is for each START team to be fully certified within three years and to maintain engagement with the National START Network. I-START has been certified as a clinical program since June 2020 and has passed their six-month review following initial certification.

Training, consultation, and quality assurance monitoring provided by CSS to the I-START program include:

- Triage participation to assist with proactive crisis response and intervention

[1] Kalb, LG, Beasley, J., Caoili, A., & Klein, A. (2019). Evaluation of the START crisis intervention and prevention program. *American Journal of Intellectual and Developmental Disabilities,* 124(1), 25-34.

[2] Beasley, J., Kalb, L., & Klein, A. (2018) Improving Mental Health Outcomes for Individuals with Intellectual Disability through the Iowa START (I-START) Program. *Journal of Mental Health Research in Intellectual Disabilities, 11*(4), 287-300.

- In-person consultation visits
- Leadership training and development
- Clinical team coaching, training, and team development
- Attendance and participation in Clinical Education Team Meetings, Advisory Council meetings, and other regionally specific outreach efforts
- Iowa specific training workshops
- Program evaluation (monthly, quarterly, and annual reports)
- SIRS database training and technical assistance
- Clinical record reviews
- Coordinator training and certification
- START National On-Line Training Series
- START Practice Improvement Groups
- START National Training Institute

START Response to the COVID-19 Pandemic

Regardless of START enrollment status, people with IDD are at high risk of stress and mental health related distress associated with the COVID-19 pandemic. Without maintaining appropriate supports for this vulnerable group, they are at risk for increased mental health crises that affect their safety and the safety of their families and heightens the human and financial costs to the broader community. In collaboration with the Center for START Services and the national START Network, the I-START program is committed to supporting the IDD community through this public health crisis.

During the COVID-19 shutdown, the Center for START Services rapidly and strategically initiated the development of telehealth crisis support protocols across the START network. Telehealth is identified as an evidence-based method to delivering mental health services and supports on virtual or remote platforms[3]. A series of virtual meetings with START program directors, administrators, funders, and other stakeholders were held to review the telehealth protocols, and revisions to the SIRS database were made to accurately capture telehealth service delivery by START programs.

The START Network collaborated and provided accessible information and training about COVID-19, therapeutic supports, clinical services, and crisis response using telehealth methods.

In addition to the modification of protocols for START programs, CSS also initiated the development of a *COVID-19 Resources* page on the CSS Website, which was used by START programs and community stakeholders nationwide. The National START Emergency Management Committee was convened in response to the pandemic as well. The committee's initial objective was to address immediate gaps in emergency response to COVID-19, and three task forces were developed to address the needs of service users, families and communities across the country present as a result of COVID. These task forces were: 1) mobile START crisis response; 2) therapeutic interventions and 3) transition planning.

The National START Emergency Management Committee

The Emergency Management Committee is a national forum developed by and with START network partners and is designed to provide comprehensive, interdisciplinary support to START service users, families, providers, and START teams in response to emergency circumstances. The EMC is committed to developing a framework for rapid mobilization across the START network, building on linkages across the START network, available resources, expertise, innovation, and collective intelligence. The goal is to establish a "think tank" to develop, review, and

[3] Totten AM, Womack DM, Eden KB, et al. (June 2016). Telehealth: Mapping the Evidence for Patient Outcomes from Systematic Reviews (Technical Brief 26) [Internet]. Rockville (MD): Agency for Healthcare Research and Quality.

evaluate practices designed to support START service users during times of local/national crisis. The committee addresses macro level (community-level) crises as well as assists START network providers in addressing micro level (individualized) needs.

One example of the work of the Emergency Management Committee beyond the COVID-19 pandemic was the rapid response to the CA wildfires. It was brought to the attention of the committee that many across the state of California, including START staff and service recipients, were forced to evacuate their homes. Emergency shelters needed resources and training materials to aid in the effective support of persons with IDD. Members of the committee came together and developed brief information sheets specific to supporting persons with IDD in crisis situations that were distributed to CA regional centers and shelters.

Information and resources developed by the National START Emergency Management Committee can be found in the *Resources* area of the Center for START Services website https://www.centerforstartservices.org/Resources/EMC.

Section II. I-START Highlights

Despite the effects of COVID-19 on their communities, the I-START program provided services and supports to over 160 persons with IDD-MH across the state in FY2021. The following are program highlights from throughout the year.

Transition to telehealth and virtual service delivery: When COVID-19 shelter in place orders were implemented, I-START program staff quickly pivoted to new methods of service delivery. To support those enrolled in I-START, staff shared plain language materials, and provided resources and training about COVID-19. In addition, the I-START program began providing telehealth services, which continued throughout FY2021. Additional fields in SIRS were added to track telehealth outreach and crisis follow-up. Nearly all I-START enrollees received at least some telehealth services throughout the year. While preliminary findings show positive outcomes associated with telehealth, additional study is needed. The Center for START Services looks forward to continuing to collaborate with the I-STAR START program in evaluating telehealth START services to inform ongoing best practices.

Continued linkage and relationship building: Clinical Education Trainings (CETs) are an important facet to the capacity building efforts of I-START. These in-depth case studies allow for interactive learning and collaboration in a multi-disciplinary format. During FY21, the I-START continued to offer monthly CETs in a virtual, averaging 41 attendants per event.

In addition to training, linkages continue to be a vital piece of I-START's community capacity building. The program has numerous linkage agreements with partners in their region (see Appendix B). These linkages allow for collaboration and connection with many providers including mental health and IDD agencies as well as transportation, recreation, healthcare, and educational resources. The I-START team also links with emergency service providers such as law enforcement, fire departments, and hospitals to help facilitate effective collaboration during crisis events and prevent unnecessary utilization of these services. Advisory council members and community partners work with I-START team to engage the community in training initiatives to share information and best practices in IDD-MH. In FY21, The I-START team provided over 120 hours of community training to diverse audiences on a variety of topics using both in-person and virtual platforms.

Reduction in Emergency Service Use: Overall, there was a reduction in emergency service use for individuals enrolled in the I-START program with decreases in both ED and psychiatric hospitalization rates pre- to post-enrollment. Data also show a reduction in mental health symptoms as measured by the Aberrant Behavior Checklist.

Health and Wellness: The I-START team used CARES Act money to purchase, make, and distribute 400 sensory bags to individuals within the support system to help maintain engagement and wellness during the lockdown period. The I-START Clinical Director began offering wellness classes to START employees to allow them the opportunity to break from the challenges of the day and focus on themselves and be better equipped to support I-START enrollees. The

team also created a YouTube channel with training videos, mindfulness exercises and fun videos for their community. (I-START - YouTube)

Section III. Program Background

I-START has actively served individuals with IDD in their community since August 2015. The program began providing services in one region (County Social Services) with an average of about 80 individuals a year. In FY19, I-START expanded to several other regions including CROSS and Rolling Hills and that expansion continued into FY20 with the addition of East Central Region. I-START now supports individuals in counties throughout Iowa funded by CSS, Rolling Hills and ECR (Figure 1). Unfortunately, due to funding changes, individuals in CROSS no longer receive I-START services. Figure 2 represents the percentage of individuals from other Iowa regions who currently reside in County Social Services.

Iowa's mental health disability service regional structure created some challenges to the continuity of START services. Additionally, regional changes and mandates jeopardized funding and sustainability of the program. As such, County Social Services worked closely with Elevate CCBHC to explore options to sustain the I-START Program. As of July 1st, 2021, I-START merged under the operations of Elevate CCBHC. This transition will help align and prepare the I-START program for potential service expansion, improve continuity of service delivery, further strengthen the collaboration with the crisis mental health services Elevate already offers, and enhance opportunities for more sustainable funding mechanisms.

Figure III.A: Map of I-START Counties

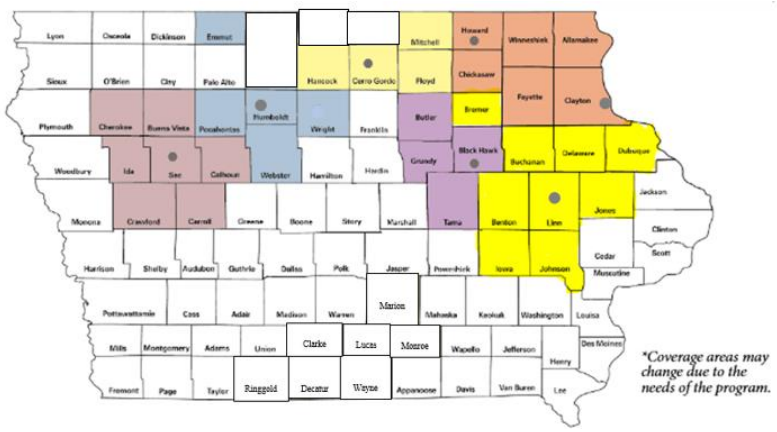
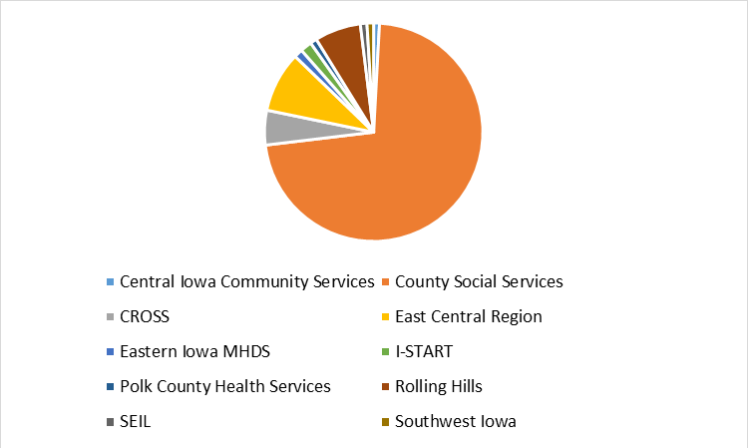


Figure III.B: Percent of Total I-START Population by Region (n=275)

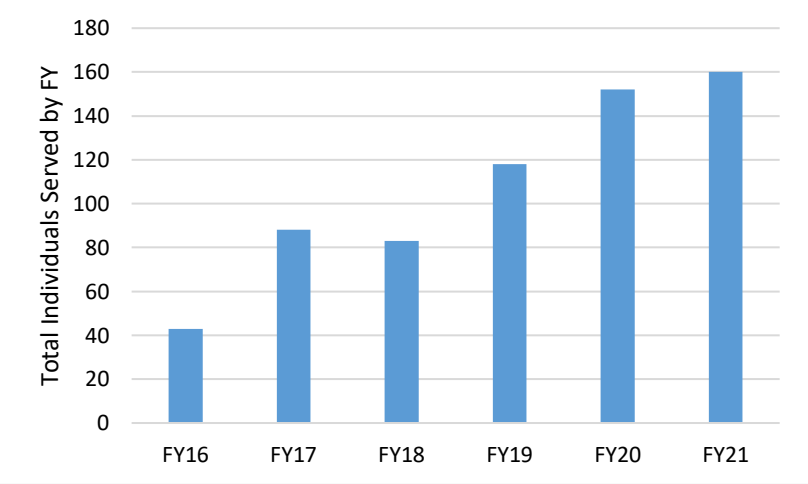


Section IV. I-START Enrollment Trends and Demographics

I-START Enrollment

I-START is a clinical START program serving primarily adults. Since program inception in August 2015, I-START has served 275 individuals with a current active enrollment population of 89. With regional expansion, I-START significantly increased program capacity, serving 160 individuals in FY21, the most of any year to date (Figure IV.A). While the census has grown, the average caseload per coordinator is 17.

Figure IV.A: Number of Individuals Served by I-START by Fiscal Year*

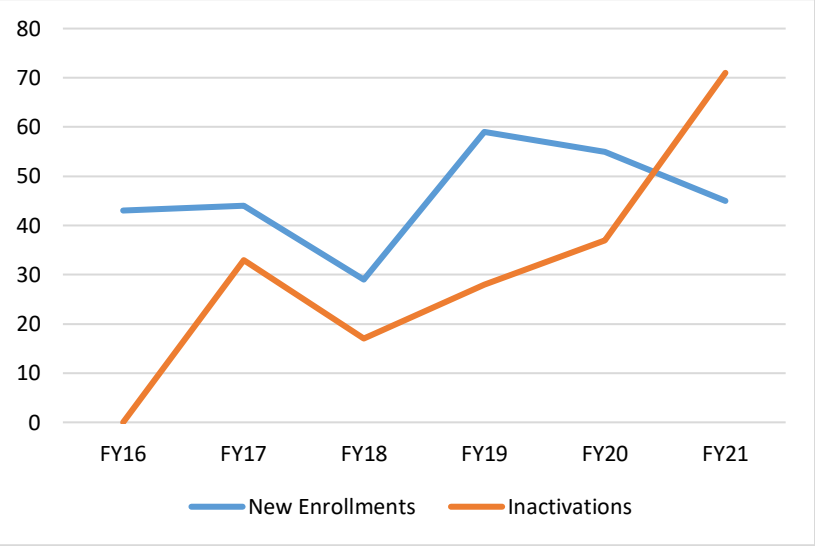


**Most Individuals have received services in multiple fiscal years.*

Table IV.A: I-START Census Summary FY21 (July 1, 2020-June 30, 2021)

I-START	FY21 (n=160)
Total Served during reporting period N (%)	**160**
FY21 New Enrollments	45
Individuals inactivated	**71**
Stable functioning	37 (52%)
Moved out of START region	22 (31%)
No longer requesting services	10 (14%)
Unable to contact	2 (3%)
Deceased	-
Active Caseload at the end of reporting period	**89**
Total Served by I-START since inception	**275**

Figure IV.B: New Enrollments and In-activations by FY



Summary

The overall I-START census increased slightly in FY21. In-activations outpaced new enrollments, but less than 20% of individuals were in-activated due to loss of engagement or loss of contact. I-START continues to have a high percentage of individual who move out of the region, but the new expansion efforts may help with this. The merger with Elevate will allow the I-START program more autonomy in assessing their ability to successfully support and individual who has moved outside of the service region. The average caseload size for FY21 was 17, which is below START fidelity expectations. However, the I-START program experienced some staff turnover throughout the year and is in the process of building caseloads for newer coordinators. Once the program is fully staff, I-START should increase their enrollment capacity to approximately 200 active individuals.

Figure IV.C: Source of Referral to I-START FY21 (n=45)

Table IV.B: Reasons for Enrollment since Program Inception (n=275)

Variable (N)	FY21 (n=45)	FY20 (n=55)	FY 19 (n=59)	FY18 (n=29)	FY17 (n=44)	FY16 (n=43)
Most Common Reasons for Enrollment (%)						
Aggression	87%	95%	76%	83%	82%	77%
Family Needs Assistance	22%	15%	25%	38%	34%	26%
Risk of losing placement	42%	36%	37%	38%	59%	58%
Decreased Daily Functioning	40%	36%	51%	45%	57%	23%
Dx and Treatment Planning	40%	40%	41%	41%	32%	21%
Mental Health Symptoms	53%	51%	59%	69%	61%	51%
Leaving Unexpectedly	18%	22%	19%	31%	32%	14%
Suicidality	24%	13%	15%	21%	18%	21%
Self-Injurious Behavior	36%	29%	37%	24%	36%	16%
Sexualized Behavior	31%	20%	15%	17%	18%	23%
Transition from Hospital	-	6%	14%	3%	20%	21%

Summary

I-START has a very diverse referral base with nearly half (47%) of referrals coming from someone other than case managers. While aggression remains the most common reason for referral, there are high percentages of individuals with other recognized needs at enrollment including mental health symptoms, diagnostic and treatment planning needs, and risk of placement loss. Current research suggests that overall mental health symptoms have increased during the COVID-19 pandemic compared to similar time periods pre-pandemic, so I-START will continue to work with referring providers to help identify mental health needs at enrolment. [4] In FY21, 19 individuals referred to I-

[4] Czeisler MÉ , Lane RI, Petrosky E, et al. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. MMWR Morb Mortal Wkly Rep 2020; 69:1049–1057. DOI: http://dx.doi.org/10.15585/mmwr.mm6932a1external icon

START were reportedly at risk for placement loss. Of those, 37% (n=7) experienced at least one placement change during the year, compared with about 25% of the I-START population overall in FY21. This is a trend that warrants additional review in the coming year to further explore predictors of residential instability of START service users in Iowa.

Demographics

This section provides demographic and diagnostic trend data for all persons served by I-START (n=739) during FY21.

Table IV.C Age, gender, race, level of ID, and living situation of START service users

I-START	**FY21**
Variable (N)	n=160
Mean Age (Range)	32 (14-65)
Median Age	30
Gender (% male)	62%
Race	
White/Caucasian	79%
African American	4%
Asian	1%
Other	3%
Unknown	2%
Ethnicity (% Hispanic)	-
Level of Intellectual Disability (%)	
No ID/Borderline	6%
Mild	54%
Moderate	27%
Severe-Profound	13%
None Noted in record	-
Living Situation (%)	
Family	16%
Foster/Alternative Family Living	3%
Group Home and Community ICF/DD	46%
Independent/Supervised	29%
Psych. Hospital/IDD Center	3%
Other (Jail, Homeless, "Other")	3%
Unreported	-

Summary

I-START has a significantly lower percentage of adults living in their family home. Nationally, 49% of adults in START live with family compared to about 16% in Iowa. This trend may correlate with the trend that those referred to I-START are likely to experience persistent mental health concerns and may also contribute to the higher percentage of individuals at risk of losing placement at enrollment.

Mental Health and Chronic Health Conditions

Table IV.D: Mental health conditions reported at intake

I-START	FY21
Variable (N)	n=160
Mental Health Conditions (%)	
At least 1 diagnosis	89%
Mean Diagnoses (range)	2.6 (1-7)
Most Common MH Conditions (%)	
Anxiety Disorders	25%
ADHD	36%
ASD	28%
Bipolar Disorders	21%
Depressive Disorders	30%
Disruptive Disorders	31%
OCD	9%
Personality Disorders	6%
Schizophrenia Spectrum Disorders	14%
Trauma/Stressor Disorders	16%

Table IV.E: Chronic medical conditions reported at intake

I-START	FY21
Variable (N)	n=160
Medical Diagnosis (%)	
At least 1 diagnosis	71%
Mean Diagnoses	2.3 (1-7)
Most Common Medical Conditions (%)	
Cardiovascular	14%
Endocrine	16%
Gastro/Intestinal	25%
Immunology/Allergy	7%
Musculoskeletal	6%
Neurologic	22%
Obesity	9%
Pulmonary disorders	9%
Sleep Disorder	12%

Figure IV.D: Frequency of most common mental health conditions for enrolled adults

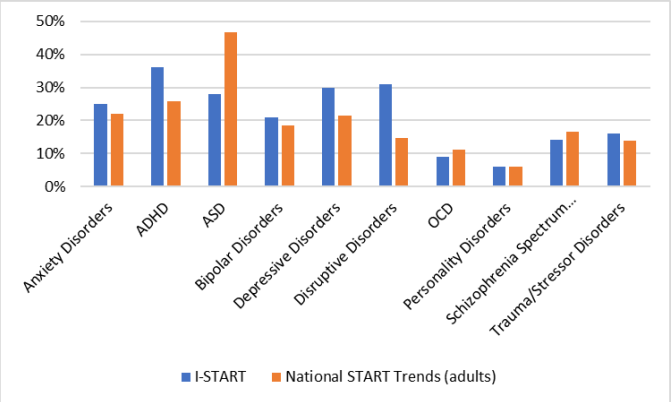
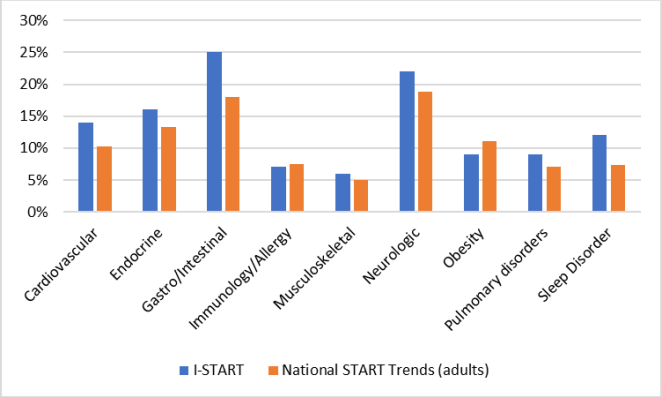


Figure IV.E: Frequency of most common medical conditions for enrolled adults



Summary

The frequency of trauma/stressor related disorders in I-START enrolled adults is slightly higher than START numbers nationally (14%). This suggests education and acknowledgement of the impact of trauma and other stressor related disorders across the system. These findings support the need to continue to support community education around trauma informed care.

Just over a quarter of I-START adults have a diagnosis of autism spectrum disorder compared with nearly half of adults in START nationally. The average age of I-START adults is 32 (median 30) compared with an average of 29 (median 27) nationally. The lower rate of ASD may also be related to living situation. I-START has a low percentage of adults living with family and nationally, nearly 60% of adults with ASD live with family.

The older age of I-START participants may also contribute to the very high rate of medical co-morbidities (71%). The continued work of I-START on identifying medical issues is a critical role of START teams, since, when not identified and treated, persons with IDD may experience challenges that are identified as related to the person's mental health when there may be other root causes for distress.

I-START embraces a wellness model that extends beyond just biological health and incorporates emotional, social, and spiritual fulfillment as a proactive strategy for improving overall health of enrolled individuals. This model extends to program staff- working to infuse a culture of wellness and self-care within the team. This has been especially important during the COVID-19 pandemic. Therefore, team meetings often include a time to work on personal coping techniques and emotional status so that fundamentals of PERMA and well-being are being modeled both within I-START and applied to the people and community systems supported by I-START.

Section V. I-START Program Outcomes

Primary outcomes of the START model are decreases in emergency service use and challenging mental health presentations, which secondarily improve quality of life and PERMA for enrollees, their families, and the system of support. START cross-systems crisis prevention and intervention planning along with 24-hour crisis response are designed to directly affect these outcomes.

Emergency Service Trends

A number of I-START service recipients have a history of emergency service use prior to enrollment. Figure V.A looks at emergency service trends for individuals one year prior to enrollment in START and emergency service utilization for individuals post START enrollment. A target goal of the START program is to help avoid unnecessary emergency service use and reduce recidivism. While results reflect consistent overall trends in the reduction of emergency service use post enrollment in I-START services, the overall rate of emergency room utilization remains quite high and I-START leadership should continue to work with both providers and first responders on plans to divert individuals from the emergency department whenever clincally appropriate. The reduction in emergency service use suggests that the START commitment to principles of positive psychology and wellness in addition to maintaining fidelity to START service elements such as comprehensive assessment and evaluation, cross-systems crisis planning, outreach, and emergency response can be effective in improving the outcomes for individuals enrolled in services.

In addition to planned START clinical services, the I-START team provides 24-hour crisis support to enrolled individuals and their families/caregivers. I-START responded to nearly 350 calls in FY21. Since nearly all crisis contacts occurred during COVID-19 restrictions, the majority (97%) were conducted using phone and telehealth technology. About 82% of those contacts resulted in individuals remaining in their current setting (75%) or being treated and released from the emergency department (7%). Only a small number (4%) had a psychiatric admission

following a crisis contact, and about 10% utilized non-START crisis stabilization beds as an alternative to more intensive treatment options.

Table V.A: Change in frequency of pre- and post-START emergency service utilization

I-START	**FY21 (n=160)**	
Variable	Psychiatric Hospitalization	Emergency Department Visits
Prior to enrollment, N (%)	**48 (30%)**	**64 (40%)**
Mean Admissions (range)	2.5 (1-10)	3.8 (1-20)
During START, N (%)	**36 (25%)**	**57 (36%)**
Mean (range)	3.2 (1-21)	3.9 (1-24)
Average length of stay (hospital)	12 days	N/A

Figure V.A: Change in frequency of pre- and post- START enrollment emergency service utilization

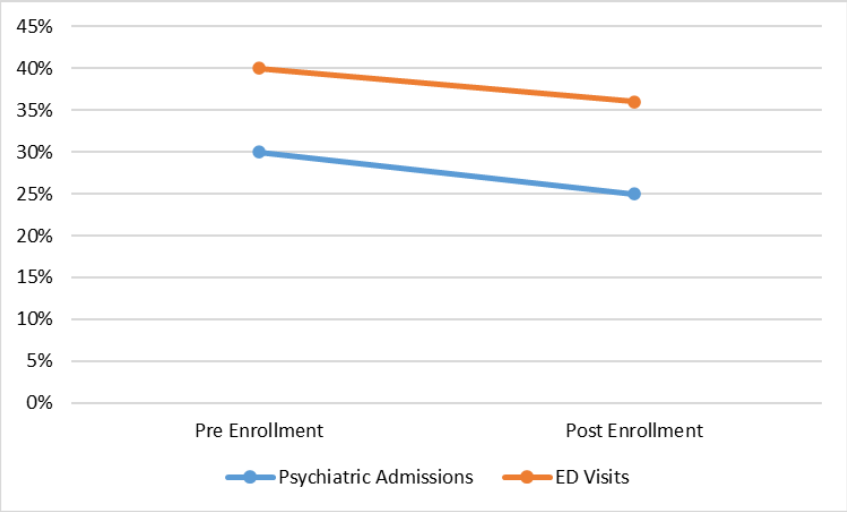
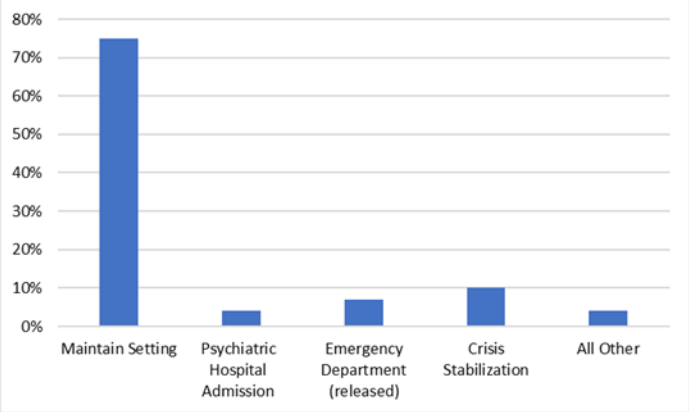


Table V.B: I-START crisis response FY21

I-START	FY21
Crisis Contacts	
Number of Individuals with a contact	44
Number of Crisis Contacts	348
Range of Contacts	(1-67)
Frequency of calls with each type of Intervention N (%)	
In-Person	3 (1%)
Phone Consultation	299 (86%)
Virtual response	41 (12%)
Average Length of In-Person Intervention	2 hours
Crisis Disposition for each crisis contact N (%)	
Maintain Setting	262 (75%)
Psychiatric Hospital Admission	15 (4%)
Emergency Department (released)	23 (7%)
Emergency Department (held)	4 (1%)
ED (disposition not specified)	6 (2%)
Medical Hospital Admission	-
Jail/Incarceration	1 (-)
Crisis Stabilization	34 (10%)
Unreported	3 (1%)

Figure V.B: Disposition of START crisis contacts



Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item informant reported psychopathology rating tool designed specifically for use with individuals with IDD (Aman, Burrow, & Wolford, 1997). It is administered to enrollees at intake and 6-month intervals. The ABC has been reported in literature as an *outcome measure*, demonstrating sensitivity to changes in psychopathology ratings over time. The ABC is used by START teams to determine if services provided are associated with reduced psychopathology ratings over 6-month periods. The authors suggest the use of ABC subscales, not a total scale score. Through factor analysis, three of these subscales have been found to be sensitive to START treatment effects: *Irritability*, *Hyperactivity* and *Lethargy*. These subscales are reported below for I-START enrollees.

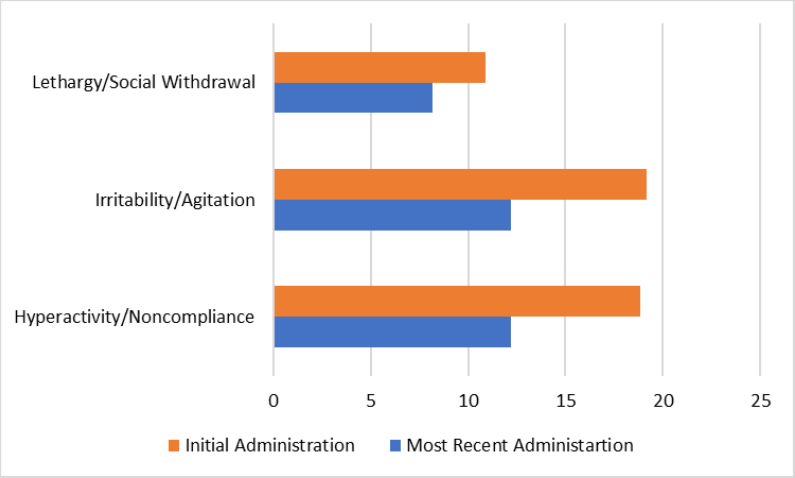
For this analysis, individuals enrolled in START for at least 6 months with at least two ABCs were included. Table V.C shows the percentage of individuals in I-START who had a decrease in scores (improvement in symptoms) between initial assessment at intake and the most recent ABC assessment completed (avg. of 29 months later). A t-test analysis was conducted and for all three subscales the decrease in mean scores between initial and most recent ABC was statistically significant.

Table V.C: ABC Analysis

		Mean Score			
(n=132) Average elapsed time: 23 months	**Percent with Improvement**	**Initial**	**Most Recent**	**t Stat**	**P(T<=t) one-tail**
Hyperactivity/Noncompliance	71%	18.86	12.18	6.24	0.00
Irritability/Agitation	77%	19.15	12.21	6.59	0.00
Lethargy/Social Withdrawal	61%	10.89	8.20	2.55	0.01

Alpha=0.05

Figure V.C: Change in mean ABC scores between first and most recent administrations



Summary

Research of ABC scores for individuals receiving START services indicates that the lethargy and irritability subscales are strong predictors of emergency service use[5]. I-START data for the three main subscales used to assess intervention effectiveness show a significant decrease in the psychopathology ratings following initiation of START services. This is consistent with results in previous years and is another indication that I-START continued to work effectively with START enrollees during COVID.

I-START consistently demonstrate success in the three outcome measures shown in this section (decreased emergency service utilization, maintaining environment following a crisis and decreased ABC scores). The team will continue to work with individuals not just in decreasing crisis events, but also in improving PERMA and well-being. Next year's report will include data on coordinator spotted strengths of enrolled individuals, residential stability following enrollment in I-START, and caregiver stress as measured by the START plan.

[5] Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalization among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research*, *60*(12), 1153-1164.

Section VI. Planned START Services

This section provides a descriptive analysis of I-START planned services for FY21, including Clinical Education Team Meetings (CETs) held, community outreach and training, and clinical services.

I-START Clinical Education Teams and Community Trainings

The I-START program continued to conduct virtual CETs and community trainings throughout the fiscal year. I-START CETs are very well attended and reached more than 450 professionals statewide. The attendance rates ranged from 31 to 59 participants and the average attendance was 41. Table VI.A provides a list of CET topics offered over the last year.

Table VI. A: I-START Community Education Team Meetings (CETs)

Training Topic
ADHD
Anxiety
Compassion Fatigue
Nonverbal Communication
PERMA
Polypharmacy
Reactive Attachment Disorder
Suicide in The IDD Population
Suspected Brain Injury
Urinary Tract Infections and Mental Health
Verbal De-escalation

In addition to CETs, I-START provides regular training to a variety of partners including emergency services, residential and day providers, mental health providers and educators. Table VI.B provides the total training episodes and training hours offered by the I-START program. More details about the type of training offered to community partners, as well as linkage agreements can be found in the Appendix B.

Table VI. B: I-START Community Training Events and Hours

	I-START
Total Community Outreach/Training Episodes (N)	103
Total Hours of Community Outreach/Training	122 hours

I-START Clinical Services

START model service interventions aim to ensure that individuals are getting the supports they need and are designed to intervene effectively in times of stress and crisis, avoiding costly and restrictive emergency services. All START programs offer the following planned services. Time spent on these activities is tracked in SIRS.

- *Intake/Assessment:* Work done to determine the needs of the individual, the team, and the services to be provided. This includes: Information/record gathering; intake meetings; completion of assessment tools; and START Action Plan development.

- *Outreach*: Any time a START Coordinator provides education or outreach to the system of support (families/natural supports, residential programs, day programs, schools, mental health facilities), or any entity that may seek or need additional outreach and education.
- *Clinical Consultation*: Consultations provided by the Clinical Director with community team members who support individuals. Recommendations are given and facilitation of goal and action plan development is done by the START Coordinator.
- *Medical Consultation:* Consultation provided by the Medical Director about diagnostic, medical, or polypharmacy issues. Services can include collaboration with the individual's team prior to a psychiatric appointment, accompanying the team to the appointment, medication history review by the START team, and outreach provided by the Medical Director to the treating provider.
- *Cross System Crisis Prevention and Intervention Planning (CSCPIP)*: Collecting and reviewing relevant information; brainstorming with the system of support; developing/writing, distributing, reviewing/revising the CSCPIP; training and implementation.
- *Crisis Follow-Up*: Time spent following up to coordinate services and supports after a crisis.
- *Facilitation of Planned Therapeutic Supports (Resource Center, Therapeutic Coaching)*: Coordination, preparation for, and/or facilitation of planned center admission or therapeutic coaching.
- *Comprehensive Service Evaluation (CSE)*: Receiving and reviewing records; interviewing the individual and system of support; writing the CSE; collaborating with START Clinical and Medical Directors on development of evaluation and recommendations; reviewing recommendations with person's system of support and developing an action plan.

The I-START program began providing telehealth services in response to COVID-19 and statewide social distancing requirements. Telehealth services began in March 2020 and continued throughout the year. Additional fields in SIRS were added to track telehealth outreach, therapeutic coaching visits, and crisis follow-up. The percent of individuals who received telehealth services is in the table below. Table VI.C shows the percent of individuals enrolled who received planned START services during the report period. Since individuals are enrolled at different points in time and have unique strengths and needs, not all enrollees received each planned service in the reporting period. However, there are certain expected benchmarks that all START programs should be meeting in order to assure fidelity.

Table VI.C: Provision of Planned START Clinical Services: In-person and Telehealth

I-START	Planned Clinical Support	Telehealth Supports
N	160	160
Utilization of Planned Services (% of Individuals)		
Outreach	99%	96%
Intake/Assessment	98%	80%
CSCPIP	86%	47%
Clinical Consultation	93%	
Medical Consultation	54%	
Crisis Follow-Up	39%	31%

START Tools and Assessments

All individuals enrolled in START services participate in an initial Intake/Assessment process in which the START team gathers important historical and biopsychosocial information about the individual and his/her system of support. This process informs the next step, which is the development of a START Action Plan, outlining specific services and resources that the START Program will provide. Assessment tools used during the initial intake process, including the Aberrant Behavior Checklist (ABC), Recent Stressors Questionnaire (RSQ), and START Action Plan are re-administered or updated on a regular basis as long as the individual is enrolled and actively receiving START Services.

Table VI.D: Percentage of active individuals who received assessments/tools: Completed and up to date at conclusion of FY

START Tools	Tool was completed (active)	Current and up to date (active)
START Action Plan	98%	80%
Aberrant Behavior Checklist (ABC)	98%	89%
Recent Stressors Questionnaire (RSQ)	98%	N/A
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	97%	93%
Comprehensive Service Evaluations CSEs Completed	16%	N/A

Section VII: Conclusion and Recommendations

The I-START program continue to meet clinical team fidelity requirements and operates as a certified clinical program. The following are START model recommendations for the I-START program for fiscal year 2022. The team will work directly with Center for START Services project managers to develop plans to address these recommendations.

Recommendations

- I-START leadership should develop a plan for maximizing new enrollments in the coming fiscal year. They should target active caseloads of 25-30 individuals per full-time START coordinator.
- I-START program should continue to document all residential transitions in SIRS to help determine if enrollment in START can impact placement loss over time.
- Program leadership should continue to review monthly SIRS reports carefully to ensure that program fidelity is maintained. Team leaders are also encouraged to utilize built-in program reports from SIRS to track progress and address any concerns promptly.
- Closely monitor all occurrences of individuals enrolled in START who are made inactive due to disengagement, in order to inform new approaches to engaging referral sources, families, and individuals who can potentially benefit from START services.
- The I-START team should continue to monitor length of stay and assure that services provided are comprehensive, effective, and timely. It is recommended that that all cases that are active for 2 or more years be assessed and staffed with Center for START Services and program staff.
- Primary outreach and educational efforts should continue on the importance of identifying the bio/psycho/social needs of all individuals supported by I-START. The I-START program should continue to offer training on accurate diagnostic case formulations and the recognition of anxiety, trauma related issues, and medical comorbidities in individuals with IDD to a broader audience of community partners.

- The I-START program should continue to educate and encourage caregivers on the value of utilizing the START crisis line prior to calling law enforcement or going to the emergency room whenever clinically appropriate. When contacted first, I-START is often able to support individuals in avoiding higher levels of care and improved education around the use of the crisis line may further decrease emergency department utilization and police involvement with enrolled individuals.
- In addition to the current linkage agreements, I-START leadership has identified over 30 additional community partners with whom they wish to pursue linkages in the coming year.

Appendix A: Center for START Services Training, Technical Assistance, and Consultation

Center for START Services Training Groups

Many START methods are unique to the model and incorporate best practices, START tools, and strategies to implement them. To develop proficiency, program staff participate in comprehensive training on these methods along with didactic training on the mental health aspects of intellectual and developmental disabilities. Training provided by the Center for START Services is targeted to the NC START programs along with the community as a whole.

START Coordinator Training

START Coordinators and leadership staff complete a training course through CSS's online learning platform, Moodlerooms, with the goal of achieving START Coordinator Certification. Participation in the course requires enrollment in a 19-week Coordinator Training Group facilitated by CSS instructors. A combination of asynchronous training and web-based group dialogue is used. For office hours connected to the course, the participant identifies topics based on areas for their own professional growth. Frequent topics for office hour sessions include crisis planning, emergency response and evaluation, outreach, case conceptualization, and systemic consultation strategies.

Additional Center for START Services Training and Consultation

In addition to technical assistance and training provided directly to I-START program staff, there are other ongoing training offerings sponsored by the Center for START Services that are available to NY START and their partners.

START National Online Training Series

The START National Online Training Series (NOTS) on Mental Health and IDD is designed to provide innovative and topic-focused training to professionals that serve individuals who experience IDD and mental health needs. Pre-recorded trainings from this series are released once a month to the START Network (on the 3rd Friday of each month) from September through April. The 2020-2021 series also featured a live, virtual 1-hour Q&A session with that month's presenter facilitated by CSS instructors. The series is free for the I-START programs and their partners. A comprehensive Review Guide is also provided for each presentation that can be utilized to independently facilitate small-group discussions between community partners about the material and its application to daily practice. Attendees can receive one contact hour/0.1 UNH CEU for viewing the pre-recorded presentation and completing the online evaluation. Topics offered between 7/1/2020-6/30/2021 were:

- **September 2020:** *START Therapeutic Coaching Strategies for Supporting Individuals with IDD and Suicidal Ideation,* NC START Central: Maggie Robbins, MA, LCAT, RDT, Clinical Director, Meredith Dangel, MA, CRC, Intern & Remy Jodrey, MS, LCMHCA, Therapeutic Coaching Team Leader
- **October 2020:** *Skills System: Strategies for Self- and Co-Regulation*, Julie Brown, Ph.D., President of the Skills System, LLC
- **November 2020:** *Collaborative Research in IDD and MH with a PCORI Project Update: Reconciling the Past and Changing the Future,* Jessica Kramer, Destiny Watkins, and Micah Peace (Part 1), and Jessica Kramer, Destiny Watkins, Micah Peace, Dr. Joan Beasley, Tawara Goode, Beth Grosso, and Fiorella Calle Guerrero (Part 2)
- **January 2021:** *Sexuality & IDD-MH*, Dave Hingsburger, M.Ed., Director of Clinical and Educational Supports for Vita Community Living Services
- **February 2021:** *Lost in Translation: Lessons about moving research in developmental disabilities into practice and policy*
  Yona Lunsky, PhD, Director of the Azrieli Adult Neurodevelopmental Centre and Professor in the Department of Psychiatry at the University of Toronto
- **March 2021:** *"Something's Different" –Concepts of Change in Adults with I/DD*, Julie A Moran, DO, Geriatrician/Internist, Clinical lecturer of Medicine, Harvard Medical School

- **April 2021:** *Aligning our Practices with our Beliefs: (Re) Engaging with Families in the Context of Trauma, Kelly Smith, LCSW*

2020 Virtual START National Training Institute

In light of the COVID-19 pandemic, the Center for START Services hosted a Virtual START National Training Institute (SNTI) from May 4-May 6, 2020, at no cost to participants, as an alternative to its typical in-person annual event. This three-day event featured two keynote presentations with accompanying Q&A sessions, a research panel presentation, the premiere of the new START documentary film ("*Now We Have Hope: The Strength of the START Community*") with a panel discussion, research poster sessions, and an awards ceremony. The virtual SNTI was an enormous success with over 400 participants.

START Practice Groups

Practice groups are national communities within the START Network organized around START team roles, professional disciplines, and specific topics of interest. They are designed to facilitate active learning communities where members connect with others from across the country in similar roles and remain informed about best practices regarding both START implementation and MH/IDD topics. Each group is facilitated by CSS clinical staff and occasionally features invited speakers and special guests.

As part of the National START Network and learning community, I-START personnel participates in these forums to gain the knowledge and skills needed to improve system capacity. The goal of these groups is to ensure that all START teams have the latest knowledge and technical support to provide evidence-based services. Practice groups meet once monthly (or bi-monthly in the case of Medical Directors). The practice groups include:

- Children's Practice Group, facilitated by Karen Weigle, Ph.D.
- Clinical Directors Practice Group, facilitated by Jill Hinton, Ph.D.
- Clinical Topics Practice Group facilitated by Karen Weigle, Ph.D.
- Resource Center Directors Practice Group, facilitated by Bob Scholz, M.S., LMHC
- Therapeutic Coaching Practice Group, facilitated by Anne Laforce, MA
- Medical Directors Practice Group, facilitated by Karen Weigle, Ph.D. and Jennifer McLaren, M.D.
- Team Leaders Practice Group, facilitated by David O'Neal, MS, and Alyce Benson, LCSW
- Program Director Practice Group, facilitated by Andrea Caoili, LCSW, Alyce Benson, LCSW, and Jillaine Baker, LCSW
- Certified START Program Director Practice Group, facilitated by Jillaine Baker, LCSW

Appendix B: I-START Training Topics and Linkage Agreements

Table 1: I-START Training Topics

Training Topic
ADHD in the IDD Population
Angelman Syndrome
Anxiety
Anxiety Disorder
ASD
Autism and Anxiety: Imagine the Possibilities
Autism theory of mind & self-stimming
Autism:
Building and Maintaining Relationships in the IDD population
Caregiver Fatigue
Depressive Disorder vs Medical Vulnerabilities
Developmental Disability and the Criminal Justice System
Dissociative Identify Disorder
FASD
Gut Health and Brain Connection
IDD and Mental Health:
Intellectual and Developmental Disability
Intermittent Explosive Disorder
Major Depressive Disorder
Major Depressive Disorder w/psychosis
Mosaic: Preventing and De-escalating Conflict (power struggles)
Nonverbal Communication
Post Traumatic Growth
Schizoaffective Disorder and Intellectual Disability
Sexuality video from NTS and live discussion to follow
Trauma and IDD
Trauma And Stressor Related Disorders
Trauma Training
Trauma/RAD
Understanding IDD
Verbal De-Escalation
Waterloo PD: Law Enforcement Training

Table 2: I-START Linkage Agreements

Name of Organization	Type of Service Provider
Black Hawk Grundy Mental Health	IHH Care Coordination
Prairie View	Residential Provider
Unity Point Health; Allen Hospital	Emergency Department
University of Iowa; Hospital	MI/ID
Unity Point Health; Allen	Psychiatry
Comprehensive Systems Inc	ICF ID & Residential Provider
Goodwill Services	Residential Provider
Prairie Ridge IHH	IHH Care Coordination
Mason City Community Health Center	MH Center
Amerigroup	ID Case Management (MCO)
Iowa Specialty Hospitals and Clinics (clarion)	Emergency Department
Hills and Dales	Residential Provider
B & D Services	Residential Provider
Iowa Total Care (Centine)	ID Case Management (MCO)
Christian Opportunity Center	Residential Provider
Pillar of Cedar Valley	ICF/ID
Discovery Living	Residential Provider
Mosaic	Residential Provider
Optimae (Waterloo)	Residential Provider
Four Oaks	IHH Care Coordination
Systems Unlimited	Residential Provider
Money Follows the Person	HCBS LTSS (transitional ICF)
Community Neuro Restorative CNR	BI Specialty Residential
43 North Iowa	Employment
Opportunity Center	Training Space/Community Resource
Brain Injury Alliance	Specialist
WESCO Industries	Residential Provider
One Vision	Residential Provider
REM: Mason City	Residential Provider
Invigorating Services	Residential Provider
County Social Services: Service Coord	County Case Management
Mosaic: Host Home Program	Residential Provider
Mosaic: ICF	Residential Provider
Elevate	Mobile Crisis Response
Elevate	Crisis Observation Unit
Season Center for Behavioral Health	Mobile Crisis Response
Inspiring Lives	HCBS Residential
Inspiring Lives	RCF
Mosaic: HCBS	HCBS Residential
Berry Hills	Mobile Crisis Response
North Iowa Regional Services	Crisis Stabilization Center + Subacute