Iowa START (I-START)

July 2019 – June 2020

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

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I-START Program
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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 behavioral 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 2020 (FY20), 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:

- FY20 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

Program Background and Census Trends

I-START has been actively serving 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. CSS has made a commitment to serving clinically eligible I-START recipients and their community providers regardless of their region of origin.

Figure 1: Map of I-START Counties

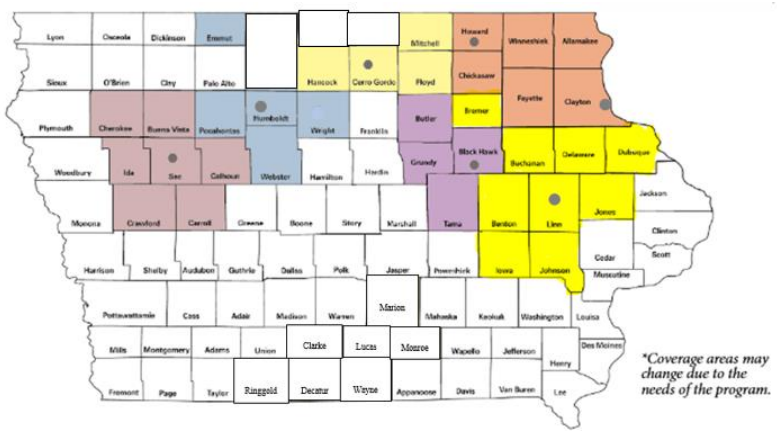
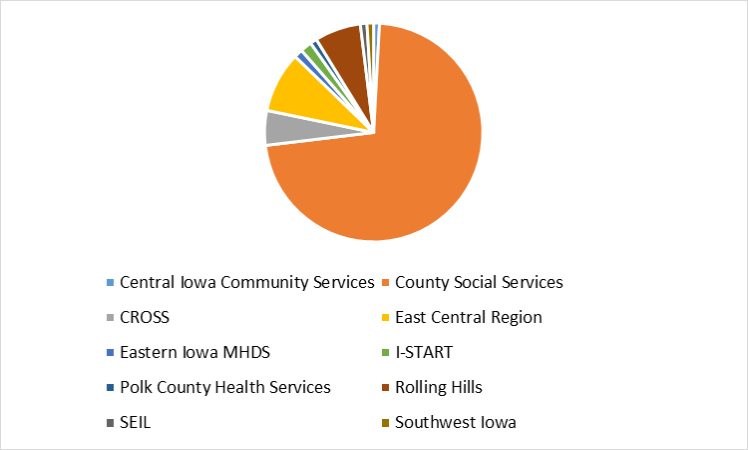


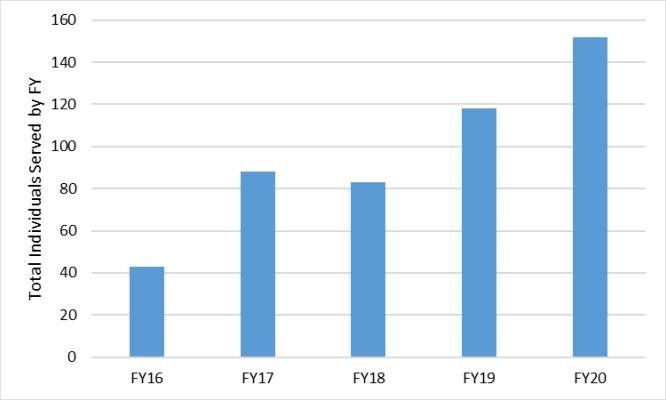
Figure 2: Percent of Total I-START Population by Region (n=230)



I-START is a clinical START program serving primarily adults. Since program inception in August 2015, I-START has served 230 individuals with a current active enrollment population of 114. With regional expansion, I-START significantly increased program capacity, serving 152 individuals in FY20, the most of any year to date (Figure 3). While the census has grown, the average caseload per coordinator is 13. It is the plan that caseloads can increase to at least 20-25 per coordinator and an active census of 150-175.

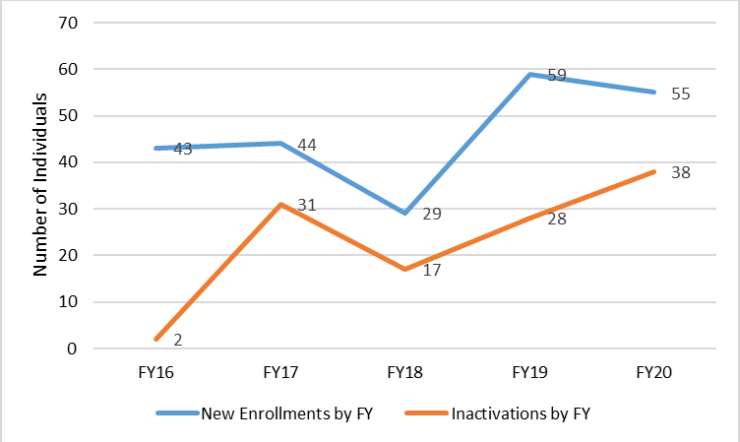
While individuals are not discharged from I-START, they are inactivated once they reach a period of stability or because their situation has otherwise changed (ex: they leave the state). To date, I-START has inactivated116 individuals. The average length of stay (LOS) in I-START is 14 months. For individuals who achieved stable functioning and inactivated in FY20, the average LOS was 25 months. Figure 3 shows the number of new enrollments and inactivations by FY.

Figure 3: Number of Individuals Served by I-START by Fiscal Year*



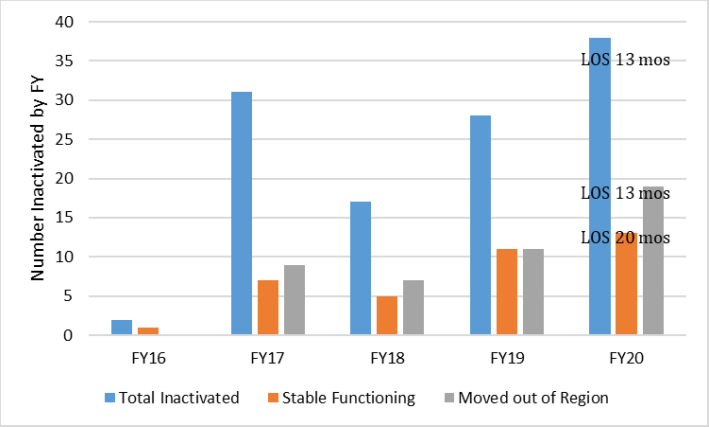
**Most Individuals have received services in multiple fiscal years.*

Figure 4: New Enrollment/Inactivation Trends by FY (FY16-FY20)



Very few individuals are inactivated from I-START services due to a lack of engagement (loss of contact, no longer requesting services). In FY20, 13 individuals were inactivated due to a prolonged period of stable functioning. 19 additional individuals were inactivated when they either moved from an I-START county or when their region no longer had I-START funding available (n=7). These individuals' average length of stay was 13 months, which is less than those inactivated for achieving stability, indicating that they would continue to benefit from START services upon their relocation if START was available in their location.

Figure 5: Number of Individuals Inactivated by I-START by Fiscal Year (n=116)



COVID-19 Response and Case Vignette

It is still largely unknown how the COVID-19 pandemic will affect people with IDD-MH and their families. However, a May 2020 American Psychological Association (APA) article suggests that individuals with IDD will likely experience

crisis related incidents and exacerbation of current mental health symptoms, secondary to uncertainty and fear associated with COVID-19, and the disruption of in-person services and supports[1]. The I-START population is at high risk of dysregulating episodes associated with the pandemic. Without maintaining appropriate supports for this vulnerable group, they are at risk for increased mental health crises, that impact their safety, the safety of their families, and the human and financial costs to the broader community.

During the COVID-19 shutdown, virtual supports were rapidly and strategically implemented. By collaborating with programs across the nation, I-START began providing plain language information and training about COVID-19, virtual outreach, clinical services and crisis response. . Virtual services began in March 2020 and were in place the entire last quarter of FY 20. Preliminary findings by CSS in this quarter show that 95% of the active I-START population that had received services prior to the pandemic were participating in virtual START services initiated after the onset of COVID-19. Ongoing evaluation of I-START outcomes in response to COVID-19 will occur into FY21.

During just the first month of the crisis (March 15-April 15, 2020), I-START continued to accept referrals, enrolling seven additional people in that first month and 14 since the crisis began.

Below is an example of COVID response for an enrolled individual during this crisis. Additional information on COVID supports in the final quarter of FY20 are embedded within the findings presented in this report.

Vignette (*name was changed to protect anonymity)

Joe is a 30-year-old male diagnosed with Generalized Anxiety Disorder, OCD, Major Depressive Disorder, Severe Intellectual Disability, Prader Willi-Syndrome and a variety of medical conditions. He was initially referred to I-START because of physical and verbal aggression and was at risk for losing placement. However, prior to the COVID-19 pandemic, Joe had a period of stability and his team was planning for START inactivation. He often shared how much he loved his life and was building a thriving business. Joe's team regularly voiced their confidence in supporting him. They had a thorough understanding of his biopsychosocial vulnerabilities as was demonstrated by their use of the CSCPIP and proactive work to ensure elements of PERMA were present in his daily life.

Given the major life stressors the COVID-19 pandemic created for Joe and his system of support, I-START recommended inactivation be delayed and planned with the team to proactively address challenges the pandemic would inevitably bring, especially given the inevitable disruption in Joe's active role in his community. I-START supported the system through this challenging time to ensure continued stability. .

Initially, Joe became increasingly anxious about the pandemic and associated restrictions and COVID-19 was the focus of most of his conversations. When grocery shopping, he would talk to store patrons asking them about COVID-19 and social distancing. Much of the conversations Joe's support staff had with him also revolved around COVID restrictions, increasing his concern and creating a strain in their relationship.

Weekly virtual team meetings were scheduled as well as bi-weekly virtual outreach with Joe and his staff to assess Joe's stability and assist with implement new interventions to reduce stress. I-START provided Joe's system with educational information such as an information sheet with 'need to know' information. The information sheet used words and pictures and allowed for facilitated conversations about fears and ways to address them. The team used this as a teaching tool for Joe as well as a visual aid to facilitate consistent messaging amongst staff to Joe. Additionally, the team, led by Joe, worked together to create a variety of activities to stay busy. Activities promoted socially distant engagement with friends and family and positive activities for his physical and mental health. I-START collaborated with his residential agency to help train staff on ways to help Joe engage in activities and understand the benefit on his mental health and wellbeing. This was especially important due to his history of generalized anxiety and major depression. The shift in focus from what Joe could not do to what he was able to do helped everyone get through a very difficult time and maintain the important gains Joe made toward achieving PERMA.

[1] American Psychological Association. (2020). How COVID-19 Impacts People with Disabilities. Retrieved from https://www.apa.org/topics/covid-19/research-disabilities.

One challenge that really affected Joe was his exposure to COVID-19 and subsequent need for testing. While the test results were in process, he had to quarantine, which is an identified stressor for Joe. He also had to relocate several times due to seasonal flooding in his community. These two incidents increased Joe's anxiety and depression and resulted in him reaching out to START through email stating that he had thoughts of harming himself. When the email was read the following day, an emergency meeting and assessment was scheduled. The Recent Stressors Questionnaire, which is completed as part of all emergency assessments helped to clearly identify the compounding stressors Joe was experiencing and create an environment for team problem solving. A plan was developed which included building on previously identified activities that decrease stress for Joe. Regular engagement, virtual outreach and telehealth medical and mental health care were facilitated. Because of the proactive planning that occurred at the onset of the pandemic, the team could support Joe in again achieving stability. While the pandemic continues, Joe and his team feel equipped to address day to day issues as they arise and supported by I-START along the way.

Recommendations from Fiscal Year 2019 Annual Report/Progress

Summary of FY 2019 Recommendations:

As part of regular practice, I-START evaluates quarterly and annual data in collaboration with the Center for START Services. Following the FY19 annual report, the program sought input from stakeholders and developed an action plan to address recommendations in the report. Since that time, I-START has actively worked toward achieving identified goals and action steps.

Areas of strength and accomplishment:

The I-START team's biggest accomplishment during FY20 is the attainment of National START Clinical Team Program Certification. Despite the COVID-19 pandemic, a program certification review was completed virtually in June 2020 with positive results. A combination of data evaluation, document review and interview (staff and community stakeholders) practices were completed by a panel of CSS expert certification reviewers; and the program met all START model fidelity requirements. I-START staff demonstrated their commitment to the START model and the individuals they support in a very difficult time.

There were several other positives that occurred throughout the fiscal year that set the stage for attaining for program certification. I-START continued its regional expansion in FY20 and served more individuals in FY20 than in any previous year. More expansion plans are in process in the coming reporting period and it is anticipated that the number of individuals enrolled and served by I-START will continue to grow.

All I-START work is done within the context of START values including cultural and linguistic competency, trauma informed care and a biopsychosocial approach. I-START team members have attended a CSS facilitated training completed Tawara Goode, the director of the National Center for Cultural Competence at Georgetown University. I-START staff work to better understand the multiple cultural identities of persons with IDD, their families and provider teams and this better allows the team to identify strengths, build rapport and influence treatment outcomes.

A major improvement for the I-START program was in the area of primary services. This year, I-START doubled formal linkage agreements with system partners and provided training to over 900 community members on a wide variety of topics, many providing specific content tailored to the audience's unique needs. I-START regularly evaluates community training and uses feedback to inform future content. With the onset of COVID-19 restrictions in the third quarter, the I-START team continued to provide community training and CETs virtually.

The team conducted numerous trainings throughout the year with a focus on the impact of medical conditions on mental health, and a holistic approach to addressing vulnerabilities so that individuals with IDD can feel their best. The addition of a new Clinical Director in FY20 has increased expertise in trauma and therapeutic best practices, facilitating further learning and growth within the team and among community partners. Completion of START assessments and the provision of planned services met minimum fidelity requirements for certified programs at the conclusion of the fiscal year and I-START has high rates of CSE completion.

Another meaningful accomplishment this year was I-START's ability to maintain and enhance START services during the challenging and evolving landscape of COVID-19. With 'stay at home' orders in place, START coordinators creatively arranged for alternative communication and virtual support options allowing for a seamless transition to virtual supports. The team also worked with community partners to learn to utilize virtual technology for coordination of services.

In addition to their success as a team, an I-START coordinator was awarded the National START Coordinator of the year award at the 2020 SNTI, which further demonstrates this team's commitment and success in providing START services. Congratulations to the team on their many other accomplishments.

Still in progress:

Much was accomplished during the fiscal year and there continues to be some areas of focus for the program moving forward. The program should continue efforts to stabilize staff turnover and increasing caseload sizes to 20-25 per coordinator. I-START should work closely with stakeholders to seek additional avenues for continuing START services to those individuals who move between regions. It is also necessary that the program stay up to date on all SIRS revisions and develop a process for immediate implementation. This will eliminate the need to fix data issues at later times. More specific practice recommendations are provided throughout the remainder of the report.

Findings

The following sections provides an analysis of enrollment, demographic and service outcome data for the Iowa START (I-START) program for Fiscal Year 2020 (July 1, 2019- June 30, 2020).

All descriptions of enrollment trends, characteristics of persons served, emergency service trends, and service outcomes of those served by I-START are based on data entered into the START Information Reporting System (SIRS) by program staff.

Section I: Fiscal Year 2020 Program Enrollment

Data below reflect all individuals served by I-START during this report period (July 1, 2019-June 30, 2020).

Table 1.A: FY20 Census Summary

I-START	FY20 (n=152)
Total Served during reporting period N (%)	**152**
FY20 New Enrollments	55
Individuals inactivated	**38**
Stable functioning	13 (34%)
Moved out of START region/region lost funding	19 (50%)
No longer requesting services	2 (5%)
Unable to contact	2 (5%)
Deceased	2 (5%)
Active Caseload at the end of reporting period	**114**
Total Served by I-START since inception	**230**

Figure 1.A: Number of Individuals Enrolled by FY20 Quarter (n=55)

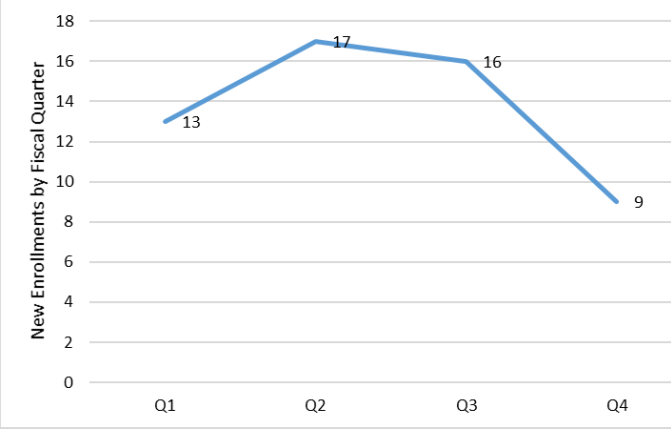


Figure I.B: Source of Referral since Inception (n=230)

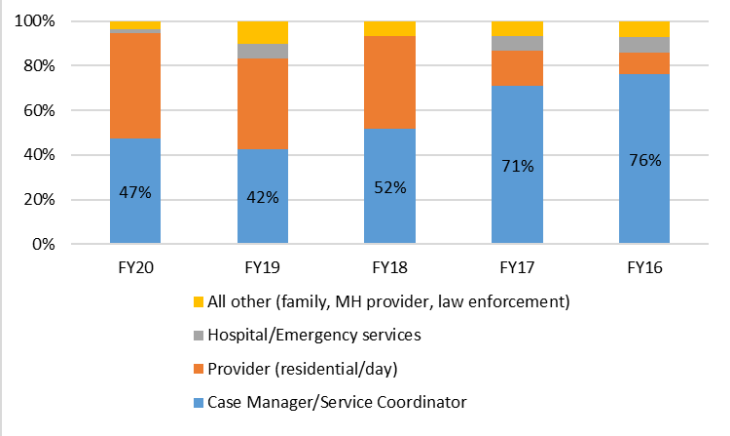
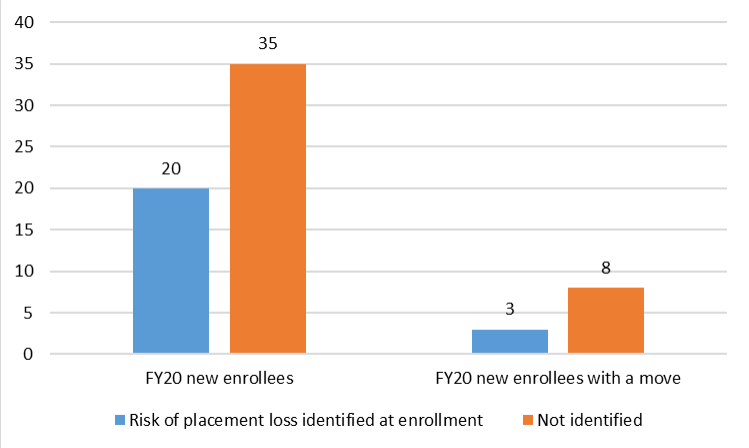


Table I.B: Reasons for Enrollment since Program Inception (n=230)

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

In FY20, I-START began tracking placement changes for individuals enrolled in START using new criteria in the SIRS database. Relative to other START programs, a higher percentage of I-START service users live in paid settings (group home, supported living) and more were at risk for placement loss at enrollment. Of the 55 new enrollees in the FY, 36% (n=20) were identified at enrollment as at risk for placement loss and of these individuals had a subsequent move within the FY. Two enrollees moved due to reported issues related to mental/behavioral health needs and one enrollee moved as a result of provider change unrelated to the individual. Of those individuals not identified as at risk for placement loss at enrollment, eight had moves- four related to mental/behavioral health needs, 3 family/individual preference and one a provider change unrelated to the individual.

Figure 1.C: Placement Loss for FY20 New Enrollees (n=55)



Summary

- I-START served 152 individuals during FY20, an increase of 28 individuals from the previous year. Expansion to additional regions continued in FY20, with nine different regions making referrals to I-START.
- As seen in Figure 1.A, new enrollments in the fourth quarter dipped by nearly half from the previous quarter, likely due to restrictions caused by the COVID-19 crisis. I-START delayed planned inactivations in the 4th

quarter to continue proactive and crisis supports to individuals during COVID-19. Only one individual was inactivated due to stability in the 4th quarter.

- In FY20, I-START inactivated 38 individuals. As seen in Table 1.A, a third (34%) were inactivated due to prolonged stability. Inactivations for moving out of a START region or loss of regional funding accounted for half of all inactivations. While this may be largely beyond the control of I-START, it is concerning due to the much lower lengths of stay for those individuals compared to those inactivated due to stability. This suggests that most of these individuals are likely leaving START prior to reaching stability.
- Enrollment trends for I-START have remained quite consistent for the last three years. The majority of referrals are received from case managers and residential providers. Most individuals were referred for multiple reasons including mental health symptoms, family in need of assistance and needing diagnostic clarification and treatment planning. Approximately 36% of adults enrolled in FY20 were identified as at risk for placement loss at enrollment. This is about 64% higher than adults in other START programs nationally (22% in FY20).

Recommendations

- As COVID-19 restrictions allow, I-START leadership should develop a plan for maximizing new enrollments in the coming fiscal year. They should target active caseloads of 20-25 individuals per full-time START coordinator with a goal of increasing the active caseload to at least 150. However, the I-START geography is rural and requires extensive travel during
- It is recommended that I-START do a review of cases being inactivated for moving to look for specific trends that might be contributing to this pattern. If there are trends towards a particular region, further expansion in those areas might be explored.
- I-START should consider an analysis of individuals who move due to mental/behavioral health concerns and work to determine if specific START supports might be helpful in mitigating the risk of a residential transition.

Section II: Characteristics of Persons Served

Demographics

Section II of this report provides demographic and diagnostic trend data for all individuals served by I-START (n=152) during FY20 (July 1, 2019-June 30, 2020).

Table II.A: Age, gender, race, level of ID, and living situation for I-START enrollees

I-START	FY20
Variable (N)	n=152
Mean Age (Range)	33 (18-64)
Gender (% male)	58%
Race	
White/Caucasian	82%
African American	3%
Asian	-
Other	1%
Unknown	14%
Ethnicity (% Hispanic)	2%
Level of Intellectual Disability (%)	
No ID/Borderline	11%
Mild	53%
Moderate	20%
Severe-Profound	8%
None Noted in record	9%
Living Situation (%)	
Family	32%
Foster/Alternative Family Living	16%
Group Home and Community ICF/DD	13%
Independent/Supervised	19%
Psych. Hospital/IDD Center	7%
Other (Jail, Homeless, "Other")	1%
Unreported	12%

Summary

- I-START has uncategorized (unknown or not noted) data for race, ethnicity, level of ID and living situation. The lack of clear data makes it difficult to see meaningful trends or complete closer evaluation to see if demographic elements contribute to other factors such as moves, disengagement, hospital/ED use or police involvement.
- I-START has a significantly lower percentage of adults living in their family home. Nationally, 49% of adults live with family compared to about a third of adults 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.

Recommendations

- I-START should review their active caseload and update all uncategorized demographic elements as soon as possible. Documentation of complete demographics should be a priority for all new enrollments in FY21.
- Research has demonstrated that important social, emotional and economic benefits result from keeping families together. The I-START program should work with regional agencies to identify individuals who

might benefit from START prior to an out-of-home placement. Earlier access to outreach and support to family caregivers including therapeutic supports could increase family capacity to continue supporting individuals at home and mitigate some risk of out-of-home placement.

Mental Health and Chronic Health Conditions

Table II.B: NH START enrollees with mental health conditions reported at intake

I-START	FY20
Variable (N)	n=152
Mental Health Conditions (%)	
At least 1 diagnosis	86%
Mean Diagnoses (range)	2.4 (1-7)
Most Common MH Conditions (%)	
Anxiety Disorders	24%
ADHD	32%
ASD	22%
Bipolar Disorders	15%
Depressive Disorders	30%
Disruptive Disorders	26%
OCD	7%
Personality Disorders	4%
Schizophrenia Spectrum Disorders	18%
Trauma/Stressor Disorders	11%

Figure II.A: Frequency of most common mental health conditions for enrolled adults (trends across START)

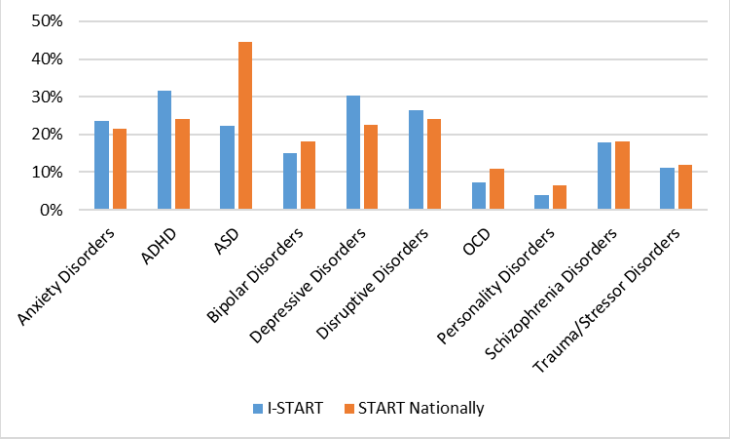
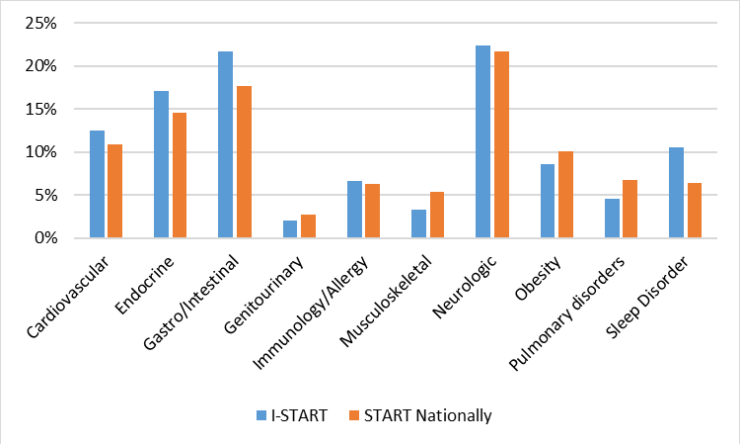


Table II.C: Chronic medical conditions reported at intake

I-START	FY20
Variable (N)	n=152
Medical Diagnosis (%)	
At least 1 diagnosis	68%
Mean Diagnoses	2.1 (1-7)
Most Common Medical Conditions (%)	
Cardiovascular	13%
Endocrine	17%
Gastro/Intestinal	22%
Genitourinary	2%
Immunology/Allergy	7%
Musculoskeletal	3%
Neurologic	22%
Obesity	9%
Pulmonary disorders	5%
Sleep Disorder	11%

Figure II.B: Frequency of most common medical conditions for enrolled adults (trends across START)



Summary

- For both mental health and chronic medical conditions, I-START closely reflects trends across adults in START nationally. One exception is in the identification of Autism Spectrum Disorder (ASD), which is 50% lower in I-START than in START programs nationally. Despite the lower rates, ASD still impacts nearly a quarter of the I-START population and the team conducts quarterly community trainings on various aspects of ASD.

- In response to a recommendation from last year, the I-START team conducted a CET on GI issues including GERD and acid reflux. The program is committed to an integrated and holistic approach to support that includes recognition and support around medical conditions.

Recommendations

- When analyzing trends for living situation changes, it might be beneficial to consider the diagnostic formulation as an additional variable to determine whether certain biopsychosocial vulnerabilities

predispose I-START service recipients to be at risk of losing placement. If trends are identified, then targeted training, outreach and supports can be designed.

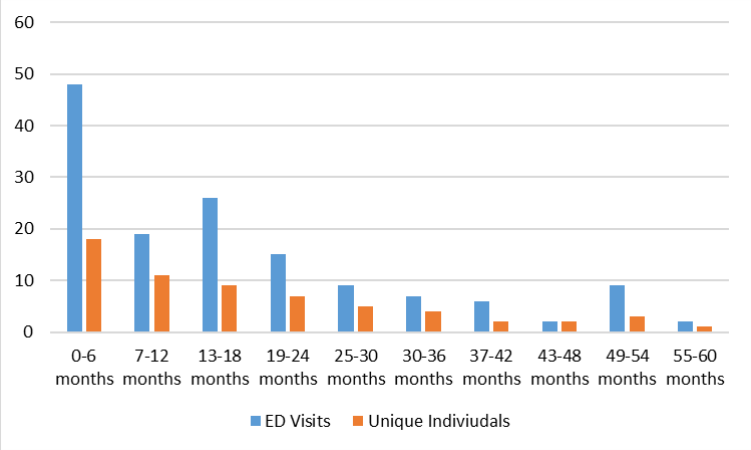
Section III: Emergency Service Trends

Table III.A: Emergency Service utilization

I-START	FY20 (n=152)	
Variable	Psychiatric Hospitalization	Emergency Department Visits
Prior to enrollment, N (%)	**34 (22%)**	**44 (29%)**
Mean Admissions (range)	1.7 (1-4)	2.9 (1-20)
During START, N (%)	**36 (24%)**	**45 (30%)**
Mean (range)	3.1 (1-15)	4.0 (1-20)
Average length of stay (hospital)	21 days	N/A

The percentage of individuals who utilized emergency services both pre and post I-START enrollment stayed relatively constant when compared to previous reporting periods. Pre-START utilization is the number of individuals utilizing the service in the year prior to enrollment. Post START utilization is the cumulative utilization of emergency services while the person is enrolled in START. Figure III.B below shows that for the 45 individuals active in FY20 who utilized the emergency department post enrollment, the majority of those visits happened in the first 6 months of enrollment. As length of stay in START increases, both the number of enrollees visiting the ED and the frequency of visits per person decreases sharply.

Table III.B: Emergency Department trends over enrollment



Summary

- An analysis of the data shows that in the last year only 25 (16%) enrolled individuals had an emergency department visit, and only 15 of these individuals had a visit after 6 months of enrollment. The data for psychiatric admissions follow a similar trend with only 21 (14%) individuals experiencing an admission in the FY20, and 11 experiencing an admission after 6 months of enrollment. These data suggest that while

individuals continue to have similar rates of emergency service utilization early on in START, there is a sharp decline after the first 6 months.

- Of the 25 individuals who utilized the emergency department in FY20, only 15 (60%) of them also utilized the I-START crisis line. This suggests that some individuals are going to the emergency department without first contacting I-START and thus eliminating the possibility for crisis intervention that might prevent the need for emergency service use.

Recommendations

- Continue to provide outreach and other planned interventions, to reduce emergency services use, while adding to the capacity of community partners to provide more proactive care in ways that promote physical and mental wellness for all individuals with IDD in the I-START network.
- I-START team members should ensure that caregivers have knowledge and education around I-START crisis intervention supports and are encouraged to use them first whenever it is safe and clinically appropriate to do so.
- All individuals with multiple emergency service utilization should be reviewed by the clinical director. A CSE should be considered if clinically appropriate.

Section IV: START Clinical Services

Based on a tertiary care approach to crisis intervention, START service measures fall into three crisis intervention modalities:

Primary (improved system capacity): Clinical Education Teams (CETs), system linkage, and community training

Secondary (specialized direct services to people at risk of needing emergency services): Intake and assessment activities, Comprehensive Service Evaluations (CSE), outreach, clinical and medical consultation, and cross systems crisis prevention and intervention planning (CSCPIP)

Tertiary (emergency intervention services): Emergency assessments and crisis response as well as other emergency services such as hospitalizations and emergency room visits used by START recipients

This section looks at utilization patterns in each of these services**.** The goal of START is to support the system in moving from tertiary care (emergency level of crisis intervention services) to primary intervention (able to assist when vulnerable) and secondary services (getting expert assistance without the use of emergency department utilization or psychiatric hospitalization). This is achieved by building capacity across the service system in order to prevent and assist with potential problems rather than manage them as crises later.

Primary Services

Building system capacity to support individuals in their homes and communities.

The following is a summary of the primary service activities reported by the I-START team during FY20. Primary START services include system linkages, clinical education and community training. These services are part of the plan to improve the capacity of the system as a whole so that the community system is effective and sustainable over time. Over the last year, the I-START team has engaged the community to provide training and education around the unique needs of individuals with IDD and co-occurring MH conditions and continues to engage the system to become active participants in the START learning community. The START team also provides education and referral/linkage as needed to individuals who are not eligible for START services.

Table IV.A: Community training activities

I-START	FY20
Number of Activities (N)	
Community linkage/affiliation	33
Community-based training	32
Host Advisory Council Meeting	5
Provided Training (N)	
Day provider	1
Emergency services	-
Family	1
Other	4
Physician/medical personnel	-
Residential provider	8
School	-
State facilities (state hospitals, developmental centers)	-
Therapist/mental health providers	1
Total Community Outreach/Training Episodes (N)	85
Total Community Outreach Hours	233
Total Linkage/Collaboration Agreements Completed (N)	30
Total Clinical Education Teams in FY20 (N)	10

In addition to the above reported specific training and linkage activities, a number of more informal outreach efforts were made. These included providing community partners with information about START and issues pertaining to the population served. While these activities are not detailed above, they are included in the total number of hours spent. More information about these activities can be obtained from the I-START Program Director.

The following is a list of some of the training provided to the community as part of the primary services provided by the region during FY20.

Table IV.B: Community training topics

Training Date	Training Topic	Number in Attendance
06.23.20	Active Listening and Strength Spotting	15
05.18.20	I-START Training (virtual) Benton County Coalition of Providers	16
05.04.20	Caregiver Fatigue (virtual)	Unknown
04.30.20	FASD	30
04.29.20	Biological and Developmental Age	Unknown
03.30.20	CSCPIP Training (virtual)	5
03.12.20	CSCPIP Training	5
02.19.20	Compassion Fatigue and Burnout; Goodwill	21
02.13.20	CSCPIP Training/ vulnerabilities explained (ADHD/Anxiety/ executive functioning)	23
02.14.20	CSCPIP Training	1
02.10.20	I-START Training: Hills and Dales	19
02.07.20	I-START Training: Discovery Living	16
02.04.20	CSCPIP Training	4
02.04.20	I-START Training: Linn County Community Services (Regional Social Workers)	12

01.30.20	CSCPIP Training	6
01.28.20	ASD and its Correlation with Communication Deficits	20
01.23.20	I-START Training: Options of Linn County	8
01.22.20	I-START Training: Linn County Community Services (supervisors)	17
01.20.20	I-START Training; Systems Unlimited	10
01.17.20	SNTS: Supporting purpose and meaning in the lives of Individuals with MH/IDD	25
01.08.20	Mental Health: A General Overview : Friends of the family	21
01.02.20	I-START Training; ECR Admin	11
12.12.19	START Overview, FASD, PERMA, Case Presentation	60
12.19.19	I-START Training; One Vision Autism Center	4
11.19.19	I-START training; RHD	8
11.18.19	Prader Willi Tips and Tricks training-general	6
11.13.19	I-START training; IHH Waterloo	18
11.4.19	Myotonic Muscular Dystrophy	9
10.18.19	SNTS: START Research 2019 SNITI poster winners	Unknown
10.14.19	CSCPIP training	7
10.09.19	I-START Training for One Vision	29
10.07.19	I-START Training for Prairie View	7
09.20.19	SNTS: Grief and Bereavement in individuals with IDD	Unknown
09.17.19	Prader Willi and General Training for NC	7
08.14.19	CET: Agoraphobia	unknown
07.15.19	Prader Willi and General Training	8
07.13.19	Understanding the effects of Trauma	19
07.11.19	Understanding IDD and Mental Illness	105
07.10.19	CET: Pharmacogenomics	17

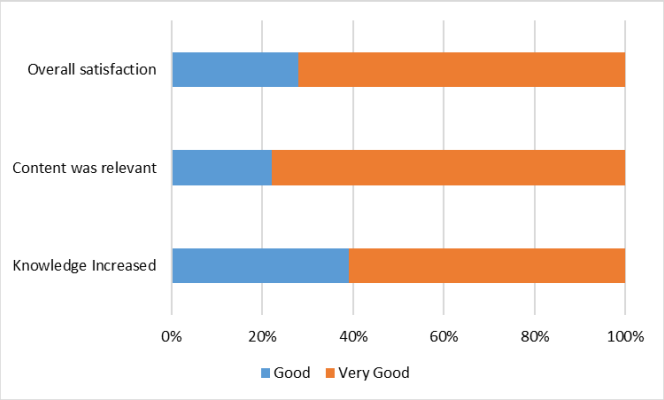
Table IV. C: Clinical Education Teams in FY20

Date	Training Topic
06.10.20	Major Depressive Disorder
05.13.20	Acid Reflux, GERD, Hiatal Hernia (virtual)
03.11.20	Autism Spectrum Disorder
02.12.20	Biopsychosocial Model
01.08.20	Trauma
12.11.19	FASD
10.09.19	PERMA Model
09.11.19	Autism Spectrum Disorder
08.14.19	Agoraphobia
07.10.19	Pharmacogenomics

The I-START team regularly evaluates the training they provide. Surveys address overall satisfaction, relevance of topic and improvement of knowledge (figure IV.A) as well as format and handout effectiveness. Program leadership is able to use feedback to guide changes for future training and offer suggestions to presenters. Figure IV.A shows the response for a training conducted in February 2020 on Compassion Fatigue and Burnout. The response was very

positive with all participants rating their satisfaction as either very good or good. Complete data from these and other training evaluations are available from the I-START program.

Figure IV.A: Training Evaluation: Compassion Fatigue and Burnout (n=18)



National START Practice Groups

As part of the START model and the national START Professional Learning Community, I-START personnel participate regularly in national practice groups with other professionals. These forums are opportunities to gain 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 in all areas of service provision. These study groups include:

- Clinical Directors Study Group, facilitated by Jill Hinton, Ph.D.
- Children's Services Study Group facilitated by Karen Weigle, Ph.D.
- Resource Center Directors Study Group, facilitated by Bob Scholz, M.S., LMHC
- Medical Directors Study Group, facilitated by Karen Weigle, Ph.D. and Laurie Charlot, Ph.D.
- Team Leaders Study Group, facilitated by David O'Neal, MS, and Alyce Benson, LCSW
- National Program Director forums held quarterly facilitated by Andrea Caoili, LCSW and Alyce Benson, LCSW
- National START Online Training Series, offered by the Center for START Services to START programs
- The START National Training Institute chaired by Joan B. Beasley, Ph.D., Director of the Center for START Services

Summary

- The I-START team continues to expand the number of linkage agreements in place with community partners. The program has 30 formal agreements in place, more than double than in FY19, as well as an additional 17 informal agreements. I-START has strengthened relationships with area agencies and providers as evidenced by the diverse training audience in the last year, and START team members consult regularly with stakeholders to enhance outcomes for individuals supported.

- In FY20, I-START staff provided over 200 hours of community training and outreach, including 10 CETS. With the onset of the COVID-19 pandemic, I-START began offering some virtual training, including one on caregiver fatigue. Training provided by I-START focus on START values such as PERMA, trauma-informed care and the biopsychosocial approach. In total over 900 participants attended community training provided by the I-START tam in FY20.

- Stakeholder evaluation of training has highlighted the success of efforts of I-START in their community. Stakeholders report high satisfaction with training and regularly suggest additional topics of interest. Primary services provided by I-START pursued simultaneously with secondary services allow the system to move out of crisis and create an empowered system of care.

- The I-START Program Director is also a member of the newly formed National START Emergency Management Committee (EMC). The EMC was developed at the onset of COVID-19 to develop resources, training and materials for START program staff, community partners, families and persons with IDD. The EMC has since evolved to address all major national and regional crises.

Recommendations

- I-START should continue to evaluate CETs and other community trainings to guide future training offerings.
- The I-START program should strategically target specific audiences for trainings. One demographic trend that requires attention is the risk of placement change at the time of enrollment and subsequent residential moves for enrollees. Perhaps trainings targeted toward residential providers would be beneficial. Formal training has also not been recorded for emergency responders.

Secondary Services

Specialized direct services to people at risk of emergency service use

Secondary services ensure that individuals are getting the supports they need to intervene effectively in times of stress and avoid costly and restrictive emergency services.

All START programs offer the following planned, secondary services and time spent on these activities is tracked in SIRS.

- *Intake/Assessment:* Work done to determine the needs of the individual and their team, and the services to be provided. Includes: Information/record gathering; intake meeting; completion of assessment tools; and START action plan development.
- *Outreach*: Any time in which the START Coordinator provides education or outreach to the system of support including 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 made for facilitation of goals and the START Coordinator does action plan development.
- *Medical Consultation:* Consultation provided medical director (facilitated by START Coordinator) regarding 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 START team, and outreach provided by medical director to the treating provider.
- *Cross System Crisis Planning*: Completion of the Cross-Systems Crisis Prevention and Intervention Plan: collecting and reviewing relevant information; brainstorming; developing/writing, distributing, reviewing/revising the plan; training on and implementing with the system of support.
- *Crisis Follow-Up*: Includes any crisis stabilization or emergency support that will be given by the START clinical team. This can include face-to-face emergency assessments, crisis check-ins from the on-call coordinator or assigned coordinator, follow-up to crisis events, etc.
- *Facilitation of Planned Therapeutic Supports (Resource Center, Therapeutic Coaching)*: Work/coordination related to preparing for and facilitating planned center based or in-home supports.
- *Comprehensive Service Evaluation (CSE)*: Completion of the Comprehensive Service Evaluation including receiving and reviewing records; interviewing the individual and system of support; writing the CSE; and reviewing recommendations through development of an action plan.

In mid-March, all START programs began offering virtual supports to continue to provide services to individuals enrolled in START during the COVID-19 restrictions.

- *Virtual Outreach*: Outreach provided to an enrolled individual and/or their support system provided through virtual communication (e.g. FaceTime, Zoom, WebEx, and Skype). Virtual outreach may be used with permission when face-to-face contact is not recommended or possible.
- *Therapeutic Coaching virtual visit:* TC services provided to an individual through virtual communication (e.g. FaceTime, Zoom, WebEx, and Skype). Virtual contact may be used with permission when face-to-face is not recommended or possible. Visits should focus on strength spotting, observation, and wellness focused goals that promote PERMA for the person and caregiver. The coach should gain a greater understanding of biopsychosocial risk and protective factors, environmental needs and offer coaching on basic strategies that can be applied across all environments.
- *Virtual Crisis Follow-up*: Any time spent following-up with the individual or his/her team after a crisis provided through virtual communication (e.g. FaceTime, Zoom, WebEx, and Skype). Virtual follow-up may be used with permission when face-to-face contact is not recommended or possible. This category is for work done following a crisis incident recorded as a service outcome.

Table IV.C shows the percent of individuals enrolled in the region who received planned START services during the year. Since each individual enrolled in START is at a different stage of case activity and has unique strengths and needs, not all individuals received all planned services throughout the reporting period. However, there are certain expected benchmarks that all START programs should be meeting in order to assure fidelity.

The I-START Program began providing virtual START services to enrollees in response to the COVID-19 pandemic and associated social distancing requirements that went into effect across many communities. Virtual services began in the last quarter of the fiscal year and therefore did not significantly impact planned or emergent service provision for the program. As illustrated by Table IV.C, the majority (95%) of individuals active in the 4th quarter (n=104) continued to receive virtual START services.

Table IV.C: Provision of Planned START Clinical (Coordination) Services

I-START	FY20	Virtual Supports (March – June 2020)
N	152	104
Utilization of Planned Services (% of Individuals)		
Outreach	99%	95%
Intake/Assessment	97%	27%
CSCPIP	89%	
Clinical Consultation	97%	
Medical Consultation	57%	
Crisis Follow-Up	40%	12%

START Intake and Assessment

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 IV.D: Percentage of active individuals who received assessments/tools

START Tools	Tool was completed (active)	Current and up-to-date (active)
START Action Plan	99%	95%
Aberrant Behavior Checklist (ABC)	98%	95%
Recent Stressors Questionnaire (RSQ)	98%	N/A
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	100%	99%
Comprehensive Service Evaluations CSEs Completed	15%	N/A

Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC) is a 58-item informant report, psychopathology rating tool designed specifically for use with individuals with IDD. (Aman, Burrow, & Wolford, 1997). The ABC is administered to START service recipients at intake and again at 6-month intervals. For this analysis, only individuals enrolled in START services for least 6 months of START service with at least two ABC scores were included (n=116). The average time between the two administrations used in this analysis was 20 months.

The ABC is reported in the literature as an *outcome measure*, having demonstrated sensitivity to detecting changes in psychopathology ratings over time. The ABC is used here to determine if use of START services is associated with reduced psychopathology ratings over a 6-month or greater period of time. When using the ABC, the authors suggest use of the subscales, and not a total scale score. Subscales were identified via a factor analytic process, and three of these have been reported in the literature as sensitive to treatment effects, including the *Irritability*, *Hyperactivity* and *Lethargy* scales so these are reported below for individuals who received I-START services in FY20.

For individuals in the I-START program receiving services with at least two administrations in SIRS (n=116), results show that average scores decreased as shown in Table IV.E.

Table IV.E: ABC Analysis

	Percent of individuals with Improvement	Mean Score Initial Administration	Mean Score Most Recent Administration	t Stat	P(T<=t) one- tail
Hyperactivity/Noncompliance	62%	17.92	13.18	4.41	<0.00
Irritability/Agitation	65%	18.60	13.83	4.19	<0.00
Lethargy/Social Withdrawal	50%	9.47	8.32	1.25	NS

Alpha=0.05

Summary

- Coordination services: Provision of START secondary services are within expected guidelines and the program was able to achieve program certification this FY.
- With the advent of the COVID-19 crisis in the last quarter of the FY, I-START quickly transitioned to virtual outreach and therapeutic coaching and maintained contact with 95% of enrolled individuals and caregivers since the crisis began and with over 50% in just the last two weeks of March.
- START tools: The documentation of START tools meets fidelity standards for a START program. The I-START team has been able to continue completing assessments and Plans according to new COVID-19 protocols.

- ABC: I-START enrollees demonstrated reduced measures of psychopathology as evidenced by ABC subscale scores. This is consistent with data from all other START programs.

Recommendations

- The I-START team should continue to update all START tools in compliance with COVID-19 protocols and continue with their internal process for SIRS data tracking and documentation timeline compliance.

Tertiary Services

Emergency interventions provided during a crisis

START tertiary services include the time spent responding to crises, facilitating necessary emergency supports, and transitioning individuals to facilities providing lower levels of care.

Crisis Contacts

A crisis contact is an emergency call received by the START team that requires immediate triage and response, likely resulting in an emergency assessment. Assessment can be conducted in a number of settings including: family home, residential setting, day program, hospital emergency department, etc. In some cases, the on-call coordinator may provide consultation to family or caregivers over the phone or may speak with the individual to help restore calm and avert the need for higher levels of intervention such as Mobile Crisis Management services or an ER visit.

Table IV.F: FY20 Crisis Contacts

I-START	**FY20**
Crisis Contacts	
Number of Individuals with a contact	42
Number of Crisis Contacts	295
Range of Contacts	(1-80)
Frequency of calls with each type of Intervention N (%)	
In-Person	37 (13%)
Phone Consultation	255 (86%)
Virtual response	3 (1%)
Average Length of In-Person Intervention	2.5 hours
Crisis Disposition for each crisis contact N (%)	
Maintain Setting	243 (82%)
Psychiatric Hospital Admission	13 (4%)
Emergency Department (released)	15 (5%)
Emergency Department (held)	6 (2%)
ED (disposition not specified)	3 (1%)
Medical Hospital Admission	3 (1%)
Jail/Incarceration	1 (1%)
Crisis Stabilization	8 (3%)
Unreported	3 (1%)

Figure IV.A: Acute Crisis Contact Trends per FY

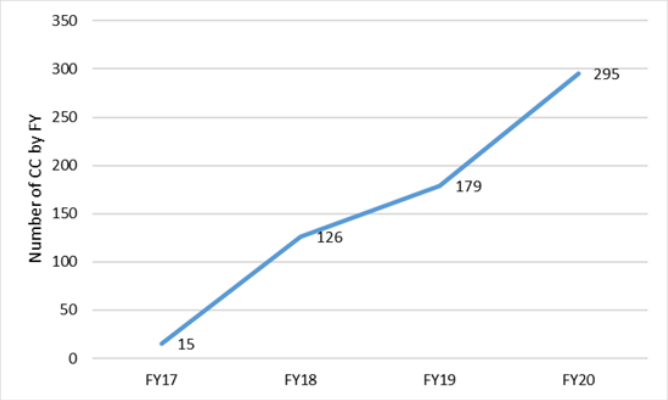
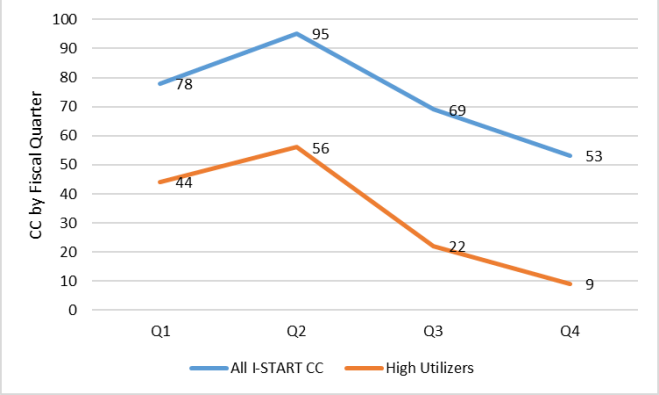


Figure IV.B: Acute Crisis Contact by Fiscal Quarter (FY20)



Summary

- In FY20, the number of crisis responses provided by I-START increased dramatically (up 116 from FY19). However, 131 of the contacts (44%) were for just two individuals. A review of these data suggests that in the majority of calls, crisis support was needed, and the calls represent actual crisis intervention, not 'warm-line' support. As seen in Figure IV.B, the number of crisis contacts for these two individuals decreased in the second half of the year, suggesting an increase in stability and reduced crises over time.

- The number of in-person crisis contacts for the I-START program is much lower than START program expectations (75% in-person). For the first three quarters of FY20 (pre COVID-19), only 16% of all crisis responses were in person. Subtracting the contacts for both highest utilizers (86% of which were phone), the percentage increases to 28%, which is still below START standards for in-person response.

Recommendations

- A CSE has not been completed in either of the two cases where frequent I-START crisis response was provided. While the number of crisis contacts decreases over time, a CSE or another for clinical review (such as a CET or medical director consult) might be helpful in further stabilization and reduced need for crisis support.

- I-START should conduct a review all cases with 10 or more crisis contacts and determine if additional planned services should be implemented to reduce the frequency of emergency contacts. A CSE or CET should also be considered in these circumstances.

- I-START leadership should continue to improve their in-person response rates whenever possible. With the expansion of the I-START programs, leadership should explore having multiple coordinators on-call covering different areas of the region. This might allow for faster response in the wide geographic area covered by I-START.

Conclusions and Recommendations for Fiscal Year 2021

Conclusion

The I-START program has continued to positively affect individuals served and their systems of support throughout the year, culminating in the achievement of National START Clinical Team Certification. Over the course of FY20, they supported over 150 individuals from several regions throughout Iowa and continued program expansion is anticipated. I-START should actively work with funding partners to ensure continuity of care for individuals enrolled in I-START who move between regions.

With high numbers of individuals living in paid support settings and at risk for placement loss, I-START is well positioned to become a leader in developing strategies to mitigate risks of and enhance factors that strengthen placement instability. The team is actively tracking residential changes and should consider additional evaluation in this area. The program continues to support individuals with a history of trauma and anxiety through regular training in the community and effective trauma informed supports. They also offer numerous training opportunities on medical conditions affecting enrolled individuals to help ensure that those individuals have pro-active strategies to encourage self-care and a healthy lifestyle.

The program as a whole consistently achieves fidelity standards, completing all START assessments and tools within expected timeframes. As a team, they continue to partner with community stakeholders to provide timely and effective crisis response despite the vast geographic area that I-START covers. Other positive developments during the past year include a more active advisory council, expansion of community trainings, and additional linkage agreements. I-START certified three coordinators in FY20 and one of their coordinators received National START Coordinator of the Year at the FY20 START National Training institute. The program demonstrated flexibility and leadership as they shifted focus and adapted to the COVID-19 crisis in late FY20. They continue to offer virtual outreach, crisis response, and virtual CETs.

As the program has expanded, they have continued to consistently apply the values and approaches of START. Three I-START coordinators achieved coordinator certification in FY20 and one coordinator was recognized as National START Coordinator of the Year at the annual SNTI. The I-START program consistently demonstrates fidelity to the START model as well as strong demonstration of START principles. We look forward to their continued success.

Recommendations for Fiscal Year 2021

Program Enrollment

- As COVID-19 restrictions allow, I-START leadership should develop a plan for maximizing new enrollments in the coming fiscal year. They should target active caseloads of 20-25 individuals per full-time START coordinator with a goal of increasing the active caseload to at least 150. However, the I-START geography is rural and requires extensive travel during
- It is recommended that I-START do a review of cases being inactivated for moving to look for specific trends that might be contributing to this pattern. If there are trends towards a particular region, further expansion in those areas might be explored.
- I-START should consider an analysis of individuals who move due to mental/behavioral health concerns and work to determine if specific START supports might be helpful in mitigating the risk of a residential transition.

Characteristics of Persons Served

Demographics

- I-START should review their active caseload and update all uncategorized demographic elements as soon as possible. Documentation of complete demographics should be a priority for all new enrollments in FY21.
- Research has demonstrated that important social, emotional and economic benefits result from keeping families together. The I-START program should work with regional agencies to identify individuals who might benefit from START prior to an out-of-home placement. Earlier access to outreach and support to family caregivers including therapeutic supports could increase family capacity to continue supporting individuals at home and mitigate some risk of out-of-home placement.

Mental Health and Chronic Health Conditions

- When analyzing trends for living situation changes, it might be beneficial to consider the diagnostic formulation as an additional variable to determine whether certain biopsychosocial vulnerabilities predispose I-START service recipients to be at risk of losing placement. If trends are identified, then targeted training, outreach and supports can be designed.

Emergency Service Trends

- Continue to provide outreach and other planned interventions, to reduce emergency services use, while adding to the capacity of community partners to provide more proactive care in ways that promote physical and mental wellness for all individuals with IDD in the I-START network.
- I-START team members should ensure that caregivers have knowledge and education around I-START crisis intervention supports and are encouraged to use them first whenever it is safe and clinically appropriate to do so.
- All individuals with multiple emergency service utilization should be reviewed by the clinical director. A CSE should be considered if clinically appropriate.

START Clinical Services

Primary Services

- I-START should continue to evaluate CETs and other community trainings to guide future training offerings.
- The I-START program should strategically target specific audiences for trainings. One demographic trend that requires attention is the risk of placement change at the time of enrollment and subsequent residential moves for enrollees. Perhaps trainings targeted toward residential providers would be beneficial. Formal training has also not been recorded for emergency responders.

Secondary Services

- The I-START team should continue to update all START tools in compliance with COVID-19 protocols and continue with their internal process for SIRS data tracking and documentation timeline compliance.

Tertiary Services

- A CSE has not been completed in either of the two cases where frequent I-START crisis response was provided. While the number of crisis contacts decreases over time, a CSE or another for clinical review (such

as a CET or medical director consult) might be helpful in further stabilization and reduced need for crisis support.

- I-START should conduct a review all cases with 10 or more crisis contacts and determine if additional planned services should be implemented to reduce the frequency of emergency contacts. A CSE or CET should also be considered in these circumstances.
- I-START leadership should continue to improve their in-person response rates whenever possible. With the expansion of the I-START programs, leadership should explore having multiple coordinators on-call covering different areas of the region. This might allow for faster response in the wide geographic area covered by I-START.