Iowa START (I-START)

July 2017 – June 2018

Annual Report

Prepared for

Iowa START

Prepared by

The Center for START Services

On August 31, 2018

County Social Services
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 and behavioral health needs in the community.

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Introduction

This report offers a comprehensive summary of services provided by Iowa START (I-START) team for Fiscal Year 2018. 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.

This report is separated into five sections:

- FY18 Program Enrollment
- Characteristics of Persons Served (demographics and clinical trends)
- Emergency Service Trends
- START Clinical Team Services
- START Therapeutic Supports

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

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Iowa START

Program Background

I-START has been actively serving individuals since August 2015 and has served 117 individuals to date.

Figure 1: Number of Individuals Enrolled in I-START by Fiscal Year (n=117)

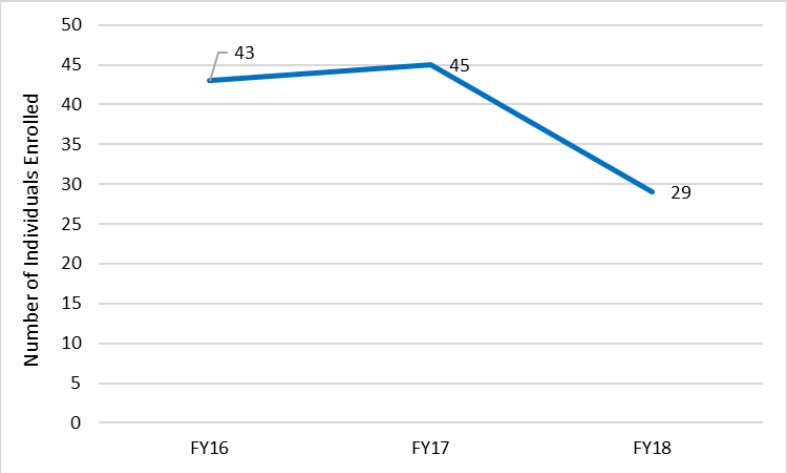


Figure 2: Number of Individuals Served by I-START by Fiscal Year

*Most Individuals have received services in multiple fiscal years.

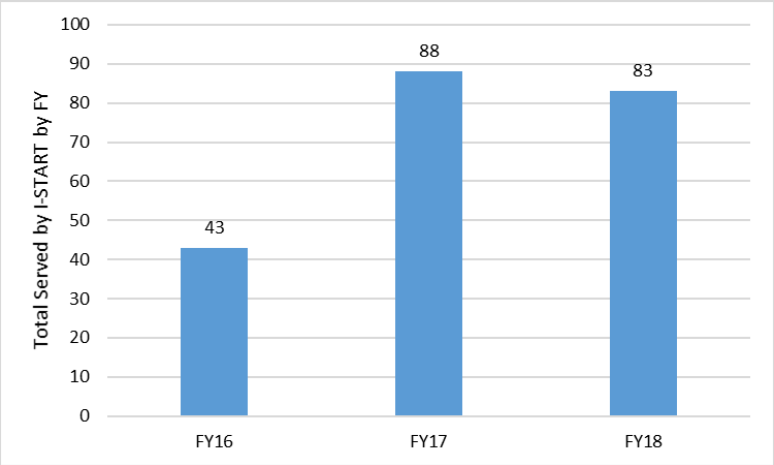


Figure 1 shows the number of newly enrolled individuals in I-START each year since program operations began. There was a decrease in new enrollments in FY18, but the overall program census has remained steady since. At capacity, with four coordinators, I-START should be serving about 100-120 individuals, so the team has capacity for additional enrollments at the conclusion of the reporting period. The START program also reports that there has been an influx of referrals to the program in Q1 of FY19.

While individuals are not discharged from I-START, they can become inactive once they reach a period of stability or because their situation has otherwise changed, (they leave the area or they no longer wish to continue services). To date, I-START has inactivated 52 individuals. The average length of stay (LOS) in I-START is just over 11 months for all individuals. For individuals who have achieved stable functioning, the average LOS is 16 months. This falls within the national average of 12 – 18 months.

Findings

The following sections provides an analysis of enrollment, demographic and service outcome data for the Iowa START (I-START) program for Fiscal Year 2018 (July 1, 2017- June 30, 2018).

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. When noteworthy, elements will be compared to national trends for adults from other START programs outside of Iowa (n=2063 adults). I-START serves adults ages 18 and older.

Section I: Fiscal Year 2018 Program Enrollment

Data below reflect all individuals served by I-START during this report period (July 1, 2017-June 30, 2018).

Table 1.A: FY 18 Census Summary

I-START	
Total Served during reporting period N (%)	**83**
FY18 New Enrollments	29
Individuals inactivated	**18**
Stable functioning	7 (39%)
Moved out of START region	7 (39%)
No longer requesting services	4 (22%)
Active Caseload at the end of reporting period	**65**
Total Served by I-START since inception	**117**

Table I.B: Source of Referral since Program Inception

Variable (N)	I-START (n=117)	National START Trends (n=2063)
Referral Source (%)		
Case Manager	70%	70%
Emergency Department/mobile crisis	-	5%
Family Member	1%	5%
Residential/Day Provider	19%	8%
Hospital/ID Center	5%	4%
Mental Health Practitioner	-	2%
Other (Behavior Analyst, law enforcement, schools)	3%	6%
Missing	2%	-

Table I.C: Reasons for enrollment since program inception

Variable (N)	I-START (n=117)	National START Trends (n=2063)
Most Common Reasons for Enrollment (%)		
Aggression	79%	82%
Family Needs Assistance	32%	36%
Risk of losing placement	54%	21%
Decreased Daily Functioning	39%	24%
Dx and Treatment Planning	29%	23%
Mental Health Symptoms	59%	54%
Leaving Unexpectedly	25%	17%
Suicidality	20%	18%
Self-Injurious Behavior	26%	30%
Sexualized Behavior	20%	11%
Transition from Hospital	16%	9%

Summary

- I-START served a total of 83 individuals in FY 18. The active caseload at the end of FY18 was 65. This is lower than expected given the team of four START Coordinators. The team has seen an increase in referrals in Q1 of FY19.
- The primary referral source for I-START enrollees are case managers. During the reporting period, 19% of referrals did come from community residential providers who have interfaced with START in the past. This is a positive trend, as providers are reporting positive experiences and therefore referring additional individuals to I-START.
- As is often the case, a large majority of people are referred to START due to aggressive behavior. However, increasingly, referring sources recognize a reason to refer someone to START may be that they have mental health symptoms.
- Risk of placement loss was quite high for I-START referrals at two times the national average. This points to an important function for the program, which is to provide outreach services that will increase capacity in the systems around these individuals allowing for them to retain their home setting.
- Most individuals served in I-START are inactivated because if achieving stability. However, four individuals (22% of those inactivated) were inactivated due to no longer requesting services.
- Data above revealed a LOS of 11 months for all enrollees but 16 months for individuals whose case was inactivated once they achieved stability.

Recommendations

- Ongoing efforts should continue to maximize enrollment of new cases within the capacities of the program. The active caseload of only 65 individuals at the end of FY18 was lower than expected.
- Data showing an average LOS in I-START of 11 months for all enrollees, but 16 months for cases inactivated due to achieving stability suggests there is need to further study to determine if people are leaving services prematurely, and why, so that remedies for this can be developed as needed.
- Additionally, although a small percentage of cases were inactivated due to "no longer requesting services", the program should examine the reason for this in order to adjust practices as needed.
- The I-START program should develop a survey to determine why stakeholders no longer want START services after a period of enrollment to ensure that capacity has been built and that they are satisfied with services and support provided by the Region.
- It would likely help to promote greater stability if I-START had a full 24 hour crisis response capacity.

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=83) during FY18 (July 1, 2017-June 30, 2018). There are no significant differences in the demographics of active individuals in FY18 compared to previous fiscal years. When relevant, the I-START population is compared to adults in other START programs.

Table II.A: Age, gender, race, level of ID, and living situation

Variable (N)	I-START (n=83)	National START Trends (n=2063)
Mean Age (Range)	33 (18-61)	32 (18-78)
Gender (% male)	54%	61%
Race		
White/Caucasian	93%	67%
African American	1%	21%
Asian	-	2%
Other	4%	6%
Unknown/Missing	2%	5%
Ethnicity (% Hispanic)	3%	12%
Level of Intellectual Disability (%)		
No ID/Borderline	11%	7%
Mild	53%	50%
Moderate	19%	30%
Severe-Profound	12%	8%
None Noted	5%	3%
Missing	-	1%
Living Situation (%)		
Family	28%	42%
Alternative Family Living/Foster Care	1%	9%
Group Home and Community ICF/DD	23%	30%
Independent/Supervised	43%	11%
Psych. Hospital/IDD Center	1%	5%
Other (Jail, Homeless, "Other")	4%	3%
Missing	-	1%

Summary

- The I-START program serves a population similar in make-up similar to other START programs that are in predominantly rural areas (an area considered "rural" by federal definitions). Racial and ethnic diversity of I-START enrollees is similar to the general population in this part of the state. While less racial and ethnic diversity is present, cultural and linguistic competency reaches beyond traditional definitions and therefore the I-START program is committed to this charge.

- More individuals served in I-START reside in a supported living situation or an independent living arrangement than is seen in the national data. There are many individuals with IDD in Iowa who are served through the HCBS Waiver, which allows for home-based direct support ranging from 8-40 hours per week. This is likely the reason for the high percentage of enrollees living in independent settings with supervision.

- While there are fewer enrollees that live in family settings, the program reports an increase from recent FY19 Q1 referrals. This is an area to continue to monitor in the coming year.

- Somewhat more enrollees of I-START were diagnosed with either Mild or no ID, when compared to other START programs. In other respects, demographics are similar to those reported for other START programs.

- Due to the numbers of individuals residing in less restrictive situations, and the report at intake of loss of residential setting as a concern for 54% of enrollees, I- START services can play a critical role in preservation of home settings for many people.

Recommendations

- The I-START team should continue efforts to strengthen partnerships with community stakeholders as reflected in their high numbers of outreach efforts (93% this fiscal year), aimed at increasing the capacity in the system of care to help people remain living in their homes and engaged in their communities.

- A plan to provide outreach and education to the system regarding referral and engagement prior to loss of placement and other more intense challenges should be developed.

- Since the percentages of enrollees residing with families is lower than national trends, it is important for the I-START program to explore this and perhaps develop a plan to educate families on I-START and how to access its services.

- The I-START program should assure that their staff receive training in cultural competency and that this is an active component of START service delivery. There are resources available through the Center for START Services and these can be accessed through collaboration with the program's CSS project facilitator.

Mental Health and Chronic Health Conditions

Table II.B: Mental health conditions reported at intake

Variable (N)	I-START (n=83)	National START Trends (n=2063 adults)
Mental Health Conditions (%)		
At least 1 diagnosis	92%	90%
Mean Diagnoses (range)	2.4 (1-8)	2.2 (1-8)
Most Common MH Conditions (%)		
Anxiety Disorders	24%	17%
ADHD	33%	24%
ASD	12%	33%
Bipolar Disorders	21%	23%
Depressive Disorders	37%	29%
Disruptive Disorders	38%	26%
OCD	8%	9%
Personality Disorders	9%	9%
Schizophrenia Spectrum Disorders	30%	24%
Trauma/Stressor Disorders	13%	15%

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

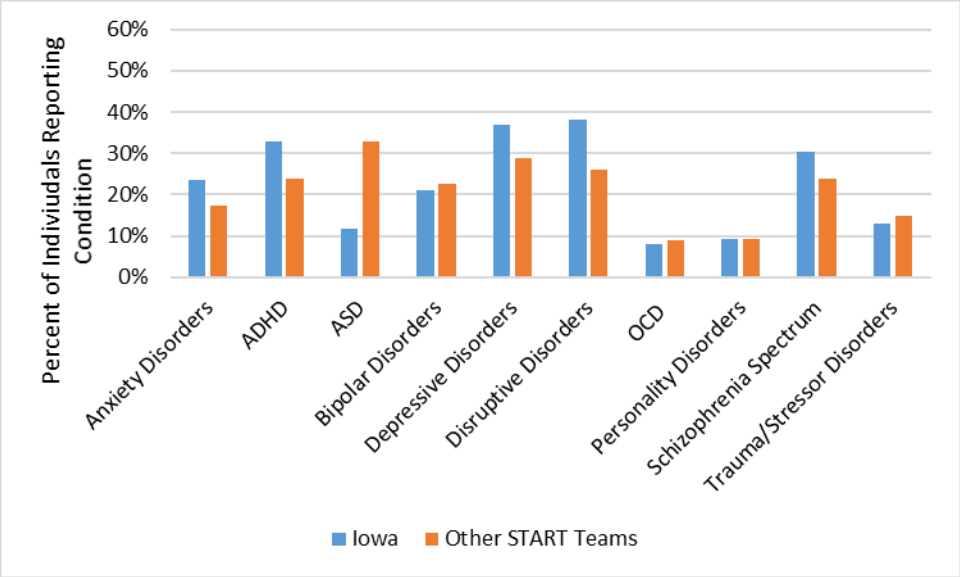
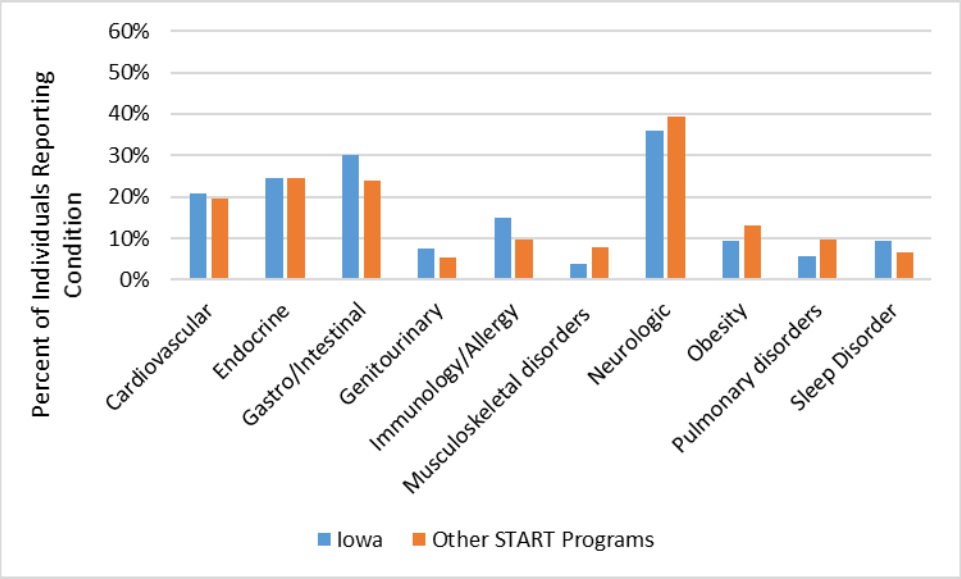


Table II.C: Chronic medical conditions reported at intake

Variable (N)	I-START (n=83)	National START Trends (n=2063
Medical Diagnosis (%)		
At least 1 diagnosis	64%	67%
Mean Diagnoses	1.9 (1-9)	2.1 (1-11)
Most Common Medical Conditions (%)		
Cardiovascular	21%	19%
Endocrine	25%	24%
Gastro/Intestinal	30%	24%
Genitourinary	8%	5%
Immunology/Allergy	15%	10%
Musculoskeletal	4%	8%
Neurologic	36%	39%
Obesity	9%	13%
Pulmonary disorders	6%	10%
Sleep Disorder	9%	7%

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



Summary

- I-START enrollees had slightly higher rates of psychiatric comorbidity than other START programs. Often, people with IDD receive multiple psychiatric diagnoses due to diagnostic confusion. START teams work to educate systems and to help improve diagnostic accuracy, increasing systemic capacity in this area.
- A somewhat higher rate of Disruptive Disorders reported here points to one of the most common areas of diagnostic confusion as labels such as Impulse Control Disorder (ICD) and Intermittent Explosive Disorder (IED) are over diagnosed in the population. Schizophrenia or psychosis is also often over reported. However, the identification of anxiety and depression is a positive finding, since these conditions are frequently missed due to an over focus on externalizing behavioral challenges.

- The 12% rate of ASD reported for I-START adults is low compared with adults served in other START programs (33%) and is low for what we know are the likely rates for adults with IDD and mental health needs. ASD may be more challenging to diagnose in adults with IDD, who may never have had access to the more up to date evaluations used now for identifying the syndrome. The I-START program cites historically limited expertise in evaluating and diagnosing ASD as a contributing factor.
- Medical Conditions: I-START data show high rates of medical comorbidities among their enrollees, consistent with reports in research regarding rates identified in large-scale investigations. It is important to identify these concerns and to increase awareness in the system of care, given the risks to quality of life generally, but also specific links to behavioral and emotional challenges. Most people had more than one medical comorbidity.
- I-START enrollees had the highest rates reported for GI and neurological conditions, similar to what has been found in studies of this topic. Many of these conditions have a major impact on mental wellness, and can lower a person's threshold for engaging in behavioral challenges or experiencing dysphoric mood states.

Recommendations

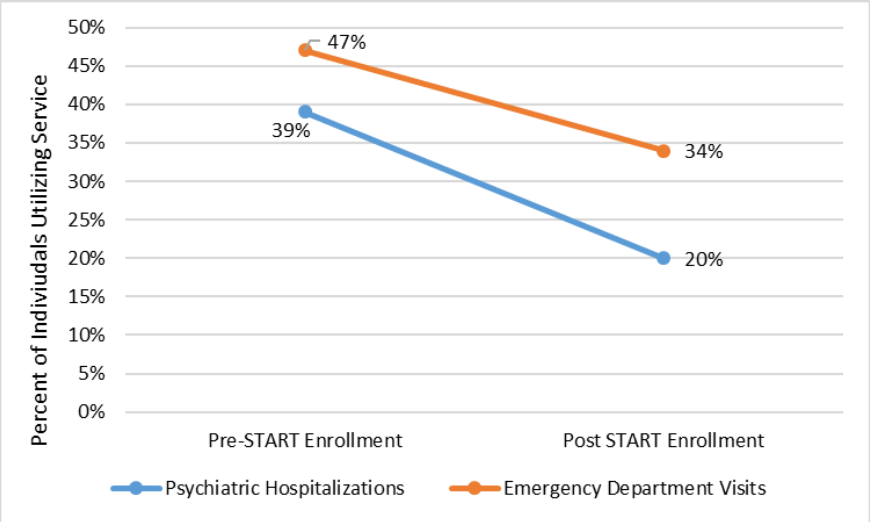
- It may be helpful to design and provide some extra trainings on challenges to accurate differential diagnosis of mental health syndromes when individuals with IDD also present with externalizing behavioral symptoms, which would increase systemic understanding of varied influences on externalizing behaviors and reduce default diagnoses like IED and ICD.
- It may be helpful for I-START to provide more education to community partners regarding identification of ASD in adults. Follow-up over time would then reveal if the reported rates for ASD rise.
- Additional training about the role medical conditions play in reducing mental wellness may also be helpful.
- The unique demographic, enrollment and clinical makeup of I-START enrollees may lend itself to more exploratory research projects. The I-START program should consult with the Center for START Services Research Committee and consider submitting a proposal outlining their research questions and ideas.

Section III: Emergency Service Trends

Table III.A: Emergency Service utilization

I-START	FY18 (n=83)	
Variable	Psychiatric Hospitalization	Emergency Department Visits
Prior to enrollment, N (%)	**32 (39%)**	**39 (47%)**
Mean Admissions (range)	3.1 (1-10)	4.9 (1-37)
Missing	-	-
During START, N (%)	**17 (20%)**	**10 (34%)**
Mean (range)	2.9 (1-13)	3.3 (1-17)
Average length of stay (hospital)	14 days	N/A

Figure III.A: Change in frequency of pre and post START enrollment emergency service utilization (adults) for individuals served in FY18.



Summary

- The change in ED and psychiatric hospitalization rates from pre to post NH START enrollment was very encouraging for both children and adults. These data provide support to the observation in START programs nationally and in research on the START model, that receiving START services is associated with reduced emergency service use.
- I-START was recently part of a study funded through the Special Hope Foundation focusing on the use of START interventions on the reduction of emergency service use. A peer reviewed journal article was recently published on this study in the **Journal of Mental Health Research in Intellectual Disabilities** titled: Improving Mental Health Outcomes for Individuals With Intellectual Disability Through the Iowa START (I-START) Program.[1]

[1] Joan B. Beasley, Luther Kalb & Ann Klein (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, DOI: 10.1080/19315864.2018.1504362

Recommendations

- While there is a significant reduction in use of emergency services once individuals are enrolled in I-START, additional resources for the provision of 24 in-person I-START crisis response as well as START Resource Center services would likely result in greater improvements over time. This has been seen in other START programs similar to the make-up of I-START so similar trends would be expected.

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), education, 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); and

Tertiary (emergency intervention services): emergency assessments and mobile support 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 and assist 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 FY18. Primary START services include system linkages, clinical consultation, 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	FY18
Number of Activities (N)	
Community linkage/affiliation	11
Community-based training	5
Host Advisory Council Meeting	6
Provided Training (N)	
Day provider	3
Emergency services	10
Family	25
Other	8
Physician/medical personnel	-
Residential provider	18
School	7
State facilities (state hospitals, developmental centers)	-
Therapist/mental health providers	-
Transition Support/Planning-Developmental Center	-
Transition Support/Planning-Psychiatric Hospital	-
Total Community Outreach/Training Episodes (N)	93
Total Linkage/Collaboration Agreements Completed (N)	15
Total Clinical Education Teams in FY18 (N)	11

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 FY18.

Table IV.B: Community training topics

Date	Title/Training Topic	Number in attendance
1. July 12, 2017	Borderline Personality Disorder vs. PTSD	13
2. August 9, 2017	Obsessive Compulsive Disorder	14
3. September 20, 2017	Impact of Sexual Violence	14
4. October 11, 2017	Sleep Dysregulation	8
5. November 8, 2017	Sexuality and Relationships	16
6. December 13, 2017	Executive Functioning	28
7. January 10, 2018	FASD	21
8. February 14, 2018	Pharmacogenomics	
9. March 14, 2018	Healing from Trauma	15
10. April 11, 2018	Minimizing Multiple Medication Trials: Pharmacogenomics	13
11. May 16, 2018	Navigating the challenging waters of co-occurring disorders	30

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, MSW
- National Program Director forums held quarterly facilitated by Andrea Caoili, LCSW and Joan B. Beasley, Ph.D.
- 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

- I-START provided a large array of outreach, education and training to their community partners this year as outline in Table IV.A.
- The 93 outreach/training events provided by I-START covered many important topics such as trauma, human sexuality and the differential diagnosis for various psychiatric syndromes and involved collaborative interface with many different entities including families, schools, emergency service providers, as well as residential and day service providers.
- I-START also developed three (3) new linkage agreements this year for a total of 15 and has been working on securing additional agreements. These efforts have been critical in building strong collaborations with community partners and have enhanced the impact of START in the region.

Recommendations

- It is recommended that relationships and linkages continue to be fostered by the I-START program throughout the region. Feedback from coordinators regarding engagement with partners should guide development and refinement of linkages
- The I-START program should develop a plan with the support of their Center for START Services Project Facilitator to target development of more linkages with emergency departments, psychiatric hospitals, and law enforcement during the coming year.

Secondary Services

Specialized direct services to people at risk of emergency service use

Secondary services help to 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 related to general issues or those specific to the individual referred. Entities to which the START Coordinator may provide outreach: families/natural supports, residential programs, day programs, schools, mental health facilities, or any entity that may seek or need additional support and education.
- *Clinical Consultation*: START Coordinators will present cases to their teams, and then share clinical consultations provided by the Clinical Director and Medical Director with community team members who support individuals, and work with the Clinical Director to provide direct, on site clinical case consultations.
- *Medical Consultation:* This includes any consultation provided by the START Medical Director regarding medication and other medical issues, includes collaboration with prescribing doctor.

- *Cross System Crisis Planning*: Completion of the Cross Systems Crisis Intervention and Prevention Plan (CSCPIP) includes collecting and reviewing relevant information; brainstorming with the team; developing/writing the plan and distributing; reviewing and revising; and training and implementation the plan with the system of support.
- *Crisis Follow-Up*: Time spent following up after a crisis contact. This includes facilitating emergency service admissions and discharges, meetings with emergency service providers and follow-up on crisis plan recommendations.
- *Planned Center Based (Therapeutic Resource Center) or In-Home Therapeutic Supports*: All of the work/coordination related to preparing for and facilitating planned center based or in-home supports.
- *Clinical Education Team (CET)*: Preparing for and holding a CET regarding the enrolled individual. Includes reviewing and identifying relevant recommendations with Clinical Director and assisting system of support with implementing recommendations.
- *Comprehensive Service Evaluation (CSE)*: Completion of the CSE, including receiving and reviewing records; interviewing the individual and system of support; writing the CSE; and reviewing recommendations through development of an action plan.

Table IV.B shows the percent of individuals enrolled in the region who received these planned 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.

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

I-START	FY18 (n=83)
Utilization of Planned Services (% of Individuals)	
Outreach	98%
Intake/Assessment	98%
CSCPIP	82%
Clinical Consultation	81%
Medical Consultation	65%
Crisis Follow-Up	37%

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.C: Percentage of active individuals who received assessments/tools

START Tools	Tool was completed (FY18)	Current and up-to-date (Active caseload)
START Action Plan	95%	88%
Aberrant Behavior Checklist (ABC)	97%	83%
Recent Stressors Questionnaire (RSQ)	97%	97%
Cross Systems Crisis Prevention and Intervention Plans (CSCPIPs)	91%	85%
Comprehensive Service Evaluations CSEs Completed	5%	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=63). The average time between the two administrations used in this analysis was 15 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 FY18.

For individuals in the I- START program receiving services with at least two administrations in SIRS (n=63), results show that average scores decreased as shown in Table IV.

Table IV.D: 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%	18.54	14.57	2.85	<0.00
Irritability/Agitation	65%	18.08	14.19	2.81	<0.00
Lethargy/Social Withdrawal	52%	8.78	6.37	2.29	<0.01

Alpha=0.05

Summary

- Enrollees received a wide range of planned START services in FY18. In order to meet program certification compliance, which is a goal for I-START program in the coming year, all enrollees to have an up to date START tools and plans. Up to date START plans do not meet compliance and reported rates for completion of ABCs was slightly low. ABCs should be completed every 6 months for all enrollees.
- All other planned services and assessment tool administrations were in accordance with expectations for fidelity to the START Model.
- Individuals served by I-START demonstrated reduced measures of psychopathology as evidenced by the ABC subscale scores reported. This is consistent with data from other START programs.

- Though reduced ABC scores can be a very useful outcome measure, other factors may also be important in determining the effectiveness of interventions, including helping people remain with natural supports. Other data suggest that individuals served in I-START demonstrated improved functioning based on the reduction in ED visits and psychiatric inpatient stays noted above. Collectively, these outcome measures suggest the START model is helping significant numbers of enrollees.
- Comprehensive Service Evaluations (CSE) are an important tool utilized by the I-START program when additional diagnostic and treatment clarification is needed. It requires in-depth record reviews and multi-disciplinary input and recommendations. It is expected that 15-20% of all enrollees have a CSE. At this time, 5% of I-START enrollees have a completed CSE.

Recommendations

- I-START should ensure all enrollees have an up-to-date START plans and tools. I-START should work to increase ABC administrations to meet the standard of every 6 months for all enrolled individuals.
- I-START should continue to take regular data on outcomes associated with improved functioning and service effectiveness. Over time, even greater reductions in psychopathology measured by the ABC will provide an important indicator of the significance of full START model implementation.
- The I-START program should develop a plan to increase the utilization of the CSE process in the coming year and should plan to complete at least 2-3 CSEs in each quarter of FY19.

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 Contact:* 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.

Crisis Contacts

Table IV.F: FY18 Crisis Contacts

I-START	FY18
Crisis Contacts	
Number of Individuals with a contact	22
Number of Crisis Contacts	124
Range of Contacts	(1-27)
Frequency of calls with each type of Intervention N (%)	
In-Person	**16 (13%)**
Phone Consultation	107 (86%)
Unspecified	1 (1%)
Average Length of In-Person Intervention	2.3 hours
Crisis Disposition for each crisis contact N (%)	
Maintain Setting	106 (85%)
Psychiatric Hospital Admission	2 (2%)
Emergency Department	2 (2%)
Medical Hospital Admission	-
START Therapeutic Services	-
Crisis Stabilization	9 (7%)
Other (Incarcerated, Referral to services, "Other")	4 (3%)
Unspecified	1 (1%)

Summary

- FY18 is the first year that the I-START program provided 24-hour crisis response to enrollees. Quick in-person response continues to be a challenge for the program due to the region not having mental health mobile crisis teams and the large geographic are of the region. I-START covers multiple rural counties in Central Iowa and it can take 4+ hours for some coordinators to reach parts of the region.
- Despite geographic and systems challenges, 85% of enrollees maintain setting following I-START crisis intervention.
- Too few contacts include an in-person assessment; an in-person response should occur in about 75% of contacts in order to obtain national START program certification. Data from Quarter 1 of FY19 shows an improvement in in-person crisis response, with the program responding on-site in 39% of cases. It is still necessary that an improvement occur, and this will be a goal for the new fiscal year.
- There were some enrollees who had many repeated crisis contacts (three individuals accounted for almost half of the contacts n=57), the majority of which were in the form of phone calls. The average length of the phone calls was 45 minutes, a significant amount of time. In two cases, the individual went to crisis stabilization and in one case the hospital. It is important to work to provide planned services and the full range of services to people who repeatedly call the crisis line.

Recommendations

- I-START leadership should explore the causes for low rates of in-person assessment and develop remedies so that more individuals having a crisis encounter are receiving an in-person evaluation when needed. In-person assessments should occur in 75% or more of contacts with an average response time of about 2 hours.

- An additional goal for FY19 should be to examine closely what is occurring when enrollees are engaged in repeated calling into the crisis line, in case some calls are not actual crises and/or could be reduced by employing other planned interventions.
- I-START should also monitor and ensure use of the full range of available START service options for any individuals having repeated need for use of the 24-hour crisis line. This includes ensuring that outreach visits are occurring at a high frequency, clinical consultation as well as Therapeutic Supports are being employed for individuals experiencing the most acute and ongoing challenges. Specifically:
    - For any individual with repeated calls to the crisis line, the Clinical Director should conduct a review. The clinical director working with the coordinator should then take the following steps:
        - If calling the crisis line when not in crisis, schedule phone calls to meet the person's need for contact in a preventive manner.
        - Update the CSCPIP with close involvement of the person' system of care.
        - Check the START plan and ensure this is in alignment with the high need profile of the cases reviewed.
        - Present the case to the medical director.
        - Complete a CSE.
        - Organize a systems meeting and review.
        - If appropriate, schedule a CET.
        - Develop a detailed action plan to reduce crisis events based on above and in conjunction with the person's system of care.

Conclusions and Recommendations for Fiscal Year 2019

Conclusion

I-START has served 117 adults since its inception and a total of 83 this fiscal year. Risk of placement loss was quite high for I-START referrals at two times the national START average (54% v 21%). This points to an important function for the program, which is to provide outreach services that will increase capacity in the system around these individuals allowing for them to retain their home setting. Due to the number of individuals residing in less restrictive settings and the report at intake of loss of residential setting as a concern, I-START services can play a critical role in preservation of home settings for many people.

I-START was able to provide a variety of trainings and educational opportunities for their community partners and has been developing strong relationships with many different groups. The 93 outreach/training events provided by I-START covered many important topics such as trauma, human sexuality and the differential diagnosis for various psychiatric syndromes and involved collaborative interface with many different entities including families, schools, emergency service providers, as well as residential and day service providers. The clinical services that are outlined in the START model were provided to most enrollees though some work remains to be done to be fully meet fidelity. Crisis services were provided and should be refined and expanding in the coming reporting period.

FY2018 is the first year that the I-START program has provided 24-hour crisis response to enrollees. Quick in-person response continues to be a challenge for the program due to the region not having mental health mobile crisis teams and the large geographic area of the region. I-START covers multiple rural counties in Central Iowa and it can take 4+ hours for some coordinators to reach parts of the region. As noted in the report, adding therapeutic supports to I-START (having a Resource Center and In-home Therapeutic Coaching services) would likely add benefit in terms of further reducing emergency service use and improving outcomes for enrollees.

Also during fiscal year 2018, an important peer reviewed article was published that demonstrated the positive effects of START services in reducing emergency services use. During FY 2018, this and other efforts were made to educate the system about efficacy of START. I-START expansion has also been discussed as mentioned in the Executive Summary above and is an exciting development that has been a product of the success of the current program. Planning and preparation for I-START's National Program Certification Review in the fall of 2019 is an important priority for the coming year.

The following recommendations will support the I-START Program's efforts toward achieving program certification. It is expectation that the program develop an action plan to address the recommendations and submit and review with the Center for START Services staff.

Recommendations for Fiscal Year 2019

<u>Program Enrollment</u>

- Ongoing efforts should continue to maximize enrollment of new cases within the capacities of the program. The active caseload of only 65 individuals at the end of FY 18 was low.
- Data showing an average LOS in I-START of 11 months for all enrollees, but 16 months for cases inactivated due to achieving stability suggests there is need to further study to determine if people are leaving services prematurely, and why, so that remedies for this can be developed as needed
- The I-START Team should develop a survey to determine why stakeholders no longer want START services after a period of enrollment to ensure that capacity has been built and that they are satisfied with services and support provided by the Region.
- It would likely help to promote greater stability if I-START had a full 24 hour crisis response capacity.

Characteristics of Persons Served

- Demographics
    - The I-START team should continue efforts to strengthen partnerships with community stakeholders as reflected in their high numbers of outreach efforts (93% this fiscal year), aimed at increasing the capacity in the system of care to help people remain living in their homes and engaged in their communities.
    - A plan to provide outreach and education to the system regarding referral and engagement prior to loss of placement and other more intense challenges should be developed.
    - Since the percentages of enrollees residing with families is lower than national trends, it is important for the I-START program to explore this and perhaps develop a plan to educate families on I-START and how to access its services.
    - The I-START program should assure that their staff receive training in cultural competency and that this is an active component of START service delivery. There are resources available through the Center for START Services and these can be accessed through collaboration with the program's CSS project facilitator.

- Mental Health and Chronic Health Conditions
    - It may be helpful to design and provide some extra trainings on challenges to accurate differential diagnosis of mental health syndromes when individuals with IDD also present with externalizing behavioral symptoms, which would increase systemic understanding of varied influences on externalizing behaviors and reduce default diagnoses like IED and ICD.
    - It may be helpful for I-START to provide more education to community partners regarding identification of ASD in adults. Follow-up over time would then reveal if the reported rates for ASD rise.
    - Additional training about the role medical conditions play in reducing mental wellness may also be helpful.
    - The unique demographic, enrollment and clinical makeup of I-START enrollees may lend itself to more exploratory research projects. The I-START program should consult with the Center for START Services Research Committee and consider submitting a proposal outlining their research questions and ideas.

Emergency Service Trends

- While there is a significant reduction in use of emergency services once individuals are enrolled in I-START, additional resources for the provision of 24 in-person I-START crisis response as well as START Resource Center services would likely result in greater improvements over time. This has been seen in other START programs similar to the make-up of I-START so similar trends would be expected.

START Clinical Services

Primary Services

- It is recommended that relationships and linkages continue to be fostered by the I-START program throughout the region. Feedback from coordinators regarding engagement with partners should guide development and refinement of linkages
- The I-START program should develop a plan with the support of their Center for START Services Project Facilitator to target development of more linkages with emergency departments, psychiatric hospitals, and law enforcement during the coming year.

Secondary Services

- I-START should ensure all enrollees have an up-to-date START plans and tools. I-START should work to increase ABC administrations to meet the standard of every 6 months for all enrolled individuals.
- I-START should continue to take regular data on outcomes associated with improved functioning and service effectiveness. Over time, even greater reductions in psychopathology measured by the ABC will provide an important indicator of the significance of full START model implementation.
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