

Improving Mental Health Outcomes for Individuals with an Intellectual Disability  
through the Iowa START (I-START) Program

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## **Introduction**

Outcomes are reported from a one year prospective investigation among 41 individuals with Intellectual Disabilities (ID) and behavioral health needs who received specialized supports from the I-START program (Iowa Systemic, Assessment' Therapeutic, Assessment, Resources and Treatment) operating in a rural region of Iowa. Results indicated that individuals supported by the I-START program experienced significant reductions in mental health symptoms and had fewer psychiatric emergency department visits and hospitalizations over time. Findings highlight that utilization of the START model promotes positive outcomes and improves the lives of people with ID and co-occurring mental health conditions.

## **Background**

Intellectual Disability (ID) is a type of developmental disability characterized by significant limitations in intellectual functioning (e.g. learning, reasoning, problem solving) and adaptive behavior (e.g. language, time management, daily activities, social skills) that persist throughout an individual's lifespan. The most common of developmental disabilities in the US is ID, affecting 1% to 3% of the population<sup>1</sup>. Numerous studies have documented that individuals with ID suffer from very high rates of psychiatric disorders<sup>1-4</sup> with roughly 40% meeting criteria.<sup>3</sup>. Compared to other vulnerable populations (e.g. people with seizure disorders, diabetes, or asthma), individuals with ID experience higher rates of both externalizing (e.g., aggression, disruptive behavior) and internalizing (e.g., anxiety, depression)

symptoms<sup>1-6</sup>. Psychopathology, particularly externalizing behaviors, frequently persists into adulthood and requires specialized supports. Kats and colleagues (2013) found that 25% of adults (ages 30-65) with ID needed support for self-injury, disruptive, and destructive behaviors<sup>3</sup>. McCarthy and colleagues (2010) reported even higher rates of externalizing behaviors finding that as many as 62% of a sample size of 562 adults with ID had difficulty with challenging behaviors<sup>4</sup>.

Addressing mental health problems in individuals with ID is critical because, although this population makes up a small percentage of all individuals receiving psychiatric care nationwide, the intensity, complexity, and cost of their care is disproportionately higher. Psychiatric symptoms are severely impairing for individuals with ID, resulting in poor social and academic functioning<sup>7</sup>, low overall quality of life<sup>8</sup>, and earlier mortality<sup>9</sup>. These issues also greatly affect the families of individuals with ID. Studies have shown that co-occurring mental health challenges are a robust predictor of caregiver stress and distress<sup>10</sup>, lower family well-being and functioning<sup>10</sup>, and decreased family resources (e.g., problems with employment and decreased household income)<sup>11,12</sup>.

Although the presence of mental health challenges in individuals with ID is well-known, access to outpatient mental health treatment is limited, and when services are available, caregivers often report dissatisfaction with their mental health providers<sup>13,14</sup>. The lack of community mental health professionals trained to treat people with ID is the likely cause of the problems with limited access and poor

quality, at least in part. These limitations compel many caregivers to resort to using the emergency department (ED) to manage mental health symptoms, leading to even more problems for individuals with ID.

The lack of professional expertise in addressing the unique needs of individuals with ID (including people who frequently present with agitation and aggression in EDs) increases the risk for use of sedating medications, restraint and seclusion. Use of restraint and seclusion with individuals with ID has been associated with patient injuries and deaths, staff injuries, and long-term trauma for all involved<sup>15,16</sup>. Identifying appropriate dispositions out of an ED is often challenging since there are very few inpatient psychiatric units in the US designed or equipped to meet the unique needs of these individuals<sup>17</sup>. As a result, psychiatric “boarding” (or extended ED wait time) occurs more frequently with patients with ID than with other patient populations<sup>18</sup>. Ultimately, caregivers, providers, and individuals with ID may experience stress, frustration, and disillusionment with the medical system as they experience these long wait times and are sent home with little to no additional mental health resources.

Another byproduct of ineffective community-based mental healthcare for this population is reliance on inpatient hospitalization services to manage an individual’s mental health needs<sup>19</sup>. Inpatient care is one step in a continuum of care and should be considered as a last resort given the expense and restrictiveness associated with this setting. In fact, the 1999 Olmstead Act concluded that a lack

of alternative options for community-based treatment constitutes a civil rights violation when the hospital becomes the setting for routine care<sup>20</sup>. Similar to ED admissions, stays in inpatient psychiatric units represent reactive and restrictive forms of care and can be distressing and traumatic for people with ID and their families.

Reducing dependence on the ED and inpatient units, by supporting and promoting access to high-quality community-based care, is a key goal of START (Systemic Therapeutic Assessment, Resources and Treatment) Model, a tertiary care crisis prevention and intervention program. STRT was first developed in 1988 and employs a systems linkage, multidisciplinary work-force equipped with a unique set of skills and processes to improve care for individuals with ID in the optimal treatment setting: the community.

To date, three studies have examined START. Two of these studies occurred during the early stages of START development and provided evidence suggesting use of the model could lead to a reduction in healthcare costs and emergency psychiatric service use as well as an improvement in service experiences<sup>21,22</sup>. A more 2016-2017 study examined outcomes for 111 individuals receiving START services in the northeastern and southeastern portions of the United States<sup>23</sup>. Results suggested START was effective in improving caregiver evaluation of service experiences, mental health symptoms of individuals enrolled in START services, and urgent psychiatric service use<sup>23</sup>. Since many individuals with IDD

and co-occurring mental health symptoms, including those enrolled in START, reside in group home settings, an important limitation to that study was participants solely resided with family caregivers.

This study expands the current literature on START in two ways. First, it examines outcomes among individuals who are predominately placed in paid support settings. Investigation of this group is critical since they have been identified as in need of community placement and therefore may have different challenges and vulnerabilities than individuals living with family caregivers. Second, the study takes place in the rural Midwest. This is important for generalizability to populations and systems that may be substantially different from regions in the US where previous studies of START have occurred. The objectives of this study were to examine changes in: 1) mental health symptoms 2) rates for emergency psychiatric service use in a sample of individuals with ID served by a I-START team. The Aberrant Behavior Checklist subscales were used to assess changes in mental health symptoms and emergency services were defined as the frequency of psychiatric hospitalization and psychiatric emergency department visits. The study provides a prospective, longitudinal analysis of outcomes.

## **I-START**

Iowa START (I-START) was first implemented in a region of Iowa to improve supports to people with ID and co-occurring mental health conditions in the area. Like many of the locations where START has been developed across the U.S., people with ID and mental health needs serviced in the state experienced frequent hospitalizations, emergency room visits, incarcerations, and failed placements. As a solution, in August 2015, an I-START Clinical Team was developed in collaboration with the Center for START Services at the University of New Hampshire Institute on Disability UCEDD.

A proposal was submitted to the Special Hope Foundation to study the effectiveness of the I-START clinical team services as a potential intervention to increase the understanding of a need to overcome disparities in access to effective mental health care for people with ID, targeting individuals experiencing high levels of emergency service use and restrictive interventions. The original research design was to compare I-START outcomes with another region in the state that does not have I-START. However, changes in the case management structure of the state precluded access to data to conduct the controlled analysis that was originally planned. As a result, the research plan was resubmitted and approved, with methodology for a longitudinal study of 41 individuals who entered the I-START program between 2015 and 2016. In addition, we expect to obtain claims data in the coming months to conduct a comparative analysis of hospital and emergency room costs between those with I-START and another region without I-START.

## **Methods**

### *The START Program*

START seeks to improve the lives of individuals with ID and co-occurring behavioral health needs through enhancing expertise and partnerships across state and local healthcare service systems. START is an evidence-informed model with rigorous fidelity requirements. Oversight and certification of regional START teams is tracked through the START Information Reporting System (SIRS) national database, and by the National Center for START Services at the Institute on Disability UCEDD at the University of New Hampshire. There are currently START teams in 9 states across the U.S with more in development.

### *START Clinical Team*

The foundation of the START model is built upon the START Clinical Team. As with other START teams across the country, the I-START Clinical team includes a director, medical director (licensed physician or nurse practitioner), clinical director (licensed psychologist or social worker), clinical team leader and START Coordinators. All team members must have demonstrated expertise in supporting individuals with ID and behavioral health issues and are required to participate in extensive training that culminates in national coordinator certification from the National Center for START Services. Coordinators are expected to demonstrate a clear understanding of individual and systemic needs of the individuals and systems they support. Teams also develop and maintain linkage agreements with

local providers and service systems to enhance partnerships when treating individuals in the community.

START Clinical Teams provide specific systemic interventions, including cross system crisis planning and 24 hour crisis response, outreach, training and consultation services. The primary crisis prevention tool is the START Cross System Crisis Prevention and Intervention Plan, which employs a comprehensive approach to preventing and responding to behavioral health crises. If need arises, START teams provide 24 hour crisis evaluation and response services. Protocols require immediate telephonic response and in-person evaluation within two hours of the initial contact. Regular and strategic outreach also occurs and is done in all settings including the individual's home, school, job and/or day programming. Lastly, clinical and medical consultation services delivered by the START medical and/or clinical director and facilitated by the START Coordinator, are available to all individuals enrolled in START. Services often include diagnostic assessment, follow-up, and consultation. Further information about the START Model, services and practices can be found here:

<http://www.centerforstartservices.com/default.aspx>.

*Sample*

Pre-post data were gathered from 41 individuals with Intellectual Disability (ID), between 2015 and 2016, enrolled in a recently developed START program located in Iowa. Participants were enrolled for an average of 430 days (min = 239, max = 642, SD = 115). The average age of the participants was 32.3 years (min = 15.5y, max = 58.8y, SD= 11.9y). Only 2 individuals were less than 18 years of age. Half of the subjects were female (n=21); 63% had mild ID, 15% moderate ID, and 7% severe/profound ID. Most of the subjects were white (95%). Mood-related disorders were the most prevalent comorbid psychiatric diagnoses (depression, n =15; anxiety, n = 14; bipolar, n =5), followed by psychotic disorders (n=13) and other disorders of attention and impulse control (attention deficit-hyperactivity, n = 11, impulse control, n = 7, and oppositional-defiant, n=2). Diagnoses were abstracted through information gathering during the intake/assessment process. Intake includes face-to-face interviews, observations and the review of psychiatric/psychological evaluations and reports.

Inclusion criteria for this study were a diagnosis of ID and a diagnosed mental health condition/ behavioral health need(s). At the time of enrollment, most of the sample lived in supported community settings (70%). Other study participants resided at home with family (7%), lived independently (7%), resided in locked facilities (9%), or had some other living arrangement (7%). Data were de-identified and the study was exempt from full IRB review.

### *Quantitative Analyses*

A prospective analysis was conducted to evaluate outcomes for a group of individuals receiving I-START services over a one year period. Key outcome variables included Aberrant Behavior Checklist (ABC) subscale scores and use of emergency psychiatric services. All pre-testing interviews took place during the START intake or when services began. Mean pre-post changes in ABC scores were analyzed using paired t-tests. Effect sizes for ABC scores were assessed using Cohen's *d*, which is calculated as the differences in means (post – pre) divided by the pooled standard deviation of the pre and post scores. To examine differences the probability of hospitalization and ED visits between pre and post, the McNemar's test was employed. McNemar's is a nonparametric test of dichotomous data. This test was used to account for the repeated measures design. All analyses were performed in STATA 11.0 (College Station, Tx) and considered statistically significant at the  $p < .05$  level.

### *Measures*

#### *Mental health symptoms*

The community version of the Aberrant Behavior Checklist (ABC) was employed in this study as the measure of psychiatric symptoms. The ABC is a heavily cited and psychometrically sound instrument that has been validated for use in the assessment of both adults and youth with ID (Aman, Singh, Stewart, & Field, 1985). The Irritability, Lethargy, and Hyperactivity subscales were the focus of this study since the additional subscales, including stereotypic and inappropriate speech, were not treatment targets. ABC subscale scores for these three scales

are the most frequently reported measures of psychopathology reported in the literature addressing intervention outcomes for individuals with ID. The individuals' case manager served as the informant at pre and post for the ABC.

#### *Urgent Psychiatric Service Use*

Data on emergency department use and psychiatric hospitalization admissions for mental health purposes was gathered by the I-START Coordinator. At baseline, informants provided information on use of these services in the year prior to START enrollment. START coordinators captured service use within the START, Information, Reporting System (SIRS) database during study enrollment.

Overall, there was little missing data. However, the ABC was only available on 73% of the sample (n=30); all missing data occurred at post-test. Sensitivity analyses did not find an association between pre-test lethargy ( $p=.29$ ) or hyperactivity subscales ( $p=.82$ ) and missingness at post-test, however a trend was found for irritability ( $p=.07$ ) such that those with missing post-test data had higher pre-test scores ( $M=25.1$ ) than those without missing data ( $M=17.1$ ). Since individuals with the highest irritability subscale scores at pre-test (i.e., above the pre-test median score of 15) had the largest change ( $M$  change =  $-10.2$ ) in scores compared to those in the lower half of median baseline scores ( $M$  change =  $2.12$ ;  $p<.05$ ), the results presented here are likely conservative. Said otherwise, if all data were available for the post-test ABC score, the effects may have been larger in magnitude than those reported here.

## Results

### *Mental Health symptoms*

Shown in Table 1 below, significant decreases in mental health symptoms, between pre and post, were observed for each of the ABC subscales range (all  $p < .001$ ). Effect sizes for the Hyperactivity ( $d = .58$ ), Irritability ( $d = .62$ ), and Lethargy subscales ( $d = .56$ ) were all in the moderate range.

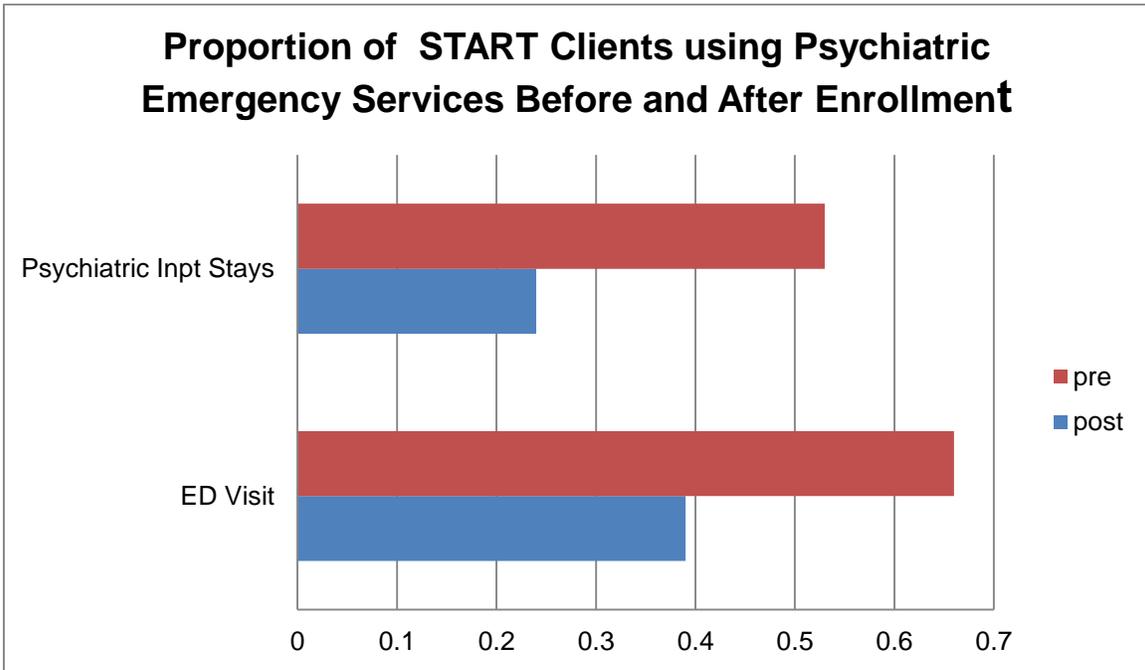
Variable	Pre-Test	Post-Test	Effect Size ( $d$ )	Test statistic	p-value
<i>ABC (Mean)</i>					
Hyperactivity	16.63	11.73	.46	T=2.12	<.05
Irritability	17.37	11.40	.60	T=2.47	<.05
Lethargy	8.43	4.90	.50	T=2.12	<.05

### *Urgent Psychiatric Service Use*

During the year prior to START enrollment, 53% of individuals enrolled in START experienced a psychiatric hospitalization. During that same time period, 66% visited the emergency department for psychiatric concerns. During the one year study observation period, the proportion of individuals who experienced psychiatric hospitalizations and who were seen in an ED for psychiatric problems significantly decreased to 24% ( $p < .05$ ) and 39% respectively. See Table 2 for further details.

Variable	Pre-Test	Post-Test	Test statistic	p-value

<i>Psychiatric Hospitalizations (%)</i>	53%	24%	Z=12.00	<.001
<i>Psychiatric Emergency Department Visit (%)</i>	66%	39%	Z=7.12	<.01



*Case Example*

*Information about “Larry” has been modified to protect the identity of the individual.*

*Larry’s case was presented by his START coordinator for national certification.*

“Larry,” is a young adult who was referred to the START program due to a high frequency of aggressive incidents, frequent emergency department visits and multiple disturbances resulting in police involvement.

Larry was adopted at age 3 by a large family in rural Iowa and has maintained a loving relationship despite many challenges they faced. Larry was diagnosed with a genetic syndrome and ID prior to age 5 and was described as an anxious child who “tantrumed” regularly. While the family received some information about Larry’s genetic disorder at the time of the adoption, little was understood about his ID or how to support him as he grew into adolescence. Larry attended special education classes in school and did better in the school setting than at home. As Larry’s challenges increased over time, he received numerous mental health diagnoses. In addition, his genetic condition pre-disposed him to a number of chronic medical issues that require regular and pro-active attention.

At the time that Larry was referred to I-START, he was a young adult and was being treated with multiple psychotropic medications to help “control his outbursts”. Because of these outbursts, it was becoming increasingly more difficult to make friends and to participate in family functions without incident, causing strain in his relationships. Another concern identified during the initial intake process was that Larry had also gained a great deal of weight and was always eating. In addition, Larry frequently scheduled his own medical appointments, which people in his life believed were unnecessary and were often frustrated by.

Based on the evaluations conducted by the I-START Coordinator at intake, both Larry and his support system were in crisis. Often people caring for Larry did not feel they could handle the difficulties with which he presented, and outside emergency assistance from the local police department and community hospital was sought. Despite his young age, Larry was reported to have numerous medical appointments and emergency room visits every week. Police involvement was required to help manage many of his crises. All of these issues had an impact on the way Larry was viewed in his community. The focus was on managing his bad behavior because it was so disturbing for others.

#### *I-START Services Provided*

The I-START Coordinator worked with Larry's providers and family to better understand Larry and needs. Outreach visits to the home and day settings, 24-hour crisis response, cross systems crisis planning and training with the system of care were provided. A solutions-focused, strengths-based dialogue was facilitated by the I-START Coordinator with Larry, his providers and family to create a common understanding of goals. Based on this, a collaborative plan was developed that included diagnostic clarification, treatment modification, and modification of his day and residential programs. Weekly outreach meetings (more often during times of crisis), occurred in which Larry's character strengths, skills and interests were discussed, as essential components for crisis prevention and

intervention. When Larry and his team needed support, I-START was available to help, reducing dependence on the community hospital and police.

Since Larry was referred for multiple, often conflicting diagnoses, clarification and case formulation was one of the important functions provided by the I-START team. With the help of the Medical and Clinical Director, the team was able to develop a better understanding of Larry's genetic syndrome, compromised executive functioning and anxiety in the context of his mild ID. These combined with the vulnerabilities associated his low self-esteem contributed to many of the communication and adaptive challenges he faced.

### *The Turning Point*

Training about Larry's genetic syndrome to better understand how it might impact him, proved to be very informative for the team. As part of the training, the START coordinator facilitated a shifting of focus from managing Larry's behavior to promoting support strategies to help him with anxiety, executive functioning deficits and a need for predictability in his life. Education regarding challenges typically faced by people with his genetic syndrome was provided to the people in his life, and helped all to better understand how these may impact Larry. For example, during the course of the discussion, Larry's mother reported that Larry intentionally walked into walls, stubbed his toe, and hit his hands onto things as a way of seeking attention. Through learning together, the team identified that a common issue associated with Larry's genetic syndrome is compromised depth perception.

With additional information Larry's challenges and diagnoses, Larry's mother and team were able to question assumptions their about "attention seeking" behavior. The I-START coordinator reported that this was a turning point for everyone, as it created an opportunity to challenge everyone to think differently about Larry. While understanding the symptoms associated with a diagnosis is one small step toward understanding the whole person, it allowed the team to take the very important step of reexamining old assumptions.

#### *Comprehensive service evaluation and diagnostic clarification*

A Comprehensive Service Evaluation (CSE) was conducted to gain a better understanding of Larry's mental health and medical conditions, treatment and service needs over his lifetime. Larry has a long list of medical diagnoses more commonly found with people with an intellectual disability and challenging behavior including a thyroid condition, Gastro-Esophageal Reflux Disease (GERD), Urinary Tract Infections (UTIs), constipation and obesity.

Larry was prescribed a many PRN (as needed) medications and some of the side effects associated with these medications were likely contributing to his insatiable appetite and weight gain. Larry was prescribed multiple antipsychotics without having a diagnosed psychotic disorder. While medication can help some people with aggression, there was no evidence that it was helpful for Larry and may have actually increased his physical discomfort and were likely a contributed factor in his ongoing chronic health conditions.

As a result of this evaluation, the I-START Medical Director recommended titration down and discontinuation of many of Larry's medications, a process which continues. All recommendations were supported by evidence in literature, Larry's history and training and support provided by the I-START Coordinator. Primary medical issues also included strategies to improve GI health. The final recommendation was to ensure that Larry took his thyroid medications on an empty stomach. Larry and his staff were taught that if the medication was taken with food (which often occurred) it would bind with the food in the stomach and not be metabolized properly, causing the medication to be less effective. This could result in shifts in weight, the presence of depressive symptoms, fatigue, and constipation, all of which had contributed to Larry's challenges in the past.

Additional recommendations aimed at the promotion of Larry's health and wellbeing included development of an improved diet and exercise routine. In addition, opportunities to see his family and enjoy more community activities were initiated, along with a plan to attain meaningful work. The CSE also provided guidance to teach Larry skills in the context of his adaptive abilities (documented in childhood test scores), as well as how to use his character strengths, identified through a positive psychology survey. Positive, strength based approaches are emphasized in the START model, and formed the basis of strategies recommended to promote Larry's use of his abilities. A key goal was to help Larry experience more enjoyment and cope with the inevitable stressors in life.

### *Outreach*

The I-START Coordinator conducted outreach visits and attended medical appointments to help with follow-up of recommendations from the CSE and other information gathered. Regular and frequent outreach meetings continued throughout the process. Improvements in collaboration between support staff, medical personnel and family members were encouraged to reduce the number of appointments needed for Larry. Finally, an emphasis was placed on caregivers helping Larry to have friends in the community to expand his natural supports.

### *Outcomes for Larry*

After 11 months of I-START services and in collaboration with community partners, great strides were made. Larry resides in his own apartment with staff supports. Staff members are trained to understand Larry, his mental health conditions and his genetic syndrome, which allow them better support him. Support staff help Larry attend to wellness routines, develop and maintain friendships, and to engage in meaningful activities. Larry does not have paid employment yet, but he is developing skills and the team has confidence and hope that this will occur in the near future. Larry has more positive interactions with family members and can attend some family functions and his time with family is slowly increasing.

There has been improvement in Larry's overall health, with a dramatic reduction in doctor's appointments. Larry used to see his primary medical doctor three times a

week and now maintains appointments every two months. He has shown independence in managing his medical conditions, reducing the constant discomfort he experienced in the past. While Larry still has some episodes of difficulty, his support team is better able to help him without escalation to acute crisis situations and he is no longer hitting, punching or scratching himself or others.

The cross-systems crisis plan was implemented, and Larry no longer relies on emergency rooms and law enforcement, as his support team is better able to help him. In fact, emergency room visits and law enforcement contact have decreased dramatically, from 3 to 4 times per week to zero incidents in the last 5 months.

All clinical assessments indicate Larry has improved. The support system and Larry are no longer in crisis. As a community of caregivers, Larry's team has learned how to better support not only Larry, but also others like him who have similar genetic syndromes or presentation. While there is much more work to do with Larry and his team, everyone involved has a renewed, more hopeful perspective and Larry has greater opportunity for improved quality of life.

## **Discussion**

In the present prospective study of the implementation of the I-START program, improvements in mental health symptoms and a decrease in urgent psychiatric service use were found after a one year period, including both hospitalization and ED use. These data suggest that START can help to improve outcomes for

individuals who are at high-risk of emergency service use, which can be both highly restrictive and expensive. Findings address an important gap in the literature, since mental health services for individuals with ID have been historically underdeveloped and understudied.

Improvements in the hyperactivity, lethargy, and irritability subscales of the ABC were observed. Addressing mental health and behavioral symptoms is important since individuals with ID are known to have elevated psychiatric symptomatology compared to the general population. In fact, these symptoms are the principle reason for referral to START and are a primary reason for caregiver stress and decreased family wellbeing.

The final outcome assessed changes in urgent psychiatric service use, including hospitalization and emergency department visits. It should be noted that more than half of this sample experienced an ED visit or inpatient hospitalization, which is an extremely high level of urgent service use. It is nearly two times higher than START service users in general and exponentially higher than the national average<sup>23,26,27</sup>. The fifty percent reduction in urgent and acute service use in only one year of I-START is quite encouraging. Prevention of and active support before and during a crisis are directly targeted by START interventions such as cross systems crisis planning, crisis response, outreach, and clinical/medical consultation services. Further research employing a larger sample is needed to parse out what elements of START are most responsible for the decrease in emergency service use.

The positive changes observed in this study mirror those found in previous research among START programs in different parts of the US<sup>23</sup>. Most critical however, is that the present study followed individuals prospectively, while prior investigations conducted a retrospective data review. This sample is also unique in that it was comprised of individuals with high levels of urgent psychiatric service use, primarily living in paid supportive settings. Previous samples included a much larger proportion of individuals living with family. I-START services were then associated with improved outcomes even the individuals who had a number of paid support workers caring for them were frequently in significant crisis.

The case example of Larry demonstrates how the I-START Clinical team provided services and supports to Larry and his system of care. The goal of all START programs is to collaborate with providers to improve care for specific individuals, but also to increase the overall capacity and understanding of the population as a whole. Key elements of the START model employed with Larry's team are aimed at mediating the effects of risk factors commonly associated with ID that contribute to behavioral health problems which then drive restrictive and expensive emergency service use.

### *Limitations*

There are several limitations to the study. First and foremost is the inability to compare individuals participating in START with individuals receiving services as

usual, which limits our ability to estimate treatment effects. A larger sample size would add power to the analysis as well, though studies involving individuals with ID often use small samples. Use of a control group and inclusion of two or more follow-up periods is an important next step in studying the effects of START. Despite these limitations, this study was conducted in a “real-world” setting and provides some initial evidence of potential effectiveness for a population that is so often neglected in this type of research. The potential for meaningful translation to practice is also enhanced by the fact that the START model is being implemented across many sites in the US, and is expanding. As noted, though individuals with ID and co-occurring behavioral health needs comprise a small percentage of people receiving psychiatric care, they consume a significantly disproportionate amount of available resources. The impetus for further study is then doubly supported by the need to improve the quality of life of people with ID and behavioral health challenges, and to reduce the proportion of mental health services funding spent on reactive, restrictive care.

### *Next Steps*

We are currently gathering Medicaid claims data from I-START participants and a control group in another region of Iowa with the help of stakeholders. The control group will be matched with the START intervention group, based on pre-intervention service use patterns, diagnoses, and regional locality. Data will be collected regarding changes in outpatient care, including mental health and primary care services, psychotropic medications, and ED as well as inpatient

services. Based on these preliminary findings and experiences in applying the START model, we hypothesize that START enrollees will use more outpatient services and less urgent psychiatric services, compared to controls. Findings from each phase of investigation will be submitted to a scientific journal and conferences for dissemination. The Special Hope Foundation will be identified as the source of funding among all dissemination initiatives.

In the future, we will submit an R01 grant to either the NIMH or NICHD to study START using the gold standard study design: a randomized trial. Data gathered through the current project will be critical to substantiate the level of funding requested to conduct such a study. We thank you for your support for this important project and hope that this is just the beginning to improving care for this historically underserved and frequently overlooked population.

#### *Dissemination plan*

Dissemination of findings from this study will occur through presentations at the annual national AUCD and NADD meetings in the fall of 2017. In addition, a paper will be submitted for peer review publication. A poster presentation of the results will occur in the spring of 2018 at the National START Training Institute. As mentioned earlier, we plan to continue this analysis with claims data evaluation. In addition, the results of this study will be presented to stakeholders in the state of Iowa.

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