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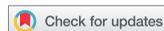
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Improving Mental Health Outcomes for Individuals With Intellectual Disability Through the Iowa START (I-START) Program

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ABSTRACT

Individuals with intellectual disability (ID) experience high rates of psychiatric disorders, and coinciding high rates of emergency service use. The current study seeks to explore strategies to improve outcomes by reporting a one-year prospective investigation among 41 individuals (Mean age = 32 years, *SD* = 12) with ID and mental health needs who received specialized supports from the I-START program (Iowa Systemic, Therapeutic, Assessment, Resources and Treatment) operating in a rural region of Iowa. To supplement these data, a qualitative case study details the application of the START model. Results indicate that individuals supported by the I-START program experienced significant reductions in informant-reported problem behaviors and fewer psychiatric emergency department visits and hospitalizations over time. Findings illustrate the benefits of START in improving outcomes for individuals with ID and mental needs as well as their systems of support.

KEYWORDS

Intellectual disability; mental health; START; outcomes; cross-systems collaboration; crisis intervention

Intellectual disability (ID) is a developmental disability characterized by significant limitations in intellectual functioning (e.g., learning, reasoning, problem solving) and adaptive skills (e.g., language, time management, daily activities, social skills) that persist throughout an individual's lifespan. With prevalence estimates ranging from 1–3% of the U.S. population, ID is one of the most common developmental disabilities (King, Toth, Hodapp, & Dykens, 2009). Numerous studies have documented that individuals with ID experience high rates of psychiatric disorders (Kats, Payne, Parlier, & Piven, 2013; King et al., 2009; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004; McCarthy et al., 2010), with roughly 40% meeting diagnostic criteria (Kats et al., 2013). 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 (Davies, Heyman, & Goodman, 2003; Kats et al., 2013; King et al., 2009; La Malfa et al., 2004;

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McCarthy et al., 2010; Scott et al., 2008). Psychopathology, particularly externalizing behaviors, frequently persists into adulthood and requires specialized supports. Kats et al. (2013) found that 25% of adults (ages 30–65) with ID needed support for self-injury and disruptive and destructive behaviors. Another study completed in 2010 by McCarthy et al. 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 behavior.

Literature Review

The Importance of Addressing Mental Health Needs

Addressing the mental health needs of individuals with ID is critical because psychiatric symptoms are severely impairing, resulting in poorer long-term outcomes and functioning for the individual (Salomon & Trollor, 2017). Most often, family caregivers are the primary support system for the individual with ID. When the individual with ID has co-occurring mental health needs, this creates an additional layer of complexity, resulting in increased caregiver stress (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005), decreased family well-being and functioning (Baker-Ericzén et al., 2005), and decreased family resources (e.g., problems with employment and decreased household income) (Kogan et al., 2008; Zablotzky, Kalb, Freedman, Vasa, & Stuart, 2014). The combination of these factors places this population at particularly high risk for out-of-home placement across the life course.

Outpatient Mental Health Treatment

Although the presence of mental health needs in individuals with ID is well-documented, access to outpatient mental health treatment for this population is limited, and when services are available, caregivers often report dissatisfaction with the care provided (Krahn, Hammond, & Turner, 2006; Krauss, Gulley, Sciegaj, & Wells, 2003). The lack of community mental health professionals trained to treat people with ID contributes to limited access to mental health treatment and poor quality of care. For instance, general and child psychiatry training directors reported their trainees only received a few hours of didactics focused on developmental disabilities (DD), and they saw fewer than six patients with DD per year (Marrus et al., 2014).

Emergency Department Utilization

With limited outpatient options, caregivers may resort to using their local hospital emergency department (ED) to address their loved ones' mental health symptoms (Cheng, Chan, Gula, & Parker, 2017). Use of the ED for

psychiatric care is problematic since treatment in this setting can lead to the use of sedating medications, restraint, and seclusion (Lunsky, Paquette-Smith, Weiss, & Lee, 2014). These restrictive interventions have been associated with patient injuries and deaths, staff injuries, and long-term trauma for all involved (Fish & Hatton, 2017; Wilkins, 2012). Identifying appropriate dispositions after the ED is often challenging since there are very few inpatient psychiatric units in the U.S. designed or equipped to meet the unique needs of these individuals (Siegel & King, 2014). As a result, psychiatric “boarding” (or extended ED wait times) occurs more frequently with patients with ID than with other patient populations (Wharff, Ginnis, Ross, & Blood, 2011). Consequently, caregivers, providers, and most certainly individuals with ID may experience stress, frustration, and disillusionment with the medical system as a result of long wait times and discharge plans that include little to no mental health resources.

Inpatient Hospitalization

Another byproduct of ineffective community-based mental health care is reliance on inpatient hospitalization services to manage an individual’s ongoing mental health needs (Mandell et al., 2012). Inpatient care should be considered a last resort, given the expense and restrictiveness associated with this setting, when outpatient options are not available. 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 (Salzer, Kaplan, & Atay, 2006). Similar to ED admissions, unwarranted stays due to lack of alternative care in inpatient psychiatric units represent reactive and restrictive forms of care, which can be distressing and traumatic for individuals with ID and their families (Loch, 2014).

The START Model

START, designed for persons and families with DD and co-occurring mental health needs, was first developed in 1988. START is an evidence-informed, tertiary care, crisis prevention and intervention model with rigorous fidelity requirements. The program utilizes many different approaches, including strengths-based, solutions-focused, person/family centered, biopsychosocial, and multidisciplinary assessment and treatment methods. START works to address the needs of individuals and their support networks, while enhancing expertise and partnerships in community-based systems of care.

There are currently 19 regional START teams in nine states across the U.S., with more in development. 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 University Center for Excellence in Developmental Disabilities

(UCED) at the University of New Hampshire. Further information about the National START model can be found at www.centerforstartservices.org.

The I-START Clinical Team

The I-START clinical team was developed by County Community Services (CSS) in 2015 to provide more effective community supports and services for people with DD and mental health needs in a large, primarily rural, region of Iowa. The I-START clinical team is comprised of a program director/team leader (masters-level mental health clinician/social worker), part-time medical director (licensed physician), clinical director (licensed psychologist), and masters-level I-START coordinators. In addition, there are network partners—comprised of but not limited to families and various providers (residential, primary medical, mental health, schools, and other social services)—who work in close collaboration with the clinical team. I-START team members receive extensive training in the mental health aspects of DD and are required to demonstrate core competencies in START coordination before receiving national certification. The average cost per client receiving I-START services was reported by CSS to be \$9,500.00 (U.S.) per year. It is likely that a client's costs for I-START can be recouped through the reduction of a single psychiatric hospitalization and the accompanying emergency department visit, which often facilitates the admission (Bakken & Martinsen, 2013; Brown, Brown, & Dibiasio, 2013; Kalb, Stuart, Freedman, Zablotsky, & Vasa, 2012).

The I-START clinical team provides cross-systems crisis planning and 24-hour crisis response, outreach, training, and consultation services. I-START team members facilitate ongoing linkage meetings to include each person's system of care. A START Cross Systems Crisis Prevention and Intervention Plan (CSCPIP) is developed with the support system of each person enrolled in the program. In addition to linkage meetings, crisis planning and response, outreach occurs in all settings including the individual's home, school, job and/or day program. Lastly, clinical and medical consultation services delivered by the I-START medical and/or clinical director and facilitated by the I-START Coordinator are available to all individuals enrolled in I-START. Services often include comprehensive reviews of service history (Comprehensive Service Evaluations), diagnostic assessment, follow-up, and consultation.

Prior Research on the START Model

In total, three studies have examined outcomes associated with START. Two of these studies occurred during the early stages of START development and provided evidence that the model could lead to a reduction in health-care costs and emergency psychiatric service use, as well as an improvement in service experiences (Beasley, Klein, & Weigle, 2016; Fahs, Weigle, Smith, & Benson, 2007). A

more recent study examined outcomes for 111 individuals receiving START services in the northeastern and southwestern portions of the United States (Kalb, Beasley, Klein, & Caoili, 2017). Results suggested START was effective in improving caregivers' evaluation of service experiences, problem behaviors, and emergent psychiatric service use (Kalb et al., 2017). Since many individuals with ID and co-occurring mental health symptoms, including those enrolled in START, reside in group-home settings, an important limitation to Kalb et al.'s (2017) study was that participants solely resided with family caregivers.

The current study of I-START expands previous research on the START model in three ways. First, it examines outcomes among individuals who are predominantly placed in paid-support settings. Investigation of this group is critical since many individuals with ID and co-occurring mental health conditions reside in paid-support settings and 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 U.S. where previous studies of START have occurred. Third, this study includes a qualitative case analysis which will assist readers in understanding how the START model was applied by I-START.

Methods

This study employed a prospective design using a variety of psychometric, services utilization, and qualitative metrics. First, quantitative data are presented on one-year, pre and post changes in (1) problem behaviors and (2) use of emergency psychiatric services, including both inpatient hospitalization and emergency department visits, in a sample of individuals with ID served by the I-START team. Second, a case study of an individual receiving START services is detailed.

Sample

Pre and post data were gathered from 41 individuals who were enrolled in a recently developed START program located in Iowa between 2015 and 2016. 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 = 15.5, max = 58.8, $SD = 11.9$). Only two individuals were under 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 disorder, $N = 5$), followed by psychotic disorders ($N = 13$) and other disorders of attention and impulse control (attention-deficit/hyperactivity disorder, $N = 11$, impulse control, $N = 7$, and oppositional defiant disorder, $N = 2$). Diagnoses were abstracted through

information gathering during the intake assessment process. The intake includes face-to-face interviews, clinical observation, and the review of psychiatric/psychological evaluations and reports.

All individuals who received I-START services were included in this study. All data were gathered prior to discharge. At the time of enrollment, 70% of the sample lived in supported community settings. 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 Institutional Review Board (IRB) review.

The START model relies on data to provide feedback to state and local policymakers, project managers, and administrators as they assess the effectiveness of START services. To capture such crucial information, START has built and refined a custom online database, the START Information Reporting System.

Measures

Problem Behaviors

The community version of the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985) was employed in this study as the measure of problem behaviors. The ABC is a well-known and psychometrically robust measure that was designed specifically for individuals with ID (Aman et al., 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. The individuals' case managers served as the informant at pre and post for the ABC, outside of the three individuals who were living with their families. The case manager was an independent source of information and, therefore, not affiliated with START. The same case manager served as the informant at both time points.

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, the individuals' case manager provided information on use of these services in the year prior to I-START enrollment. During I-START involvement, the individuals' I-START coordinator prospectively captured service use within the national START Information Reporting (SIRS) database.

Analysis

Mean pre and 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 in the probability of hospitalization and ED visits between pre and post, 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 version 11.0 and considered statistically significant at the $p < .05$ level.

Overall, there was little missing data. However, the ABC was only available for 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. There was no association between ABC missingness and gender ($p = .80$), race ($p = .21$), total number of psychiatric symptoms ($p = .54$), pre-visit hospitalization ($p = .13$), or emergency department use ($p = .13$). However, those with missing ABC data were enrolled in START for a shorter time period (357 vs. 455 days; $< .01$) and had higher pre-test irritability scores ($M = 25.1$ vs. 17.1; $p < .01$). Since there was no association between length of time enrolled in START and change in ABC subscale scores (all $p > .50$) and 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 may actually be conservative. That is, if all data were available for the post-test ABC score, the effects may have been larger in magnitude than those reported here.

Results

Problem Behaviors

As shown in Table 1, significant decreases in problem behaviors, between pre and post, were observed for each of the ABC subscales range (all $p < .05$). Effect sizes for the Hyperactivity ($d = .46$), Irritability ($d = .60$), and Lethargy subscales ($d = .50$) were all in the moderate range.

Urgent Psychiatric Service Use

During the year prior to I-START enrollment, 53% of individuals enrolled in I-START experienced a psychiatric hospitalization. During that same

Table 1. Changes in mental health presentation.

| Variable | Pre-Test | Post-Test | Effect Size (d) | Test statistic | p -value |
|---------------|----------|-----------|---------------------|----------------|------------|
| ABC (Mean) | | | | | |
| 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 | $t = 2.12$ | $< .05$ |

Table 2. Changes in urgent psychiatric service use.

| Variable | Pre-Test | Post-Test | Test statistic | <i>p</i> -value |
|---|----------|-----------|----------------|-----------------|
| Psychiatric Hospitalizations (%) | 53% | 24% | $z = 12.00$ | $< .001$ |
| Psychiatric Emergency Department Visits (%) | 66% | 39% | $z = 7.12$ | $< .01$ |

time period, 66% visited the ED for psychiatric concerns. Over the following year, the proportion of individuals who experienced psychiatric hospitalizations and who were seen in an ED for psychiatric problems significantly decreased to 24% and 39%, respectively (both $p < .05$). See Table 2 for further details.

Case Description

“Larry” (a fictitious name; other modified identifiers were used to protect the identity of the individual) is a young adult who was referred to the I-START program due to a high frequency of aggressive incidents, emergency department visits, and disturbances resulting in police involvement.

Larry was adopted at age three by a large family in rural Iowa and has maintained a loving relationship. Larry was diagnosed with Fragile X 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 at the time of the adoption, little was understood about his disorders or how to support him as he grew into adolescence. Larry attended special education classes and did better in a structured school setting than at home. As Larry’s challenges increased over time, he received numerous mental health diagnoses from community providers and emergency departments. In addition, he had a number of chronic medical conditions that required regular and proactive attention. Larry was constantly concerned about his own health.

Both Larry and his support system were in crisis at the time of referral. The residential program staff were overwhelmed by Larry’s challenges and struggled to intervene effectively. There was frequent police involvement to manage his aggression, along with frequent ED visits. Larry insisted on and made many doctor appointments, a concern to his caregivers and treaters. This, along with many ED visits and police involvement, was a strain on Larry, his residential provider, and his family, and contributed to negative perceptions of Larry in his community. Thus, the focus of treatment and supports was centered on managing Larry’s externalized behavior to reduce disrupting others in his community.

I-START Services Provided

The I-START coordinator worked with Larry's providers and family to better understand Larry and his needs. Outreach visits to the home and day-program settings, 24-hour crisis response, and cross-systems crisis planning and training that included increased understanding of how to support an individual with Fragile X were provided. Crisis-prevention and intervention-planning meetings focused on Larry's strengths, skills, and interests to build capacity to ride out difficulties at home. A solutions-focused, strengths-based dialogue was facilitated by the I-START coordinator to reframe perceptions about Larry with his system of support to foster a collaborative plan that included diagnostic clarification, treatment modification, and changes in his day and residential programming. When Larry and his team needed crisis support they contacted I-START to reduce dependence on the ED and police.

The Turning Point

Education regarding challenges typically faced by individuals with Fragile X helped people to view Larry's presentation differently and, as a result, Larry's mother and providers questioned prior assumptions about his "attention seeking" behavior. The ongoing dialogue and exploration of Larry's point of view and what he might be experiencing created an opportunity to challenge their thinking and approaches. While understanding the symptoms associated with a diagnosis is one small step toward understanding the whole person, it fostered the reexamination of old assumptions and reduced conflicts between caregivers and Larry.

Comprehensive Service Evaluation and Diagnostic Clarification

A Comprehensive Service Evaluation (CSE) was conducted to evaluate Larry's mental health and medical conditions and treatment, psychosocial stressors, and service needs over his lifetime. Larry was found to have a thyroid condition, gastro-esophageal reflux disease (GERD), urinary tract infections (UTIs), constipation, and obesity. To treat Larry's challenging behavior, a polypharmacy of medications were prescribed and side effects associated with these medications were likely contributing to his medical problems. The medical director of I-START recommended that prescribers consider this and work to improve treatment. While antipsychotic medication can help some people with aggression, there was no evidence that it was helpful for Larry. In fact, it may have actually increased his physical discomfort, contributed to his health conditions, and exacerbated his behavioral challenges.

Recommendations from the CSE included titration and discontinuation of many of Larry's psychiatric medications. Additional recommendations included strategies to improve gastrointestinal health and having Larry take his thyroid medications on an empty stomach, a practice that had not occurred prior to the review. Larry and his staff were taught that if the medication was taken with food it would bind with the food in the stomach and not be metabolized properly and result in shifts in weight and the presence of depressive symptoms, fatigue, and constipation. Once successful medical strategies began to be implemented, Larry felt less discomfort and the frequency of doctor's appointments declined.

Positive, strength-based approaches formed the basis of strategies recommended to promote an improved quality of life for Larry. Recommendations focused on the promotion of Larry's health and well-being, including a diet and exercise routine, increased opportunities to see his family and engage in community activities, and a plan to attain meaningful work. The CSE also provided guidance to teach Larry skills in the context of his adaptive abilities, as well as how to engage his character strengths, identified through a positive psychology survey and many discussions with and about Larry.

CSE Follow-Up and Outreach

An important element of the START model is that the START coordinator helps to navigate changes in treatment and services. The I-START coordinator conducted outreach visits and attended medical appointments to follow up with recommendations from the CSE and other information gathered. Scheduled network meetings and outreach visits continued throughout the process.

Outcomes for Larry

After 11 months of I-START services in collaboration with community partners, great strides were made. There was an improvement in Larry's overall health, with a dramatic reduction in doctor's appointments from three times a week at time of intake to once every other month. While Larry still had some periods of difficulty, his support team was better equipped to help him without escalation to acute crisis situations. Since the CSCPIP was implemented and I-START provided crisis support, ED visits and law-enforcement contact decreased dramatically, from three to four times per week at the time of I-START enrollment to zero incidents in the last five months.

Consistent with the mission of START, Larry's team reported that they feel better equipped to support not only Larry, but others like him. While there is more work to do with Larry and his team, everyone involved has a renewed, more hopeful perspective and Larry has a greater opportunity for an improved quality of life.

Discussion

In this prospective study of the I-START program, improvements in problem behaviors and a decrease in both hospitalizations and ED use were found after a one-year period. Clinical application of these findings, and how START uniquely supports those with ID and co-occurring mental health needs, was demonstrated through a case study. These data add to a growing body of literature suggesting that START can improve outcomes. Findings also add to the scant body of effective interventions designed for individuals with ID and co-occurring mental health needs.

The reduction of problem behaviors is a critical outcome since these symptoms are the principle reason for referral to START. Using the ABC, improvements in hyperactivity, lethargy, and irritability were observed. This is now the second study to report such findings (Kalb et al., 2017). Future research is required to better understand if particular START interventions are responsible for these findings or if decreased problem behaviors are a product of increased access to community mental health providers.

The second outcome assessed changes in urgent psychiatric service use, including hospitalizations and ED visits. It should be noted that more than half of this sample experienced an ED visit or inpatient hospitalization prior to START, which is an extremely high level of emergency service use. It is nearly two times higher than START service users in general and exponentially higher than the national average (Blader, 2011; Kalb et al., 2017; Weiss, Barrett, Heslin, & Stocks, 2006). The 50% 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, 24-hour 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 these findings.

The positive changes observed in this study mirror those found in previous research among START programs in different parts of the U.S. (Kalb et al., 2017). This sample was unique in that it was comprised of individuals primarily living in paid supportive settings, whereas previous samples included a much larger proportion of individuals living with family. Findings from this study were similar to previous investigations, suggesting that START services work equally well for those with high levels of need in paid supportive settings as it does for individuals living with family members.

The case description demonstrates how the I-START clinical team provided services and supports to an individual (“Larry”) and his system of care. The goal of all START programs is to collaborate to improve care for specific individuals, but also to increase the overall capacity and understanding of the population as a whole. A strengths-based biopsychosocial approach with

stakeholder engagement is essential. Key elements of the START model employed by I-START with Larry's team were aimed at mediating biopsychosocial vulnerabilities commonly associated with his conditions.

Limitations

There are several limitations to the study. First and foremost is the inability to compare individuals participating in I-START with individuals receiving services as usual, which limits our ability to estimate treatment effects. A larger sample size would also improve the study power, although findings still met statistical significance and, more importantly, they generalized to a different population than previously studied within START. Identifying a control group and following participants for longer periods of time are important next steps in studying the effects of START. Notably, this study did not have any information about clients after they were discharged from START. Future research is required to understand if there are sustained effects on the client, family, and community for significant amounts of time after termination of services.

Implications for Future Research

Understanding the mechanisms of action within START is another critical next step. Further work needs to deduce which intervention within START's armamentarium of approaches is the causal ingredient responsible for one or more of the study outcomes. This will help elucidate and refine the model as well as provide a basis for sharing successful tools and strategies.

Strengths of this study include understanding the effectiveness of START in improving meaningful outcomes in community, or "real world," settings. This study also employed a prospective design using a variety of psychometric, services-utilization, and qualitative metrics. As START expands across the U.S., it is critical to study implementation of the model in real time for a population that has been historically overlooked and underserved.

Disclosure statement

No potential conflict of interest was reported by the authors.

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