Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated With the START Program

Luther G. Kalb, Joan Beasley, Andrea Caoli, and Ann Klein

Abstract
This study examined outcomes from the Systemic, Therapeutic, Assessment, Resources, and Treatment (START) program, a community-based tertiary care model for individuals with intellectual and developmental disabilities and mental health needs. The sample included 111 START service users and their family caregivers, who were receiving START Clinical Team services, located in the Northeast and Southwest regions of the United States. Results from the analyses found a significant 1-year pre-post improvement in caregiver service experiences and mental health symptoms of the service user. A significant decrease in psychiatric hospitalizations and emergency department visits was also found (all $p < .01$). These data suggest that START holds promise in improving outcomes, for both the caregiver and service user, while reducing dependence on costly and restrictive hospital-based services.

Key Words: developmental disability; intellectual disability; mental health; services; hospital

Intellectual disability (ID) is characterized by a delay in cognitive and adaptive functioning with an onset during early development (King, Toth, Hodapp, & Dykens, 2009). ID is one of the most common developmental disabilities, with prevalence estimates ranging from 1% to 3% of the U.S. population (King et al., 2009). The impairment due to ID is substantial. For instance, the years of life lost through premature death and suboptimal health due to ID is six times greater than attention deficit-hyperactivity disorder (ADHD; Salomon et al., 2015; World Health Organization, 2013).

One common challenge among those with ID is the frequent co-occurrence of externalizing symptoms associated with mental illness, such as physical and verbal aggression, property destruction, and disruptive behavior (Borthwick-Duffy, 1994; Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Using an epidemiologically defined sample in the United Kingdom, Emerson (2003) reported a quarter of youth with ID met criteria for a conduct-related disorder; a proportion that was seven times greater than those without ID (Bradley et al., 2007). Kats and colleagues (2013) produced similar findings among adults with ID across two nationally representative samples in the United States (Kats, Payne, Parlier, & Piven, 2013). In the START (Systemic, Therapeutic, Assessment, Resources, and Treatment) program, the most common reason for referral is aggression. Addressing these mental health symptoms is critical because the presence of such has been associated with (a) poor social and academic functioning (Gadow, DeVincent, & Schneider, 2008), (b) lower overall quality of life (Kuhlthau et al., 2010), (c) earlier age at mortality (Patja, Molsa, & Iivanainen, 2001), and (d) use of expensive, restrictive hospital-based psychiatric services (Kalb, Stuart, Freedman, Zablotsky, & Vasa, 2012; Mandell, 2008).

Despite the prevalence of mental health needs, access to outpatient psychiatric treatment for individuals with ID is limited (Dom & Prout, 1993; Krahn, Hammond, & Turner, 2006). The dearth of...
mental health services is partly due to the lack of mental health professionals trained to treat them (Krahm et al., 2006). Even when services are available, caregivers describe their experiences with the mental health service system as fragmented, unresponsive, and insufficient (Krahm et al., 2006). The START program is specifically designed to address these concerns.

START serves individuals with intellectual and developmental disabilities (IDD) and co-occurring mental health needs. The goal of START is to (a) enhance local capacity, (b) promote the development of least-restrictive life-enhancing services and supports, and (c) provide education as well as training to providers and caregivers. The Center for START Services, located at the University of New Hampshire Institute on Disability/University Center for Excellence in Disability, was founded in 2007 to assist in the dissemination of the START model that was first developed in 1988. The current network of START providers serve individuals across 10 states in the United States, with more states in development.

Two previous studies have shown promising outcomes for START (Beasley, 2002; Fahs, Weigle, Smith, & Benson, 2008). Fahs et al. (2008) compared differences in service use—including emergency department (ED) visits, hospitalizations, incarcerations, and respite days—and concomitant costs between START enrollees ($n = 15$) and a non-START ($n = 14$) waitlist comparison group using Medicaid claims data. Although the findings suggested that the START condition had reduced service use and cost compared to the matched control condition, the study design (e.g., length of observation, statistical methods) was unclear and the sample size was very small. Beasley (2002), on the other hand, conducted a 4-year cohort study of 88 families receiving START services in Massachusetts. The author reported an improvement in service experiences and a decrease in ED visits and inpatient hospitalizations. However, that study was conducted nearly two decades ago in the earliest stages of START. Today, START includes many more services and fidelity procedures—such as site and coordinator certification in START practices, case conferences, formalized linkages, custom assessments—than those reflected in Beasley (2002). The present study overcomes these limitations by providing an up-to-date review of START, including data on client mental health outcomes using a larger sample size across several regions. More specifically, the goal of this study was to examine 1-year pre-post changes in (a) caregiver evaluation of service experiences, (b) the individual’s mental health symptoms, and rates of (c) psychiatric hospitalizations, and (d) psychiatric emergency department visits.

Based on prior research, that found significant effects associated with START emerged in the third year of a cohort study, we hypothesized that a trend towards improvement would be observed across outcomes (Beasley, 2002). Given the length of the study period and the newly developed programs in which the sample resides, we expected the changes to be small.

**Methods**

The **START Program**

START is an evidence-informed model that includes a community of practice for evidence-based interventions and fidelity requirements. Methods employed in the model aim to enhance expertise and partnerships across systems in order to provide effective community-based support and treatment for individuals with IDD and co-occurring mental health needs. This model includes linking all START programs through data collection, reporting and the application of START practices. More information about START can be found here: [http://www.centerforstartservices.com/default.aspx](http://www.centerforstartservices.com/default.aspx).

**START Information Reporting System (SIRS) Database**

All START Clinical Team members are required to submit data into the SIRS database. The purpose of ongoing data reporting is to evaluate the implementation, fidelity, and effectiveness of START programs that are located throughout the country. Training to accurately enter data into SIRS is provided and the quality and frequency of data entry is closely monitored by the Center for START Services, where SIRS is housed. All information entered and extracted from SIRS is fully de-identified and was used for the present study which was deemed exempt from human subjects research, by the governing Institutional Review Board, given the data were gathered during routine care and were absent of identifying information during the analysis.
START Clinical Team Services and START Coordination

This study reviews outcomes associated with START Clinical Team Services, the foundation on which the START model is built. All START programs have a Clinical Team that is made up of, at minimum, (a) a director (a master’s level clinician), (b) medical director (psychiatrist), (c) clinical director (doctoral-level psychologist), (d) clinical team leader (a master’s level clinician), and (e) master’s level START Coordinators who carry caseloads of service recipients. Once Clinical Teams consistently meet programmatic fidelity to the START model, they become certified through the Center for START Services. Certified programs are required to remain in the national training network and continue with SIRS data entry. Quality reviews are conducted annually to ensure continued adherence to the START model. The START Clinical Teams reported on in this study were newly implemented. They were chosen because enrollment trends for new programs allow for capturing a cohort of families who enter START at similar times.

START Clinical Teams develop and maintain linkage agreements with local providers and service systems that are used by START Coordinators to assist in their daily practices. The purpose of these agreements is to promote cross-system collaboration, clarify roles and responsibilities, and identify as well as overcome existing barriers in the system. START Clinical Teams operate 24 hours a day, 7 days a week, including crisis evaluation and support services.

START Coordinators receive national certification from the Center for START Services upon completion of extensive training. A central component of work for START Coordinators is to develop an integrated understanding of the individual and his needs. This knowledge, along with input from other members of the START Clinical Team, is used to conduct assessment and training as needed. All members of the Clinical Team, including START Coordinators, are experienced in serving and treating individuals with IDD and co-occurring mental health symptoms. In this study, two of the (lifespan) teams served individuals ages 6 and older. One of the (adult) teams provided services to adults 18 years of age and older. Both teams provide outreach to and coordinated care among all individuals involved in the client’s life. This approach includes, but is not limited to, the educational system and attending the individualized education program (IEP), medical providers and institutions as well as family members and caregivers.

Crisis prevention and intervention. START Clinical Teams provide 24-hour mobile crisis prevention and intervention services. The primary tool to assist caregivers and first responders is the START Cross System Crisis Prevention Plan (CSCPIP). The CSCPIP is an individualized written plan of response to provide a clear, concise, and realistic set of supportive interventions to prevent or de-escalate a crisis. The goal of the CSCIP is to build the capacity of primary caregivers to address vulnerabilities in the person’s setting through the identification of individual character strengths and effective strategies in early stages of difficulty. The plan offers a tertiary level of response that ranges from early intervention to assisting during an acute crisis. All CSCIPs are developed and implemented by START Coordinators in collaboration with the person’s system of support. Ninety-one percent of all individuals in this study had a completed CSCPIP (mean hours of crisis planning and collaboration with the primary system of care = 9.5 per individual).

START employs 24-hour crisis evaluation and response services. Emergency calls come from a variety of sources such as emergency departments, community providers, families, and law enforcement. Adherence to the model requires immediate telephonic response and in-person evaluation within 2 hours of the initial contact. In this study, 40% of all individuals were involved in a crisis evaluation (mean number of crisis evaluation events per individual during the study period = 3.0).

Outreach. Outreach involves any non-emergency contact made with the individual or their system of support by the START coordinator. Examples include (a) home- and school-based visits to observe the individual in their daily setting, (b) visiting the family home to help a parent implement a plan or strategy, and (c) checking in with the individual to assess their level of stability. In this study, 96% of individuals received outreach (mean hours of outreach during the study period = 11.1).

Medical/psychiatric consultation services. Clinical consultation services are available to all START members and their network. When consultation services are not requested by the
caregiver or client, but deemed clinically necessary, the START Clinical Team initiates the service. These services are often delivered by the START medical and/or clinical director and include, but are not limited to, (a) diagnostic assessment, (b) medication review, (c) medical or psychiatric follow-up, and (d) consultation with the individual’s outpatient providers. Sixty-three percent of individuals in this study received medical/psychiatric consultation services (mean hours of clinical evaluation during the study period = 2.7).

Inclusion Criteria and Sample Characteristics

Data were gathered during routine START operations between 2014 and 2016. During that time between 200 and 250 individuals were served. Of those, baseline data were gathered on 155 individuals, of which 117 (75%) completed the follow-up.

The present study has four inclusion criteria. First, the person must have a diagnosis of an intellectual or developmental disability. The presence of such is usually required by states for funding of START services. Second, the individual must live with a family caregiver, rather than in a group home or a supported setting, since the caregiver served as the primary informant. Third, the participant must have a state-funded autism spectrum disorder (ASD) and/or ID waiver or receive SSDI (Medicaid) insurance because this is the funding mechanism for receipt of START Clinical Team services. Fourth and finally, the individual must be enrolled in START for at least 6 months. Six individuals who were enrolled on average for 2 ½ months were therefore removed from the sample.

Data for this study were gathered from caregivers of 111 individuals with IDD from four START Clinical Teams that were providing services in two states located in the southwestern (n = 15) and northeastern (n = 96) United States. Fifty-seven of the participants were youth (Mean age = 14y, Min = 6y, Max = 17y) and 53 were adults (Mean age = 27, Min = 18y, Max = 61y). Most of the subjects were male (71%), and were White (84%); 4% Asian, 12% African American). Eighty-three percent of the sample had ID. Fourteen individuals (13%) were Hispanic and 13 interviews were conducted in Spanish. About a third of caregivers reported only attending or graduating from high school, 24% reported attending some college, and 31% reported completing an undergraduate degree.

More than half of the sample were diagnosed with ASD (58%) and most had a diagnosed co-occurring psychiatric disorder (63%; Mean diagnoses = 1.3). Slightly fewer than half of the sample (42%) were diagnosed with an internalizing disorder (i.e., depression, anxiety, or adjustment disorder), 35% were diagnosed with an externalizing disorder (i.e., impulse control disorder, ADHD/ADD), and 26% received a psychosis-related diagnosis (i.e., schizophrenia, psychotic or bipolar disorder). All diagnoses were obtained via chart review. For the informant, most were parents (84%), female (91%), married (69%), and were, on average, 48 years of age (SD = 10.5 y).

Measures

Perceived quality of mental healthcare. Caregivers perceived support from and attitudes towards the mental healthcare system were assessed via the Family Experiences Interview Schedule (FEIS), a semistructured interview (Tessler & Gamache, 1993; Tessler, Gamache, & Fisher, 1991). The FEIS was chosen since it directly aligns with and measures the mission of START: to improve access, appropriateness and accountability of the mental health service system. A total of 20 Likert-based items were gathered from the FEIS across three subsections of the Global Evaluation of Mental Health Professionals (GEMHP) subscale. Specifically, nine items from the first subscale assessed how family members appraised their own involvement as partners in treatment for their dependent. The second subscale included seven items that examined the perceived quality of services provided directly to the respondents’ dependent. The final four items from the third subscale examined beliefs about how well the mental health system responds to the needs of the caregivers. All items from the FEIS are shown in Table 1.

The FEIS used in this study was slightly altered from its original form to fit the study objectives. Changes to the FEIS included altering the reporting period to the past year, due to the study design, and dropping items 2-4, 8, and 12 on the second subscale because those items were not related to mental health services. Previous research across multiple samples have shown the GEMHP to be reliable (Cronbach’s α = .82) and internally valid (Tessler & Gamache, 1993). In this sample,
Table 1
Pre-Post Change in Family Experiences Interview Schedule (FEIS) Item Scores

<table>
<thead>
<tr>
<th>FEIS Items</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subscale 1: Involvement with professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Receive enough information</td>
<td>2.7 (1.1)</td>
<td>3.0 (.92)</td>
</tr>
<tr>
<td>2. Assistance if there was a crisis</td>
<td>2.4 (1.1)</td>
<td>2.9 (.97)</td>
</tr>
<tr>
<td>3. Information about who to call during a crisis</td>
<td>2.3 (1.1)</td>
<td>3.2 (1.0)</td>
</tr>
<tr>
<td>4. Encourage to take an active role</td>
<td>2.8 (1.2)</td>
<td>3.3 (1.0)</td>
</tr>
<tr>
<td>5. Respond to concerns</td>
<td>2.6 (1.1)</td>
<td>3.1 (.9)</td>
</tr>
<tr>
<td>6. Take into account ideas and opinions</td>
<td>2.8 (1.1)</td>
<td>3.2 (.9)</td>
</tr>
<tr>
<td>7. Involve caregiver in treatment</td>
<td>3.1 (1.0)</td>
<td>3.6 (.7)</td>
</tr>
<tr>
<td>8. Recognize burdens</td>
<td>2.5 (1.1)</td>
<td>3.2 (.9)</td>
</tr>
<tr>
<td>9. Regular contact with providers</td>
<td>3.2 (1.0)</td>
<td>3.5 (.8)</td>
</tr>
<tr>
<td>Subscale 2: Evaluations of client services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Services available were the ones that are needed</td>
<td>2.5 (1.1)</td>
<td>3.0 (.9)</td>
</tr>
<tr>
<td>11. Express opinion</td>
<td>3.0 (1.1)</td>
<td>3.4 (.8)</td>
</tr>
<tr>
<td>12. Choose between service options</td>
<td>2.2 (1.1)</td>
<td>2.8 (1.1)</td>
</tr>
<tr>
<td>13. Choose between different providers</td>
<td>2.5 (1.2)</td>
<td>2.7 (1.1)</td>
</tr>
<tr>
<td>14. Convenient to use services</td>
<td>2.6 (.9)</td>
<td>3.2 (.8)</td>
</tr>
<tr>
<td>15. Services flexible enough to meet needs</td>
<td>2.7 (1.1)</td>
<td>3.2 (1.0)</td>
</tr>
<tr>
<td>16. Satisfied with services</td>
<td>2.6 (1.1)</td>
<td>3.0 (1.0)</td>
</tr>
<tr>
<td>Subscale 3: Response to family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Respond to the wishes of the family</td>
<td>2.5 (1.1)</td>
<td>2.9 (1.1)</td>
</tr>
<tr>
<td>18. Say about services needed</td>
<td>2.7 (1.1)</td>
<td>3.3 (.9)</td>
</tr>
<tr>
<td>19. Satisfied with role in treatment</td>
<td>2.8 (1.1)</td>
<td>3.3 (.9)</td>
</tr>
<tr>
<td>20. Available help on nights/weekends</td>
<td>1.9 (1.0)</td>
<td>2.9 (1.1)</td>
</tr>
</tbody>
</table>

the internal consistency of the FEIS was similar (Cronbach’s α = .93) to those previously reported in the FEIS manual (Tessler & Gamache, 1993). Baseline FEIS interviews took place with the START coordinator at time of intake. Follow-up interviews were conducted by an individual who was not involved with the family’s care. All interviewers were trained in conducting FEIS interviews by the site director, who has previous expertise in conducting the measure. Each interview took approximately 20 min to complete.

Mental health. The community version of the Aberrant Behavior Checklist (ABC) was used to measure the presence of mental health symptoms. The ABC is a heavily cited and psychometrically sound measure of psychiatric symptoms for both adults and youth with ID (Aman, Singh, Stewart, & Field, 1985). The ABC consists of 58-items across five subscales. Three of the five subscales—the Irritability, Lethargy, and Hyperactivity subscales—were employed in this study. The Stereotypic and Inappropriate Speech subscales were omitted because they are more closely related to autism symptomatology, such as stereotypies and echolalia, than mental health. Data on the ABC was available for 82% of the sample (n = 91).

Urgent psychiatric service use. Data on urgent psychiatric services, including psychiatric hospitalization and use of the emergency department for mental health purposes, was gathered separately from the study interviews. At baseline, informants provided information on use of these services in the year prior to START enrollment. While receiving services, START coordinators

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cataloged, in real time within the SIRS database, the number of visits an individual had to these settings due to mental health reasons. Capturing psychiatric service utilization is part of the routine duties of all START coordinators.

**Design and Analysis**

The present study used a 1-year pre-post design to examine changes in the FEIS, ABC, and urgent psychiatric service utilization from at or before participation in START to 1 year following START enrollment. The median time between pre- and postinterviews was 382 days (Mean = 403 days, SD = 105 days, Min = 196, Max = 715). Time enrolled in START was not associated with any study outcome (all p > .05). The difference between pre- and posttesting for 63% of interviews was > 365 days. All pretesting interviews took place during the START intake or when services began.

Mean pre-post changes in FEIS and ABC scores were analyzed using paired t tests. To maintain the full sample size for the FEIS, mean imputation at the item level was used because there was some missing data; although it was relatively rare (i.e., only 3 items had > 7% missingness). The within-person procedure imputed the missing value based on the individual’s grand mean from the remaining subscale items (Graham, 2009). Beyond the FEIS, the only other variables that had missing data of concern (i.e., > 5%) was ethnicity (12%) and education (12%).

Effect sizes for the FEIS and 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 postscores. To examine differences in the number of hospitalizations and ED visits between pre and post, the Wilcoxon signed-rank test, a nonparametric test for matched-pairs, was employed due to the highly skewed nature of the count-based data (Wilcoxon, 1945). All analyses were performed in STATA 11.0 (College Station, TX) and considered statistically significant at the $p < .05$ level.

**Results**

**Perceived quality of service experiences.** Shown in Table 2, significant improvements from pre to post were observed for each of the FEIS subscales as well as the overall score. For family members evaluations of their involvement with mental health professionals (subscale 1), the average increase in scores between pre and post corresponded to a moderate effect size ($d = .66$). Similar effect sizes were observed between pre and post for the family member evaluations of client services subscale ($d = .59$; subscale 2), the evaluations of system response to family members subscale ($d = .67$; subscale 3) and the total score ($d = .70$; all $p < .001$).

**Mental health.** Significant decreases were observed for each of the ABC subscales. Also shown in Table 2, effect sizes for the Hyperactivity ($d = .56$), Irritability ($d = .60$), and Lethargy subscales ($d = .56$) were in the moderate range (all $p < .001$).

**Urgent psychiatric service use.** During the year prior to START enrollment, 20% and 32% of individuals experienced a psychiatric hospitalization or emergency department visit for mental health or behavioral concerns, respectively. During the study observation period, 10% and 15% of individuals experienced a psychiatric hospitalization or emergency department visit, respectively. Shown in Table 3, a significant decrease in the number of visits in a year, between pre and post, was found across both service settings (all $p < .01$).

**Discussion**

Results from this study found improvements in caregiver service experiences and mental health symptoms of the individual with IDD, as well as a decrease in urgent psychiatric service use, associated with receipt of START Clinical Team services. These data suggest that START Clinical Team services can help to improve outcomes for both the individual within the community, while living with natural supports, for a population at high-risk of institutionalization. These findings also fill an important gap in the literature since mental health services for individuals with IDD have been historically underdeveloped and understudied (Krahn, Hammond, & Turner, 2006).

Significant improvement in caregivers’ perceived support from and attitudes towards the mental healthcare system was observed between pre and post. Moderate effect sizes were found for each of the FEIS subscales as well as the total score. The effect sizes observed were larger than originally hypothesized. Two of the FEIS subscales focused on similar topics: (a) caregivers’ perceived inclusion in their dependents’ care and (b) how responsive the mental health system was when they expressed their concerns. All elements
Table 2
Changes in Mental Health Outcomes and Caregiver Service Experiences

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th>Posttest</th>
<th>Effect Size (d)</th>
<th>Test statistic</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEIS (Mean, SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involvement with professionals</td>
<td>24.5 (7.4)</td>
<td>29.1 (6.2)</td>
<td>.67</td>
<td>T=5.4</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Evaluations of client services</td>
<td>18.1 (5.8)</td>
<td>21.4 (5.3)</td>
<td>.59</td>
<td>T=5.8</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Response to family members</td>
<td>10.1 (3.5)</td>
<td>12.3 (3.2)</td>
<td>.66</td>
<td>T=5.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Total Score</td>
<td>52.8 (15.2)</td>
<td>62.8 (13.5)</td>
<td>.70</td>
<td>T=6.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>ABC (Mean, SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>26.3 (11.2)</td>
<td>19.5 (12.6)</td>
<td>.56</td>
<td>T=6.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Irritability</td>
<td>24.9 (10.5)</td>
<td>18.7 (10.0)</td>
<td>.60</td>
<td>T=5.9</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Lethargy</td>
<td>15.7 (8.6)</td>
<td>11.0 (8.3)</td>
<td>.56</td>
<td>T=4.9</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Note. ABC = Aberrant Behavior Checklist; FEIS = Family Experiences Interview Schedule.

of START, especially START coordination and outreach, are designed to include caregivers in their dependents care whenever possible. These findings also address a known gap in mental health services research since providers can fail to prioritize caregiver perspectives and priorities (Ahmedani & Hock, 2012; Krahn et al., 2006; Zablotsky et al., 2014).

The other FEIS subscale examined the perceived quality of services provided directly to the caregivers’ dependent. Significant improvements in this subscale suggest START can improve both the access and appropriateness of services. Enhancing the quality of care that is afforded to the individual with IDD—through services such as medical/clinical consultation, crisis planning and intervention, provider education and linkage agreements—is another principle goal of START and a well-known gap for those with IDD (Krahn et al., 2006).

Improvements in the hyperactivity, lethargy, and irritability subscales of the ABC were observed. Addressing mental health symptoms is critical because those with IDD are known to have elevated psychiatric symptomatology compared to the general population (Borthwick-Duffy, 1994; Emerson, 2003; Kats et al., 2013) and these symptoms are the principle reason for referral to START. To put these findings in context with other interventions, the effect sizes observed for both caregiver services experiences and mental health symptoms are tantamount to those observed in recent meta-analyses of wraparound interventions for youth (Suter & Bruns, 2009) and psychiatric medications (Leucht, Hierl, Kissling, Dold, & Davis, 2012).

The final outcome assessed changes in urgent psychiatric service use, including hospitalization and emergency department visits. Although hospitalization is an important step along a continuum of care, this service is expensive, restrictive, and only a few inpatient units are designed for those with IDD (Siegel et al., 2012). Emergency Department use, on the other hand, offers little to caregivers in terms of treatment. The ED may ultimately be traumatic due to long wait times, use of chemical and physical restraints, and lack of provider knowledge about those with IDD (Lunsky, Paquette-Smith, Weiss, & Lee, 2014; White, McMorris, Weiss, & Lunsky, 2012).

There are several limitations to the study. First is the inability to compare the individuals participating in START with individuals who do not, which limits our ability to estimate treatment

Table 3
Changes Urgent Psychiatric Service Use

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th>Posttest</th>
<th>Test statistic</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric Hospitalizations (Mean, Median)</td>
<td>.38, 0</td>
<td>.16, 0</td>
<td>Z=2.60</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Emergency Department Visits (Mean, Median)</td>
<td>.69, 0</td>
<td>.28, 0</td>
<td>Z=3.00</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>
effects. Use of a control group and inclusion of more than two follow-up periods is an important next step in studying START. Another limitation is the lack of data from multiple informants and sources as well as the dearth of information about the services received outside of START. A final limitation is the sample was very heterogeneous, including children and adults as well as those with differing levels of ID and ASD. Future research employing larger sample sizes should examine the effects START among these different populations to better understand if START is more effective for particular subgroups.

Despite these limitations, this study was conducted in a “real-world” setting that provides some measure of ecological validity to the findings. This study also assessed several different outcomes—across a diverse socioeconomic and geographic sample—over a substantial period of time. Perhaps most important, results provide some measure of confidence for positive outcomes among a program, which is rapidly expanding across the country, for a population with great need.

References


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