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Experiences With the Mental Health Service System of Family Caregivers of Individuals With an Intellectual/Developmental Disability Referred to START

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Abstract

People with intellectual and developmental disabilities (IDD) frequently have behavioral or mental health needs, but experience obstacles to treatment. Family caregivers are often responsible for coordinating the care of individuals with IDD. This study examined family caregiver experiences using intake data from a national tertiary crisis intervention model designed for people with IDD and mental health needs. Caregivers ($n = 488$) completed the Family Experiences Interview Schedule. Less than half of families reported satisfaction with the mental health services received. Notable gaps were in crisis, night and weekend services, choice of services and providers, communication and coordination between providers, and specialized training. Experiences were worse for caregiving fathers and individuals with IDD with co-occurring chronic medical conditions.

Keywords: intellectual disability, family caregiving, mental health services, START

Psychiatric disorders and behavioral health issues are common among people with intellectual and developmental disabilities (IDD), with prevalence rates estimated to be as high as 60% (Cooper et al., 2007; Deb et al., 2001a; 2001b). Despite the elevated prevalence, people with intellectual disability and mental health needs (IDDMH) experience multiple barriers to effective treatments and supports (Havercamp & Scott, 2015). One explanation for this gap is people with IDDMH and their caregivers report feeling stigmatized, dismissed, and/or disregarded (Spassiani et al., 2017; Weiss et al., 2009). In fact, treatment providers themselves report a lack of confidence in their own ability to adequately care for this population (Wilkinson et al., 2012). Disparities in access to mental health and healthcare limit the availability of preventive care and health promotion activities, which can result in greater rates of hospitalization, a known problem among this population (Kalb et al., 2016). Taken together, mental health and primary health disparities ultimately manifest as lower quality of life and greater mortality rates for those with IDD (Krahn et al., 2006).

Most people with IDD across the United States reside with family caregivers (Williamson & Perkins, 2014). Family caregivers are tasked with negotiating the complex system of care, including medical, specialty, and mental health care. A recent study found that the mental health system did not meet the needs of family caregivers of people with IDDMH (Nicholas et al., 2017). The goal of the START (Systemic, Therapeutic, Assessment, Resources, and Treatment) program, a national tertiary crisis intervention model implemented in 25 regions across the United States, is to help fill this gap. Approximately 45% of adults and 87% of children referred to START reside with and depend on family caregivers.

Established in 1988, START is designed as a lifespan service for individuals ages 6 and older diagnosed with IDDMH. The program aims to strengthen experiences and service outcomes for people with IDDMH (Beasley & Kroll, 1994). The goal is to create service linkages, promote health and wellness activities for both the individual with IDD and the caregiver, and decrease the need for emergency services (Beasley et al., 1992).

Investigating service experiences among START recipients is highly important to the mission of the program in order to improve mental health service outcomes (Beasley, 2000; Kalb et al., 2016). To gain insight into caregiver experiences and challenges with the mental health system, the Family Experiences Interview Schedule (FEIS; Tessler & Gamache, 1995) is conducted at the time of enrollment into the program. Information from the FEIS is utilized by START staff members to develop a cross systems crisis plan and other mental health services to assist the caregiver and the START enrollee (Beasley et al., 2016).

The current study examines family caregiver experiences with the mental health service system at time of referral to START. Several studies have shown START is successful in improving caregiver service experiences with the mental health system, decreasing psychopathology, and reducing use of psychiatric emergency department use and psychiatric inpatient hospitalization (Beasley et al., 2018; Kalb et al., in press). However, this is the first study to examine baseline mental health services experiences across the entire START network.

The first objective of this study was to analyze trends in caregiver responses from the FEIS, a validated interview schedule that uses Likert measures to examine mental health service experiences conducted just prior to START enrollment. We hypothesized that caregivers would report low levels of satisfaction with the mental health system, especially when it comes to availability of services during a crisis. Our second objective was to identify factors associated with reported caregiver mental health service experiences via the FEIS. A host of demographic factors (e.g., geographic region, caregiver education level) and characteristics about the individual with IDDMH (age, race, gender, recent emergency psychiatric service use) were examined quantitatively. Given the high-risk population, it was important to explore trends in service experiences and how they impacted the population across the country. We hypothesized that those caring for individuals with more psychiatric and medical conditions would have worse experiences with the mental health system, given the challenges associated with treating behavioral symptoms in the presence of comorbidities.

Caregivers also responded to open-ended questions. These questions afforded caregivers the opportunity to provide qualitative feedback about service experiences and needs of their dependent to assist START in planning. Our motivation for the use of the open-ended questions was to gain a deeper understanding of how to improve family experiences with the mental health system. Although our quantitative data allowed us to identity predictors of family experiences, the themes from the two open-ended questions provided caregivers an opportunity to voice both concerns and solutions for improving the mental health system.

Methods

Study Population

The informants for this study were the self-identified primary family caregivers of an individual with IDDMH referred to START. START is an evidence-informed model that requires adherence to fidelity requirements, through the University of New Hampshire Institute on Disability Center for Excellence in Developmental Disability Center for START Services. START methods aim to enhance expertise and partnerships across systems in order to provide effective community-based support and treatment. All methods are overseen by START coordinators, who are trained and certified by the Center for START Services (CSS). Further information about START can be found at http://www.centerforstartservices.com.

START is a community of practice model and, therefore, all START programs are linked and evaluated through ongoing data collection via the START Information Reporting System (SIRS), the national START database. All data entry into SIRS is closely monitored for quality and frequency by the CSS. The SIRS data used for this study were fully de-identified, making it exempt from human subject research by the governing institutional review board. All data were collected and reported as part of the intake process at the time of enrollment to their local START program.

SIRS data used for this study were reported between 2014 and 2017 from nine START regional teams throughout the United States. A total of 448 individuals were included in this study. Most of the sample lived in the Northeast (46%) and Southwest (44%), although the remaining came from various other regions (10%) across the United States. Referrals to START are provided through a variety of mechanisms, including case managers for developmental disabilities services, local and outpatient providers, hospitals and emergency departments, and emergency responders. Individuals are eligible for START if they have an IDD diagnosis and co-occurring behavioral health diagnosis (Beasley, 2002; Fahs et al., 2007). To be included in this study, the person referred must live with family caregiver(s), and the informant responding to the FEIS must identify as the primary caregiver (resulting in a removal of 28 observations).

Primary caregivers who participated in the FEIS were, on average, 46 years old, mostly women (81%), parents of the individual with IDD (81%), and more than half had some college education (see Table 1 for details). Individuals enrolled in START were split between adults and children; most (72%) were male and white (66%). Over a third of the sample had mild levels of ID (40%); a similar proportion had autism spectrum disorder (ASD; 37%). Most had a psychiatric disorder (78%) and over half (52%) had one or more chronic medical conditions (see Table 2 for details). During the day, individuals attended school (53%), a day program (17%), work or a vocational program (3%), or something else (2%; not mutually exclusive); about a fifth (21%) did not report any such program during the day. Most START-enrolled individuals received ongoing services in the IDD and/or school system (81%) and less than half received their mental health care

Table 1
Demographic Characteristics of the Primary Caregiver (N = 448)

Demographic Characteristic	Count (Percent)
Region	
Northeast	206 (46)
Southwest	197 (44)
Other	45 (10)
Caregiver Relationship	
Parent	362 (81)
Age of Caregiver, years[a]	46 (12)
Gender Caregiver (female)	363 (81)
Education Caregiver	
Less than high school	29 (6)
High school diploma	127 (28)
Some college	103 (23)
College grad+	149 (33)
Income	
Less than 29k	168 (38)
30–49k	74 (17)
50k+	177 (26)

[a]Median (standard deviation).

Table 2
Demographic and Clinical Characteristics of the Individual With IDD (N = 448)

Demographic/Clinical Characteristic	Count (Percent)
Age[a]	17 (10)
Age Category	
Child (<18)	225 (50)
Transition age (18–24)	120 (27)
Adult (>24)	94 (21)
Gender (female)	127 (28)
Race/Ethnicity	
White	291 (66)
Black/African American	79 (18)
Other/Multiracial	20 (4)
Hispanic	96 (21)
Level of IQ Disability	
None noted/Borderline	86 (19)
Mild	179 (40)
Moderate	115 (26)
Severe/Profound	60 (13)
Psychiatric Diagnoses	
Any diagnosis	348 (78)
Any internalizing	135 (30)
Any externalizing	166 (37)
Bipolar or psychosis	97 (22)
Autism spectrum disorder	165 (37)
Number Psychiatric Conditions[a]	1.5 (1.3)
Any Medical Condition	235 (52)
Number of Chronic Medical Conditions[a]	0.8 (1.0)
Common Medical Disorders	
Neurologic	91 (20)
Gastrointestinal	44 (10)
Endocrine	33 (7)
Cardiovascular	31 (7)
Immunology/Allergy	29 (6)
Pulmonary	24 (5)
Obesity	22 (5)
Aberrant Behavior Checklist[a]	
Hyperactivity	25 (12)
Irritability	25 (11)
Lethargy	13 (8)
Speech	5 (4)
Stereo	5 (6)

Note. IDD = intellectual and developmental disabilities.
[a]median (standard deviation).

in the mental health system (44%). About a third of individuals had visited the emergency department (31%) and about a fourth had been hospitalized for psychiatric issues in the past year (26%). See Table 1 for details about informants and Table 2 as well as Table 3 for a description of demographic and clinical characteristics of the START enrollee.

Table 3
Living Situation and Services Among the Individuals With IDD (N = 448)

Living Situation/ Services Variable	Count (Percent)
Living Situation	
Family home	429 (96)
Foster care home	11 (2)
Alternative family living	4 (<1)
Independent living	4 (<1)
Attend During Day[b]	
Does not attend	95 (21)
School	236 (53)
Work/Vocational Training	14 (3)
Day program	74 (17)
Other	11 (2)
Services Currently Receive[b]	
IDD services	364 (81)
MH services	197 (44)
Special education	217 (48)
Other	41 (9)
Where Receive MH Services	
Community mental health	126 (28)
School	96 (21)
Home/Group home	58 (13)
Provider Site	51 (11)
Private Clinic	41 (9)
PCP	25 (6)
Other	24 (5)
Past Year Emergency Psychiatric Service Use	
Emergency department visit	139 (31)
Psychiatric hospitalization	116 (26)
Either	192 (43)

Notes. IDD = intellectual and developmental disabilities; MH = mental health; PCP = primary care provider.
[b]categories not mutually exclusive.

Measures

OUTCOME: Family Experiences Interview Schedule (FEIS)

Primary caregivers participated in a modified version of the Family Member Evaluations of Mental Health Professionals (Module M) from the Family Experiences Interview Schedule (Tessler & Gamache, 1995). This module consists of three subscales. The “involvement with professionals,” made up of nine items, assesses how family members appraised their own involvement as partners in treatment for their dependent. The “evaluations of client services” is a 7-item subscale that assesses the quality of care delivered directly to the dependent. The final four items comprised the “response to family members” subscale, a measure of how well the mental health system responds to the needs of the caregivers. All items are shown in Table 4. The total FEIS score in this study took the sum of the items from the FEIS scores (scores range 1–80). Families also reported how difficult it was to provide care (5% not difficult at all, 10% slightly difficult, 29% somewhat difficult, and 49% very difficult).

The FEIS used in this study was slightly altered from its original form to fit the study objectives. The reporting period was extended to the past year. The current scales have been shown to be internally consistent to be reliable (Cronbach’s $\alpha = .92$) and internally valid (Schene, Tessler, & Gamache, 1994). In this sample, the internal consistency of the FEIS was similar (Cronbach’s $\alpha = .95$) to those previously reported in the FEIS manual (Tessler & Gamache, 1995).

CLINICAL Characteristics and Service Utilization

Clinical characteristics of START enrollees reported in SIRS were captured via chart review, referral, and intake information by the START coordinator. This included the participant’s level of intellectual disability (classified as no ID/borderline, mild, moderate, or severe/profound) and the presence of psychiatric and medical conditions. A total of 27 and 19 psychiatric and medical disorders, respectively, were present. Psychiatric diagnoses were classified as any (vs. none), number of diagnoses (0–3+), ASD, and externalizing (e.g., conduct disorder) and internalizing (e.g., anxiety or depression). Medical diagnoses were classified as discrete (yes/no), counts (0–3+), and as individual disorders (i.e., neurological, gastrointestinal, endocrine, cardiovascular, and pulmonary disorders; immunologic disorder/allergy; and obesity). Only count of disorders was used in the quantitative analyses. In addition, the Aberrant Behavior Checklist (ABC), a reliable and valid tool for assessing psychiatric symptoms in individuals with ASD or IDD, was also completed by the caregiver (Aman et al., 1995; Aman et al., 1985) and entered into SIRS. All five subscales of the ABC (irritability, lethargy, stereotypy, hyperactivity/noncompliance, inappropriate speech) were used in this study as continuous variables.

As part of the FEIS, the family caregiver provided information about the living situation and service utilization of the individual with IDD. This included the type of living situation (family home, foster care home, alterative family living, or independent living). Family caregivers reported whether the individual with IDD attended school, work/vocational training, a day program, or nothing. They also provided information on specialty services (IDD or mental health services, special education, other), and where those services were received (community mental health, school, home/group home, provider site, provider clinic, primary care physician, other). Lastly, caregivers specified whether the care recipient had experienced an emergency department visit or psychiatric hospitalization in the past year.

Quantitative Analysis

Descriptive statistics (median, proportions) describe the sample, service use, and evaluate caregivers overall perceived satisfaction with care. This analysis revealed missing data. Although all participants were missing data on at least 1 item of the FEIS, a small proportion (23%) were missing data on five or more items. To account for the missingness, multiple imputation via chained equations was employed to impute variables. A total of 50 imputed datasets were estimated and analyzed using the MICE package (mice 2.46.0) in R (R version 3.4.3; R Core Team, 2015; van Buuren & Groothuis-Oudshoorn, 2010). All available data were used in the imputation procedure. The imputed data was only used to carry out regression analyses. Imputation was used to produce the correct standard errors and maintain the sample size when compared to case-wise deletion (van Buuren et al., 1999).

Following imputation, a series of simple linear regression models were conducted. Separate models were conducted for each FEIS subscale and the total score. A host of caregiver demographics (region, caregiver status [parent vs. other], gender, age, income, education level), characteristics about the individual with IDD (level of difficulty caring for person with IDD, age, race, ethnicity, gender, ABC subscales, number of psychiatric and medical conditions, and psychiatric hospitalizations or emergency department visits in the past year) were examined. We used backwards selection. This involves beginning with the full model, which included all of these variables, and eliminating one predictor at a time until all predictors in the model were $p < 0.10$. This served as the final model for each FEIS outcome. As this is an exploratory study, we interpret any predictor with a $p < 0.10$ as significant.

Qualitative Study

As part of the FEIS at intake, primary family caregivers were asked “What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?” and “Would you like to add anything before we end?” as part of the FEIS interview. A general inductive approach was used for analyzing this data in order to identify themes from the responses that we might not have anticipated or predicted (Thomas, 2006). One author (CH) carried out close reading of the transcripts and then performed overlapping coding, in which one part of a text response could be coded into one or more themes. The authors discussed and refined the themes to reduce overlap and the text was re-coded as needed. Subthemes were combined into larger themes, which are presented in this article. All qualitative analyses were carried out in MaxQDA Analytics Pro 12, release 12.3.5 for data analysis (VERBI Software, 2017).

Results

FEIS Scores

Table 5 summarizes the quantitative FEIS scores in the study sample. The mean score for the first subscale (involvement with professionals) was 23.21 ($SD = 8.86$); the overall item mean was 2.8

Table 4
Results From the Multivariable Linear Regression Models

Variable	Beta	95% CI	*p*-value
FEIS Subscale 1: Involvement With Professionals			
Gender of the Caregiver/Informant			
Female	Reference	—	—
Male	−2.8	(−5.4, −0.2)	0.03
ABC Hyperactivity subscale	0.1	(0.0, 0.1)	0.06
Number chronic medical conditions			
0	Reference	—	—
1	−1.7	(−3.6, 0.2)	0.07
2+	−1.0	(−3.2, 1.1)	0.35
FEIS Subscale 2: Evaluation of Client Services			
Number chronic medical conditions			
0	Reference	—	—
1	−1.3	(−2.8, 0.1)	0.07
2+	−1.4	(−3.0, 0.3)	0.10
FEIS Subscale 3: Response to Family Members			
Region			
Northeast	Reference	—	—
Southwest	0.4	(−0.4, 1.2)	0.30
Other	1.6	(0.3, 2.9)	0.01
Caregiver Income			
Less than 29k	Reference	—	—
30–49k	−0.4	(−1.4, 0.7)	0.50
50k+	−0.9	(−1.9, 0.0)	0.05
Total FEIS score			
Gender of the Caregiver/Informant			
Female	Reference	—	—
Male	−5.4	(−10.8, 0.0)	0.05
Number chronic medical conditions			
0	Reference	—	—
1	−4.0	(−7.9, −0.2)	0.04
2+	−3.0	(−7.4, 1.4)	0.18

Note. FEIS = Family Experiences Interview Schedule.

(*SD* = 1.06). Items with the lowest scores, or areas where caregivers felt the least amount of support, were receiving assistance and information about who to contact during a crisis. Although only about half of informants reportedly felt providers recognized their burdens, caregivers reported having regular contact and involvement with their providers and their dependents' treatment.

The mean score of subscale two (evaluations of client services) was 16.64 (*SD* = 6.75); the overall item mean was 2.60 (*SD* = 1.12). Scores were lower for this subscale compared to the first. Less than

Table 5
FEIS Scores

FEIS Items (each item ranges 1–4)	Item Mean	Standard Deviation	Some/All That Was Needed (Percent)
Subscale 1: Involvement With Professionals			
1. Receive enough information	2.79	1.05	60
2. Assistance if there was a crisis	2.45	1.10	45
3. Information about who to call during a crisis	2.47	1.16	46
4. Encourage to take an active role	2.91	1.15	59
5. Respond to concerns	2.79	1.02	60
6. Take into account ideas and opinions	2.92	1.08	61
7. Involve caregiver in treatment	3.23	1.01	70
8. Recognize burdens	2.67	1.12	53
9. Regular contact with providers	3.39	0.86	70
Total subscale 1 (range 1–26)	23.21	8.86	—
Subscale 2: Evaluations of Client Services			
10. Services available were the ones that are needed	2.69	1.08	57
11. Express opinion	3.09	1.04	67
12. Choose between service options	2.37	1.10	40
13. Choose between different providers	2.33	1.20	41
14. Convenient to use services	2.17	1.19	36
15. Services flexible enough to meet needs	2.76	1.14	61
16. Satisfied with services	2.61	1.11	55
Total subscale 2 (range 1–28)	16.64	6.75	—
Subscale 3: Response to Family Members			
17. Respond to the wishes of the family	2.62	1.08	51
18. Say about services needed	2.91	1.07	61
19. Satisfied with role in treatment	2.97	1.04	65
20. Available help on nights/weekends	1.95	1.07	25
Total subscale 3 (range 1–16)	9.36	4.05	—
Total FEIS score (range 1–80)	49.21	18.15	—

Note. FEIS = Family Experiences Interview Schedule.

half of families reported (some/all) being able to choose between service options or providers, and services were perceived as inconvenient to use. Overall, only half were satisfied with their dependents services. For the final subscale (response to family members), mean scores were 9.36 (*SD* = 4.05); the overall item mean was 2.60 (*SD* = 1.07). Notably, only 1 in four parents reported having all/some of the services available on the weekend.

Regression Analyses

Results from the multivariate analyses are shown in Table 4. For the first model, examining "involvement with professionals" as the outcome, male caregiver informants had lower FEIS scores compared to female caregiver informants. The presence of one chronic medical condition in the START enrollee was also associated with lower scores, and having higher scores on the ABC hyperactivity subscale was surprisingly associated with significantly better experiences. For the second model, "evaluation of client services," having a chronic medical condition was associated with significantly lower scores. For the third model, scores were highest among individuals located in regions other than the Northeast or Southwest when examining "responses to family members." Caregivers with a

50k+ income, relative to less than 29k income, had significantly worse experiences as well. For the total FEIS score, fathers (or male caregivers) and chronic medical conditions in the person with IDD were both significantly associated with worse mental health service experiences (all $p < 0.10$).

Qualitative Themes

Table 6 shows informants responses to "What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?" Most often, the responses focused on funding and accessibility of services; specifically, that the mental health service system needs more funding, the system needs greater accessibility and availability of services, and families need financial support. The second most common responses reported were that families and people with IDD should be more actively included in decision making about their own care and treatment. The third most frequent feedback reported was that there is poor communication and coordination of services between service providers and with the family. A number of participants also expressed that service planners need to be more knowledgeable to do their job, including the need for specialized training to better meet the mental health needs of people with IDD. Exemplar quotes are shown in Table 6.

Table 7 displays responses to a concluding question to the FEIS, which asks "Would you like add anything before we end?" The most common feedback was that families need more services, more options, and better access to services. Although most family caregivers also reported that they were tired, struggling, and felt that the system failed them, some families reported that the services they received are good, that they are happy with their providers, and feel supported. Finally, many caregivers stated that they simply want a good future for their family member. Exemplar quotes from this question are shown in Table 7.

Discussion

There is a well-known gap in healthcare services for those with IDDMH (Edwards et al., 2007; Fisher, 2004; Krahn et al., 2006). The present study supports this literature among START enrollees, a high-risk population. Results from this study found, on average, less than half of families report overall satisfaction with the quantity and quality of mental health services. The satisfaction was far lower for tertiary (crisis related) services. Families reported a lack of assistance during a crisis, especially on nights and weekends. These results are consistent with prior studies that found scarcity of crisis resources for individuals with IDD (Kalb et al., 2016; Lunsky et al., 2008; Spassiani et al., 2017; Weiss et al., 2009). As a result, families may resort to taking their family member to the emergency department or calling the police during a crisis. This may indicate why there is a large proportion (more than four in 10) of emergency service use in the present sample of START referred clients. It is noteworthy that START is specifically designed to address these gaps, which is reflected in recent studies demonstrating a significant improvement in the availability of crisis services and help on nights and weekends (Beasley et al., 2018; Kalb et al., in press).

Caregivers also reported a lack of choice in services. Particular gaps included choosing between providers, services, and lack of convenience. These findings were clearly underscored in the qualitative data. Narratives emerged about struggles with accessing services, both in terms of financial obstacles, availability of providers, and the confusing nature of the complex healthcare system.

When families did receive services, only about half were satisfied. On a positive note, family members had frequent contact with their providers, were encouraged to be involved with their dependents' treatment, and to express their opinion. On the other hand, they reported issues with communication and coordination between service providers, noting the need for providers to have more specialized training. Caregivers stated they wished providers would just "do their job" and "listen to families." These findings replicate previous studies that show poor quality of care for individuals with IDD (Lennox et al., 1997; Vohra et al., 2014; Williamson et al., 2016). To address this issue, START employs several tools including a comprehensive service evaluation and linkage agreements between providers (Kalb et al., in press).

Families in the current study reported that they wanted a better life for their child and less than 1% requested out of home placement. This is consistent with prior studies with regard to family caregiver experiences (Williamson et al., 2016). Like Williamson et al, we found that families

Table 6
What Advice Would You Give to Service Planners Regarding the Mental Health Service Needs of Persons With IDD and Their Families?

Theme	Exemplar Quotes
MH service needs more funding; we need financial support and more accessibility and availability of services	"Have it readily available, no long waiting lists. Doesn't want residential placement, but there is not enough family support to keep everyone safe." "We need more doctors that will see children and that accept Medicaid. These kids are our future…." "I can't work because I am the only one that can take care of him … just got approved for services but none are available to him … workers aren't paid enough to want to do the work because my son is aggressive."
Family part of solution, should be treated as equal partners	"Collaborate with family members." "Listen to families." "Recognize that family members are experts when it comes to their children's individual needs; it can be very isolating to deal with the issues the kids are dealing with; don't be dismissive with families."
Poor service communication and coordination	"Need help knowing what the options are. Things need to be made more clear and there need to be more options." "Don't know where to go." "Services are too confusing … too many acronyms … no one knows what each service offers or who qualifies."
Be knowledgeable, do your job	"Go to learn more about the families." "Do your job!" "[Be] more knowledge of IDD and how it affects MH ymptoms."
Providers need specialized training	"Providers need a broader knowledge on disabilities and treatment." "Better training is needed for the people taking care of individuals."

Note. IDD = intellectual and developmental disabilities; MH = mental health.

reported they know their child/family member best and want to be treated as equal partners in finding the solution. Families also reported that they do not want their dependent overtreated or institutionalized; rather, they want to partner with mental health providers in seeking the best possible long-term outcomes for their dependent in the community.

Another objective of this study was to identify the factors related to quality of care experiences. The factor that most clearly emerged was that caregiver experiences with mental health services were less effective for individuals with IDD who had chronic medical conditions. This finding is consistent with prior literature in the general population showing those with comorbid physical and mental health conditions experience a poorer quality of care, worse treatment outcomes, and more stigmatizing attitudes (Bahm & Forchuk, 2009; Barnett et al., 2012; De Hert, Cohen et al., 2011; De Hert, Correll et al., 2011; Jones et al., 2008; Lawrence & Kisely, 2010). These health

Table 7
Would You Like to Add Anything Before We End?

Theme	Exemplar Quotes
Need more services, options, and promotion of services	"Services should be advertised more to families." "There are not enough providers for children in this area."
Need help; tired, struggling, system has failed	"Please help us." "My health has not been good over the past year . . . I have lost a lot of weight . . . I am very overwhelmed. I don't want to place my son outside of the house but I don't know what else to do. I feel like that is the only option." "Feels the system has failed her and her family."
Services, providers are good, feel supported	"She is happy for the support we have given her." "Satisfied with mental health services that her son is getting."
Want good things for person with IDD	"I don't want an overmedicated zombie of a child, I want him to reach his full potential but because of lack of doctors and resources because we're poor, there isn't much available to him and I'm afraid he will not reach his full potential." "I want to see [child's name] in a good place." "Mother reports that she wants [child's name] to be able to be taken care of properly. She does not want him to be hurt."

Note. IDD = intellectual and developmental disabilities.

disparities, including those due to diagnostic overshadowing, also extend to individuals with IDD (Edwards et al., 2007; Fisher, 2004; Krahn et al., 2006; Mason & Scior, 2004; Ouellette-Kuntz et al., 2005; Ward et al., 2010). Over half of study participants had at least one chronic medical condition; a fifth of individuals had two or more, highlighting the need for an integrated health approach to care.

An additional finding was that caregiving fathers reported having less positive involvement with providers than their female counterparts. In the present study, 20% of the caregivers were fathers; this is greater than was expected, as a far greater majority of primary caregivers are mothers in other studies (Kalb et al., 2018; Zablotsky et al., 2014). However, there is increasing recognition that fathers play a more significant role in interacting with the healthcare system than previously thought. Our finding suggests that fathers felt less support by the mental health service system, compared to mothers. Future research is needed to replicate this finding and, if observed, the reasons for their perceived disconnect with the healthcare system (Davys et al., 2017; Lamb, 2004; MacDonald & Hastings, 2010; Ricci & Hodapp, 2003). Qualitative methods are particularly well suited to address this question.

There are several strengths and limitations to the current study. First, the sample was large and heterogeneous. It should be recognized that the findings observed in this study were among a select population with great need and are not reflective of the general population of individuals with IDD and mental health service needs. The uniqueness of our sample is not seen as a limitation, but, rather, a strength, because it taps into a hard-to-reach population that suffers from great disparities. Additional strengths include use of quantitative data retrieved from a standardized interview and database, both of which have strong fidelity requirements. Data were also enriched with qualitative narratives. This study also fills an important gap in the literature, identifying new and well-known avenues for future work. For limitations, psychiatric and medical diagnoses were extracted by chart review, leaving potential for misclassification. There was also some missing data, although imputation methods were employed to account for this bias in the multivariate analyses, and greater information about various other family factors (e.g., caregiver stress) would have been valuable.

Conclusions

It is not surprising that many of the families referred to START reported that their services were not as effective as they needed. START is designed for individuals who require assistance in their communities. However, the study provides an important description of what families face and can help to inform policy planners to address the needs of high-risk populations. The qualitative data matched many of the quantitative findings, suggesting families need greater assistance, are tired and struggling, and frustrated with the mental health system; sentiments shared in previous non-START related studies (Green, 2007; Willingham-Storr, 2014; Yoong & Koritsas, 2012). Within START, the findings can be leveraged to provide additional supports for those with chronic medical issues, because START does not provide medical services, and START can modify its practices to better meet the needs of fathers. Ultimately, findings point to the aims of the START program, including the need for timely access to well-trained mental health providers, greater accountability of the system to meet the needs of families and service users, 24-hour mobile crisis support, strength-based and inclusive approaches, as well as cross systems collaboration and linkages.

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