RUNNING HEAD: SERVICE UTILIZATION PATTERNS

Service utilization patterns in parents of youth and adults with intellectual disability who

experienced behavioral crisis

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Abstract

Family caregivers play an important role in supporting people with intellectual disability (ID) and mental health problems or serious challenging behaviors across the lifespan. Relevant services for parents of people with ID may vary depending on the age of the child and the severity of mental health problems. Often, individuals with ID experience behavioral crisis, and the purpose of this study is to understand parents' service utilization patterns. Forty mothers of youth and adults with mild ID shared their experiences of crisis, and commented on service needs, receipt, and effectiveness as well as on the barriers to service access, using an adapted version of the Need for Help Questionnaire (Douma, Dekker, & Koot, 2006). All parents had high levels of service need. Although most parents noted that they received services, many found that service effectiveness was limited. A greater proportion of parents of youth rated the information and mental health care for their child as effective compared with parents of adults. Barriers to service access for parents of youth centered around perceptions of their child's problem behavior, whereas parents of adults focused on perceptions of the service system. Input from caregivers can help identify deficiencies in the system that lead them to crisis and help tailor services to meet their needs. Research is needed to further elucidate different ways of engaging parents of youth and of adults to help them promote mental health in people with ID and prevent behavioral crises from occurring.

KEYWORDS: intellectual disability, families, caregivers, service utilization, dual diagnosis

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Parent caregiving of people with intellectual disability (ID) has been recognized as a lifelong commitment (Haveman, van Berkum, Reijnders, & Heller, 1997), with an increasing number of people with ID who are living with their families well into adulthood (Fujiura & Braddock, 1992; Lakin, Prouty, & Coucouvanis, 2007). In such cases, families are an instrumental part of service coordination and delivery, and understanding their needs is of utmost importance (Fiedler & Antonak, 1991; Hayden & Heller, 1997; Seltzer & Krauss, 1989; Smull, 1989), especially when children develop mental health problems or serious challenging behaviors.

The purpose of this study is to investigate service utilization in caregivers of youth and adults with ID who have had behavioral crises in the province of Ontario, where service provision is separated based on age. Services for individuals under 21 years of age are funded by the Ministries of Education, and of Child, Youth, and Family. All children identified as requiring special education have access to certain types of services, as do their families. At age 21, school ends and adults with ID then apply for services through the Ministry of Community and Social Services, which has a different structure, access mechanisms, and eligibility criteria. Similar to other jurisdictions, the Ontario government aims to create a fair, accessible and sustainable community-based service system that promotes independence, dignity and self reliance for people with ID and their families across the life span (Ministry of Community and Social Services, 2006). The Ministry recently closed the last of the institutions for persons with ID in Ontario with the understanding that, moving forward, individuals with ID access services

in their local communities. Given the increased risk of mental health problems faced by these individuals, it is urgent that information related to their health care and service use be made available to researchers and government decision makers to monitor changes in this evolving policy context.

There is a growing body of knowledge regarding the service needs and utilization patterns of family caregivers of people with ID (Haveman et al., 1997; Hayden & Heller, 1997; Pruchno & McMullen, 2004; Smith, 1997; White & Hastings, 2004). Relevant services for parents of children with ID include information, respite care, social support, community activities, counseling, financial assistance, and health care (Bailey et al., 1999; Carr & O'Reilly, 1996; Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002; Petr & Barney, 1993), and a handful of studies have highlighted how services needs can differ based on the age of the parent and child (Haveman et al., 1997; Maes, Broekman, Dosen, & Nauts, 2003; Suelzle & Keenan, 1981). One large-scale study assessed the burden and support needs of 2,573 Dutch families of children with ID ranging from infancy to adulthood (Haveman et al., 1997). The authors found a negative relationship between child age and the number of formal services used by families, with the number of families using no formal supports increasing from 5% in the "0-9 years" group to 20% in the "40-years and older" group. As well, the content of families' top three service needs showed a logical trend, with parents in the "0-9 years" group requiring help for developmental and medical issues, in the "10-19 years" group requiring help with developmental issues and advice about future residential living, and in the adult age groups requiring information and concrete help regarding future out-of-home residential supports, transportation for their child, and medical issues. Lower rates of service utilization by parents of older

children have been hypothesized to reflect either a cohort effect of older parents not being accustomed to accessing services, or a system that is largely unavailable to parents of adult age children, despite these parents' high needs for respite, social services, and financial support (Haveman et al., 1997; Heller, Caldwell, & Factor, 2007).

Maladaptive behavior can have a significant deleterious effect on parent caregivers, and formal supports are often recognized as potential moderators of this impact (Blacher & McIntyre, 2006; Hastings, 2002; Hastings & Beck, 2004; Hayden & Goldman, 1996; Heller, Hsieh, & Rowitz, 1997; Nachshen & Minnes, 2005; Perry, 2005). Douma, Dekker, and Koot (2006) assessed the support needs of 282 Dutch parents of adolescents with ID who had "somewhat" problematic behavioral or emotional problems, as indicated on the Child Behavior Checklist; they then examined whether these service needs were met, and asked parents to identify any barriers to service receipt. The three most often required needs were "a friendly ear" (78%), "information" (68%), and "child's mental health care" (57%), followed closely by "activities" for their child (51%). There was a disparity between the need for help and receipt of services where in most cases less than half of parents requiring supports received them (the two exceptions being "a friendly ear" (75%), and "respite care" (61%)). The study also surveyed respondents with a list of possible factors that may keep parents of children with ID and mental health problems from obtaining the help that they require. Regardless of the types of support needed, parents' main barriers to support receipt were "wanting to solve the problems themselves," "considering the problems not so serious," "not knowing where to find support," and "considering the problems as temporary". To our knowledge, no one has asked similar questions with regard to parents who have adult age children with ID

This study reports on the accessibility, effectiveness, and barriers to service use for parents who provide care to youth compared with adults with ID who have had behavioral crises. Based on the operational definition of *crisis* by Roberts (as cited in Lewis & Robert, 2001, p. 19), we view a behavioral crisis as the subjective reaction to a disruptive life event that is related to the mental illness or challenging behavior. Further, this disruptive event is stressful, traumatic, or hazardous, is perceived by the caregiver as the cause of considerable distress, and is not resolved by previously used coping methods.

It is particularly important to study service needs, service receipt, and service effectiveness during periods of behavioral crisis. It has been well established that individuals with ID are at greater risk of developing physical and mental health problems or serious challenging behaviors compared with the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Emerson & Hatton, 2007; van Shrojenstein Lantman-De Valk, Metsemakers, Haveman, & Crebolder, 2000). These health needs are often unrecognized and unmet (U.S. Department of Health and Social Services, 2002), which in turn can precipitate behavioral crisis (Bradley & Lofchy, 2005; P. W. Davidson et al., 1994; Lunsky, Gracey, & Gelfand, 2008). In such cases, behavioral crisis can reflect a disparity between the needs of the person with ID, and the service system's provision of supports. These healthcare inequities have been identified in many countries (Dekker & Koot, 2003; Frahn, et al. 2006; Krauss, Gulley, Sciegaj, & Wells, 2003; McCarthy & Boyd, 2002; Ouellette-Kuntz, 2005). In Australia for instance, it is estimated that although 40% of children with ID are identified with comorbid psychopathology, only 10% receive mental health care (Einfeld et al., 2006), an inequity

that certainly predisposes an individual to behavioral crisis. It is critical that we understand the experiences of parents of people with ID in crisis, if we are to address the systemic inequities to effective mental health care in this population. Of particular interest is the differences in need between parents of children who are still served by the child and youth service sector, under 21 years of age, compared with parents of children who are served by the adult sector (21 years of age and older) and who are no longer attending school daily.

Given that all respondents in this study had children who had experienced a behavioral crisis, we hypothesized that most families would report high levels of service need. Based on Douma, Dekker, and Koot (2006), we expected that approximately half of parents who required services would not receive them. We also expected that families of older children would receive services less frequently than younger families, and that the barriers to service receipt would be more prevalent for older families.

Method

Participants

Forty mothers of individuals with mild ID participated in this study. Participants were eligible if the parent lived with their child, the child with ID was in crisis in the past year as a result of their mental health problem or challenging behavior, and the child was diagnosed with an ID and/or autism spectrum disorder.

Parents' ages ranged from 30 to 75 years ($M = 50.8$, $SD = 8.7$), and children's ages ranged from 7 to 40 years ($M = 22.1$, $SD = 8.5$). Table 1 lists the child characteristics with regard to psychiatric diagnoses, types of challenging behavior, and

whether the child went to the emergency room as a result of crisis. Ten percent of the sample identified themselves as being new to Canada.

The sample was divided into two age groups using 21 years of age as the criterion (< 21 years of age vs. ≥ 21 years of age), given that this is when individuals with ID transition from the child to adult service sector in Ontario. Forty-seven percent of the sample was under 21 years of age (Youth group), with a mean age of 14.5 years (SD = 4.3), whereas the remaining children were coded into the Adult group, with a mean age of 27.4 years (SD = 5.7). Parents of adults were significantly older (M = 55.7, SD = 7.5) than parents of youth (M = 46.3, SD = 6.0, $t(38)$ = 4.32, p < .001). When asked for a primary etiology of ID (keeping in mind that Autism may be a secondary diagnosis in addition to another known or unknown cause of ID), parents reported autism spectrum disorder (40%), Down Syndrome (7.5%), Fragile X Syndrome (5%), Prader-Willi Syndrome (2.5%), Rett Syndrome (2.5%), Turner Syndrome (2.5%), or unknown cause (40%). A greater percentage of adult age children had formal psychiatric diagnoses compared with youth-age children, largely due to more diagnoses of depression.

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Measures

Adapted need for help questionnaire. We used a variation of Douma, Dekker, and Koot's (2006) Need for Help Questionnaire, which was designed to ascertain parents' needs for support and barriers to support in youth with ID and behavioral or emotional

problems. We designed a telephone interview based on the Need for Help Questionnaire, which consisted of six parts:

1. Parent perception of problems. Parents were asked to describe any crises that their child had experienced in the last year. Parents were asked to indicate any formal psychiatric diagnoses that their children had received (e.g., anxiety disorder, major depression, bipolar disorder, psychotic disorder/schizophrenia, other), or serious problems and disruptive behaviors that were not diagnosed but contributed to the crisis (anger/temper problems, aggression to self, aggression to others, destruction of property, threats of suicide/self-harm, anxiety problems).

2. Need for support. Parents were asked to what extent in the past year they required any of seven types of support because of, or related to, their child's crisis ("no need," "some need," "reasonably strong need," and "very strong need"). The types of support were identical to those used by Douma, Dekker, and Koot (2006): (a) a friendly ear for the parents to talk to, (b) information, (c) activities for the child, (d) respite care, (e) financial help, (f) child's mental health care (psychopharmacology or therapy), and (g) parent counseling. We dichotomized level of need into "no need" and "need," similar to Douma, Dekker, and Koot (2006).

3. Met need and effectiveness of support. We then asked parents whether they received each type of support they required, which was rated in a similar fashion to Douma, Dekker, and Koot (2006), as a dichotomous variable (Received/Not Received). If parents received the service, we asked them to

rate the degree to which their needs were satisfied ("Not at All," "Somewhat (i.e., not enough to help with the crisis)," "Very helpful").

4. Barriers to support receipt. We then presented a list of 11 reasons for not obtaining help, and asked parents to note the reasons that applied to them in the past year, and whether there were any other reasons why they did not receive the supports they required. All parents were asked about barriers they experienced, regardless of whether they received supports. These reasons were the top 11 barriers noted by parents in a prior study of service utilization (Douma, Dekker, De Ruiter, Verhulst, & Koot, 2006).

5. Sharing their story. Parents were also invited to share their experience of crisis with the interviewer, by "sharing their story" of the antecedents and consequences of the crisis in an open-ended manner. This section was included in order to use a mixed-method approach to research and allow for narrative view of the parent experience. Such qualitative investigations have been purported to be useful to inform clinical practice (Goering, Boydell, & Pignatiello, 2008) and policy (L. Davidson, Ridgway, Kidd, Topor, & Borg, 2008).

Procedures

We used a process of convenience and snowball sampling to recruit parents. Flyers advertising the study were distributed to a specialised mental health program for people with ID, a specialized community crisis center, and through a larger study on behavioral crises in people with ID in Ontario. Interviews were conducted over the telephone in both rural and urban areas of the province. Although most questions were

close ended, interviewers were instructed to write down all of the caregivers' comments. Parents were asked about the services that were used during the crisis period. Phone interviews lasted between 20 and 40 minutes and were done at a time convenient to parents. The study was approved by the Research Ethics Board at the Centre for Addiction and Mental Health, and all participants gave informed consent.

Results

Chi-square tests of independence were conducted to assess a relationship between age group and sample characteristics, with percents displayed in Table 1. Fisher's Exact Test (two-tailed) was used instead of Pearson chi-square when cell n < 5. Children in the Adult group had a greater proportion of at least one psychiatric diagnosis (95% vs. 47%). Children in the Adult group also displayed a greater proportion of anger problems (91% vs. 42%) and showed a trend for more anxiety problems (62% vs. 32%) compared with the Youth group. Children in the Youth group showed a trend for a greater proportion of chronic medical conditions (63% vs. 33%). Both groups had similar levels of autism diagnoses, visits to the emergency department, and challenging behaviors. Aggression directed toward others was the most frequently occurring type of challenging behavior for the Youth group (74%), with similar levels found for the Adult group (67%).

Given that eligibility criteria included experiencing a crisis in the past year, it is not surprising that all parents required supports. In fact, the total number of support needs ranged from 3 to 7, with 72% of parents requiring 5 or more services. On average, parents of youth required 5.58 services ($SD = 1.39$) compared with 5.52 services ($SD = .92$) for parents of adults, $t(38) = .15$, $p = .88$. Table 2 shows the percentage of parents who needed specific types of support and the percentage of those parents who received

supports. A greater proportion of parents of youth noted that they needed "parent counselling," $\chi^2(1, N = 40) = 8.34$, $p = .005$. A greater proportion of parents of adults required mental health care for their child compared with parents of youth, $\chi^2(1, N = 40) = 7.80$, $p = .007$.

Insert Table 2 here

On average, parents of youth received 4.10 services ($SD = 1.56$), compared with 3.52 services ($SD = 1.60$) for parents of adults, $t(38) = 1.16$, $p = .25$. In terms of received services, the most often received were "practical/material," "child's mental health care," and "a friendly ear," followed closely by "information". A greater proportion of parents of youth indicated they received "respite" services, $\chi^2(1, N = 33) = 9.94$, $p = .003$, and showed a trend toward receiving more "activities," $\chi^2(1, N = 32) = 4.39$, $p = .07$, than parents of adults.

We analyzed the effectiveness of received supports in a similar manner. Table 3 displays the overall parent-rated effectiveness of received supports, and compares rating of parents of youth to parents of adults. Chi-square tests of independence or Fisher's exact tests revealed that a greater proportion of Adult group parents rated "information" as "not at all" effective compared with parents of youth, and conversely, that a greater proportion of parents of youth rated "information" as "very helpful" compared with parents of adults, $\chi^2(2, N = 22) = 11.09$, $p = .005$. Although very few parents in either group rated the "child's mental health care" services they received as "very helpful," a

greater proportion of parents of adults rated their "child's mental health care" services as "not at all" helpful compared with parents of youth, $\chi^2(2, N = 25) = 16.65, p < .001$.

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Insert Table 3 here

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The final set of comparisons examined the frequency that parents acknowledged specific barriers to support receipt. On average, parents of youth acknowledged 4.16 (*SD* = 3.00) barriers, compared with 4.57 (*SD* = 2.38) for parents of adults, $t(38) = -.49, p = .63$. Table 4 displays the rank ordered barriers in terms of overall frequency, and compares each barrier between age groups. The most frequently occurring barrier for the parents of adults was "negative experiences with professional help" followed by "not knowing where to find help". The most frequently occurring barrier for parents of youth was "considered the problem temporary" followed by "steps to seek help were overwhelming". The experience of barriers appeared largely related to age groupings. A greater proportion of parents of youth noted that they "believed that the problem was not so serious," "considered the problem temporary," and found the "steps to seeking help were overwhelming" compared with parents of older children. A greater proportion of parents of adults noted "negative experience with professional help," "not knowing where to find help," "having difficulty describing the problem," and "no trust in professional help" compared with parents of youth.

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Insert Table 4 here

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Discussion

We studied the service utilization patterns of parents of individuals with ID who had experienced behavioral crisis, in order to better understand their needs, the current effectiveness of supports that they receive, and the barriers to service use. We conducted comparisons of the experiences of mothers of youth age and adult age children with ID and mental health problems or challenging behaviors, with the hypothesis that caregivers would report different needs and service receipt, according to the age of their child.

Service Need

Several findings from this study replicate what others have reported, and confirm our hypotheses. Child aggression was the most prevalent problem for parents. Past research has linked aggression to parent distress (Angold et al., 1998; Douma, Dekker, & Koot, 2006; Plant & Sanders, 2007), respite (Chadwick et al., 2002; Grant & McGrath, 1990), and emergency service use (Weiss, Lunsky, Gracey, Canrinus, & Morris, 2009). The current study also indicated a high level of need with three quarters of parents in our sample requiring five out of seven services. This range of need is similar to what is often found in parents who care for individuals with chronic mental illness without ID (Levine & Ligenza, 2002; Magaña, García, Hernández, & Cortez 2007; Shooter, 2004). As well, parents in the current study reported even higher levels of need compared with parents of youth with ID whose mental health problems may not have led to crisis (Douma, Dekker, & Koot, 2006). The impact of crisis-level problems on the family is well captured in these parent quotes:

> *The breakdowns hurt our whole family, and we sometimes thought and hoped she would die… because of the pain it caused us and exhausted us.* (p. 33)

My daughter needs support too; the rest of the family needs support. My husband has depression and I'm sure that it would be different if his life wasn't so stressful. And I feel like I'm an Atlas holding up the world ... I am holding the family together and I need a break but I can't. I need to be strong enough until what? Never ends. (p. 14)

Contrary to our initial expectations, the proportion of parents from the two age groups did not differ significantly in the types of services they required, with only two exceptions. Parents of youth were more likely to say they required parent counselling than parents of adults. Parents of younger children may be searching for professional support in order to help in the quest for their own successful adaptation to emerging behavior problems (Crnic, Friedrich, & Greenberg, 1983), whereas parents of adult age children have spent more time caring for their children's behavioral challenges, and may be farther along in that adaptation process. Parents of adults were more likely to note that they required mental health care for their child in line with the fact that a greater proportion of adults with ID had been diagnosed with psychiatric disorders compared with youth.

Service Receipt

In most cases, parents who noted that they needed specific supports went on to note that they had received supports. Parents in this study reported greater proportions of service receipt than what was reported by Douma, Dekker, and Koot (2006). This may be because the crisis prioritized these families for subsequent services. It may also be a difference in service availability between Ontario, Canada, and the Netherlands.

Significantly fewer parents of adults in this study received respite services for their children compared with parents of younger children, despite all children continuing to live with their parents, and despite parents in the two groups reporting similar

proportions of service need. Many authors have commented that family caregivers of adults with ID can have high needs for respite and daytime activities (as well as for information and financial support) but are often inadequately supported (Haveman et al., 1997; Heller et al., 2007; Lutzer & Brubaker, 1988). As one mother commented:

> *[My daughter] needs 24-hour-a-day support and if it is out there, I can't afford it. I found some supports in [one organization] and I spent a lot of time traveling to get to respite… 2 hours traveling for 6 hours of respite. We drive everywhere for everything, and it doesn't mean it should be that way. The staff aren't equipped to deal with her. I have sent her to summer camps and had to pull her out because she has bitten people… important to meet her needs and [be] affordable.* (p. 23)

Service Effectiveness

We also inquired into parents' satisfaction with service effectiveness, and found that in many respects, receiving a service did not imply receiving quality (i.e., effective) service. It is important that the level of support provided be tailored to meet an individual's level of need (Thompson, Tassé, & McLaughlin, 2008), and it is likely that people with ID and mental health problems have support needs that exceed the capability of nonspecialized health and community services (Wehmeyer et al., 2009). This was particularly evident in parents of adult children; mental health services were rated as needed by all of them, received by 81% of them and rated as not effective by 94% of those who received it. Many parents in our study had commented that the level of service did not meet their level of need:

> *It is fine to say that you have services. But don't ask me to wait while my child hurts us or herself and then all I get is [behavior] consultation… It would be fine if she was young and if we were young and if her problems weren't severe. But the service doesn't fit what we need so we are helpless.* (p. 15)

> *We certainly have access to funding, services, respite services, … and on and on… the challenge has been finding supports able to manage our son, who is big and his needs have increased.* (p. 17)

I felt like they looked at [my daughter] and thought the "R word" and thought she was disposable. All they did is shot her full of Ativan. And then sent us home with more sedatives and then 4 days later we're back in the ER because she was worse off and she was escalating and we were scared of giving her more. We were seen right away when during a rage, but the second time when she was escalating but not in a rage yet, we had to wait, until she exploded and then she got ahead. They gave her more Ativan and then sent us home when she was calmer and we had to still deal with it. (p. 37)

A lack of effectiveness may be related to a lack of specific training in ID within medicine and allied health services. Studies that have examined the training of Canadian students in psychiatry (Burge, Ouellette-Kuntz, McCreary, Bradley, & Leichner, 2002; Lunsky & Bradley, 2001), general medicine (Burge, Ouellette-Kuntz, Isaacs, & Lunsky, 2008), social work (Burge, Druick, Caron, Ouellette-Kuntz, & Paquette, 1999), and psychology (Weiss, Lunsky, & Morin, in press) all suggest that more specialized training is needed, particularly with regard to adolescents and adults with ID. It may also be that some parents expect services to assist them in ways that are not within the capacity of the services. Our previous research has shown that caregivers of people with ID often use the emergency department in times of behavioral crisis, with the hope that it will be able to reduce problems behaviors, and report frustration when the emergency department physician recommends medication to treat problem behaviors instead of a more integrative approach (Weiss et al., 2009). At the same time, emergency department physicians note that as a triage service, there is little else that they can provide in terms of actual intervention, and express frustration over caregivers' expectations (Lunsky et al., 2008). As one parent in this study recounted:

We ended up seeing the head of [ED] and the head of psychiatry department and we were quite adamant that we're not leaving until someone helped us, and [my child] was incredibly patient, and at the end of a very long day, and the answer to us was "We can't help you, we are not staffed to support individuals with autism

and the situation with your son" and the end of the discussion was that [the hospital] has a couple of beds and none in a room that could support him; they didn't have the care or facilities to manage him, so where do we go? (p. 22)

Barriers to Service Use

Finally, we asked about the reasons parents did not seek or obtain help. There was a problematic trend in these parents of not engaging with professional services despite high levels of need. Parental attitudes about a child's problem behaviors and about services have been noted to influence caregiver decisions to seek mental health care for children without disabilities (Flisher et al., 1997; Kerkorian, McKay, & Bannon, 2006; Owens et al., 2002; Richardson, 2001), and for adult age children with ID (Pruchno & McMullen, 2004). A cohort effect emerged in the current study, where a greater proportion of parents of youth endorsed barriers similar to those found by Douma, Dekker, and Koot (2006), related to evaluations of the problem, including believing that the problem was not so serious or was temporary, and feeling overwhelmed in finding help. It is important for specialized services to be aware that parents of youth may choose to not engage proactively at early stages because they underestimate the seriousness of the problem at hand:

> *I went to a parent support group in the beginning but it became a very stressful meeting because I was new to the disability thing... they were all unhappy and their whole lives were about this disease and everyone was too in distress... I wanted her in our life so we tried to handle it on our own.* (p. 19)

In contrast, a greater proportion of parents of adults noted not accessing services due to their negative evaluations of professionals and the service sector, such as not trusting professionals (as well as not knowing where to find help). It is important for specialized

services to be aware that resistance in parents of adults with ID may be a reaction to previous negative experiences:

> *Most important thing to us is really trusting yourself and not putting up with any crap from health professionals who are trying to play god and to not just take him home... be thick skinned about being with staff.* (p. 13)

> *Doctors' visits take up less than 10% of her life… but they take up 75% of the aggravation.* (p. 33)

Parents of adults may develop this perspective over time, and along with a need to support families early on in life, it is important to be sensitive and not minimize their negative experiences when we try to develop a therapeutic rapport with them later. Otherwise, families may be resistant to help when they need it most, feeling safer without it. Published guides for family caregivers of people with ID and mental health problems exemplify how services can include the family caregiver in the construction and delivery of supports (i.e., FORCE Society for Kids' Mental Health & Family Support Institute, 2006; Holt et al., 2004), and how caregivers require that information be combined with a recognition about their experiences with professionals and society (Gratsa et al., 2007).

Limitations

This study is limited in that we did not intend to be representative of parents of people with ID. Instead, we presented data on the experience of parents who care for people with ID and mental health problems and who have been in crisis. As well, it is entirely possible that parents who self-referred for this study are more dissatisfied or vocal than the typical parent of a child with ID, or come from specific socioeconomic conditions that make advocacy possible, and thus may not represent those families who are marginalized and disempowered or those who are satisfied with services. Given our small sample size and the higher rates of psychiatric diagnosis and anger problems found

in adult age children, it is possible that the differences reported between groups reflect differences in behavior problems or medical comorbidities, and not actual differences based on age. We did not assess the severity of behavior problems, which is known to be related to parenting stress (Krauss, 1993) and service utilization in this population (Pruchno & McMullen, 2004), and future studies should measure health and mental health domains to understand these youth/adult differences better. Future research can also address a number of these limitations by following a greater number of families as they transition from child to adult services, and by controlling for behavior and medical issues through matched cross-sectional designs or statistical means.

Conclusion

At the same time, understanding families' support utilization patterns remains an important focus of study to inform service providers and policymakers about a group of families with very high support needs. Although crisis intervention models are designed to be responsive during the occurrence of crisis, reacting to ensure that individuals are safe (Roberts & Ottens, 2005), ID services need not be designed as a reactive system of care. Many parents have highlighted the problems of depending on a reactive model of care rather than on a proactive, preventative, and stable model:

> *After they realized it was unmanageable for us, then [the services] all got together. We had meetings of over 20 people. But the pressure was still on to take her back home because there was nowhere to place her.* (p. 21)

> *It keeps me up at night… people are trying to work within a broken system. I've been cut off from funding because we started to make too much money… they give me money with one hand and take away with another… we get one program and then another and there is different criteria for eligibility and when we get some we lose others… and it is reactive programming, and I don't know if people are working on the big picture.* (p. 14)

Such evidence highlights the importance of focusing research on preventative efforts to stop the escalation of problem behaviors to the point of crisis, as well as on intensive services to prevent the re-occurrence of crisis if it occurs. Future research is required to assess the variables that make some family caregivers resilient in the face of problem behaviors and able to manage and not end up in a crisis situation. It is equally important to place an onus on the service delivery system, and compare existing service models to identify the characteristics of services that contribute to preventative care.

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Table 1. Overall Sample Characteristics and Comparison of Sample Characteristics by Age Group (%)

Characteristics	Overall	Youth (n = 19)	Adult (n = 21)	X^2 (N = 40)
Autism diagnosis	55	68	43	2.63
Presence of a psychiatric diagnosis	73	47	95	11.47***
• Psychotic disorder	15	16	14	2.48
• Depression disorder	49	11	81	20.00***
• Anxiety disorder	2.5	5	0	.66
• Bipolar disorder	7.5	16	0	4.07
• ADHD	7.5	16	0	4.07
Presence of chronic medical condition	48	63	33	3.56
Anger problems	68	42	91	9.95**
Aggression to self	30	42	19	2.53
Aggression to others	70	74	67	.23
Anxiety problems	48	32	62	3.68+
Damage to property	13	11	14	.13
Threat of suicide	14	12	17	.17
Visit to ER	75	79	71	.30

+ = < .10, * p < .05, ** p < .01, *** p < .001

Table 2. Support Needs and Receipt, Overall and Comparisons Between Age Groups (%)

Type of support	Need	Need < 21	Need > 21	p-value	Received[a]	Received[a] < 21	Received[a] ≥ 21	p value
Friendly ear	78	68	86	.27	77	69	83	.41
Information	98	95	100	.48	60	65	55	.74
Activities	80	79	81	1.00	41	60	24	.07
Respite	80	84	76	.70	76	100	53	.003
Practical/material	95	95	95	1.00	94	100	89	.49
Child's mental health care	85	68	100	.007	76	69	81	.68
Parent counselling	55	79	33	.005	36	40	29	1.00

[a]Out of the % of parents who needed this support

Table 3. Support Effectiveness, Overall and Comparisons Between Age Groups (%)

Type of support	Overall level of effectiveness			< 21 level of effectiveness			≥ 21 level of effectiveness			p value
Helpful?	No	Somewhat	Very	No	Somewhat	Very	No	Somewhat	Very	
Friendly ear	5	23	73	14	14	71	0	27	73	.29
Information	23	50	27	0	46	55	46	54	0	.004
Activities	8	54	39	0	44	56	25	75	0	.08
Respite	36	44	20	31	44	25	44	44	11	.66
Practical/material	21	59	21	17	50	33	25	69	6	.15
Child's mental health care	68	32	0	13	87	0	94	6	0	< .001
Parent counselling	0	13	88	0	0	100	0	50	50	.25

Table 4. Barriers to Service Receipt, Overall and Comparison Between Age Groups (%)

Barrier	Overall	< 21	≥ 21	X^2 ($N = 40$)
Negative experiences with professional help	70	53	86	5.20*
Not knowing where to find help	53	32	71	6.35*
Distance too far to get help	48	42	52	.42
Having difficulty describing the problem	43	21	62	6.81*
Steps to seek help were overwhelming	40	58	24	4.83*
Considered problem temporary	35	74	0	23.81***
No trust in professional help	28	11	43	5.23*
Fear of being a burden	28	21	33	.76
Wanted to handle the problems themselves	23	26	19	.30
Believed that the problem was not so serious	20	42	0	11.05**
Fear of labeling / stigma	18	16	19	.07
Busy / Other priorities	18	11	24	1.22
Other people did not want the family to seek help	18	11	24	1.22

* $p < .05$, ** $p < .01$, *** $p < .001$