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Current and Future Concerns of Older Parents of Sons and Daughters With Intellectual Disabilities

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Abstract Increasingly greater numbers of older parents are providing care at home for their sons and daughters with intellectual disabilities. As attention needs to be paid to the supports needed by such families to assist them with their caregiving activities, it is prudent to identify the types of supports that will be needed when the parents are no longer able to provide care. Working with a cohort of older parent carers in Prince Edward Island, Canada, the authors undertook to examine older carer concerns and planning issues. Using both qualitative and quantitative methods to explore the key issues that older parents of sons and daughters with intellectual disabilities are currently facing and their preferences for care in the future, the authors initiated a population-case-finding process, undertook pilot interviews with a sample, and then used the resultant qualitative data to form the quantitative component of the study. Of 132 identified families in the province, 10 parents voluntarily participated in pilot interviews, and 33 parents agreed to complete in-depth interviews. Analysis of qualitative data resulted in the following five themes: (1) worry about the future care of son or daughter; (2) concern about services funding; (3) having housing and care options; (4) lack of provider understanding of carer's needs; and (5) helping son or daughter become a productive and active member of society. Key issues identified through quantitative analysis included interactions with the government, the need for respite care, and meeting social and emotional needs. Preferred types of housing and care options included "small option homes" and services that provide care to both older parents and their sons and daughters. The authors' results emphasize the necessity of adequate supports being made available to older parents who wish to support their sons and daughters with intellectual disabilities at home and to ensure that desired supports are available in the future when they are no longer able to provide care.

Keywords: aging, Canada, family carers, intellectual disabilities, older parents

INTRODUCTION

A reduction in the rate of institutionalization of people with intellectual disabilities (ID) and an increased life expectancy has created a situation where active caregiving for people with ID by family members can currently span four or five decades (Braddock, Emerson, Felce, & Stancliffe, 2001; Essex, Seltzer, & Krauss, 1999; Harrington, Chapman, & Miller, 2005; Mulvany, Barron, & McConkey, 2007). Awareness of the impact of aging on adults with ID began in the 1960s, but extensive research in this area only gained traction since the 1980s (Allen, Blieszner, & Roberto, 2000; Ansello & Rose, 1989; Haley & Perkins, 2004; Janicki & Ansello, 2000). Even so, there continues to be a need for increased collaboration between the aging and disabilities communities, around, for example, training for professionals working with older people with ID and their family members (Clark, 2007; Hogg, Lucchino, Wang, & Janicki, 2001; Sparks, Temple, Springer, & Stoddart, 2000).

It is estimated that between 50 and 60% of people with ID live with family carers, although the likelihood of having to live outside the family home increases with age (Barron, McConkey, & Mulvany, 2006; Braddock & et al., 2001). Formal agencies are often utilized to provide care for people with ID when a primary carer parent dies or becomes too infirm to continue to provide care (McCallion & Janicki, 1997). The number of older parents providing care for sons and daughters with ID is expected to increase substantially, as some families do not seek out services until the parent or parents are unable to continue providing care (Ansello & Eustis, 1992; Ansello & Janicki, 2000). Factors that can contribute to parents no longer being able to provide care include high personal care needs of their sons and daughters with ID, being over age 75, having greater than average stress levels, and having a limited income (McConkey, 2005). As prior research has focussed more on congregate residential care rather than on families providing care for their adult children with ID (Barron et al., 2006; Jokinen, 2006; Seltzer & Krauss, 2001), additional research is needed that examines the types of supports that families need to assist them in continuing to provide in-home care (Harrington et al., 2005).

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McConkey, Sowney, Milligan, and Barr (2004) noted that most people with ID living with family members appear content and prefer to remain with family members. Thus, it is imperative to have a greater understanding of how to best support these families. Researchers who have examined current concerns among older parents, who have sons and daughters with ID, have reported that many of these concerns are linked to various aspects of service provision. Many parents who have sons and daughters with ID distrust the public sector for a variety of reasons, including difficult past relationships with service providers, a history of unsatisfactory services provided by the public sector, and a lack of information provided to them (Joffres, 2002). Examining ways to improve communication and understanding among people with ID, their families, and the government programs designated to support them is important (Bigby & Ozanne, 2001; McCallion & Tobin, 1995). Many older parents have difficulties meeting the financial obligations of providing for a son or daughter with ID (Hogg et al., 2001). Also, it is clear that older parents need to have the opportunity to become actively engaged in the policies and practices affecting their lives (Botsford & Rule, 2004; Jokinen, 2006).

It is evident that many older parents have concerns regarding the future care of their son or daughter with ID. Permanency planning, or futures planning, involves planning for the future care and supports of people with ID, including meeting their residential, legal, and financial needs, and assuring quality of life (Bigby, 1996; Freedman, Krauss, & Seltzer, 1997; MacLellan, Norris, MacPherson, & Flowerdew, 2002; Pruchno & Patrick, 1999). In some families, parents have expectations that other sons or daughters will provide care in the future (Greenberg, Seltzer, Orsmond, & Krauss, 1999; Griffiths & Unger, 1994; Krauss, Seltzer, Gordon, & Friedman, 1996). However, in many families, there is lack of permanency planning, and it is not clear who will provide long-term care after the aging parents are no longer able to provide care (Ansello & Janicki, 2000; Bigby, 2000; Heller, Caldwell, & Factor, 2007; Joffres, 2002).

Some efforts are being made to encourage older parents to engage in permanency planning. Specific interventions have shown success in engaging families in the planning process, and those involving both the parents and their sons or daughters with ID are particular beneficial (Clark & Susa, 2000; Heller & Caldwell, 2006). For example, Heller and Caldwell found that following an intervention to support families to plan for the future care of their adult child with ID, almost half included plans to use formal residential arrangements, and half made plans for other family members to provide care. In this vein, Bigby (2000) has advocated for not identifying a rigid plan for the future, as this may not be realistic or appropriate for some families, especially given changes that may occur over time. Instead, she has suggested that either explicitly or implicitly identifying a key person to oversee the well-being of the person with an ID is advantageous.

SPECIFIC AIMS

In this study, we utilized both qualitative and quantitative methods to explore (1) the key issues that older parents of sons and daughters with ID are currently facing, and (2) the parent's preferences for housing and care options for their sons and daughters in the future. The results of this study could be useful in helping to synthesize and prioritize the needs of these families (Joffres, 2002; Jokinen, 2006).

The vast majority of the available research on this topic employs a quantitative approach, which does not provide us with a rich understanding of the lives and concerns of these families (Chou, Lin, Chang, & Schalock, 2007; Stehlik, 2000). The utilization of both open- and closed-ended questions in this study reflected a mixed-methods approach drawing on the strengths and perspectives of both quantitative and qualitative research methods (Mill & Edwards, 2003).

We first undertook a case identification initiative with the goal to find as many families fitting our study criteria as possible. Once families were brought to our attention, we screened them and then conducted pilot interviews. Then, we used the resultant data to inform in-depth interviews in the quantitative component of the study. In order to clearly distinguish the two components of this study, we first described the methods and findings from the qualitative portion, and then the methods and findings of the quantitative component of this study. The University of Prince Edward Island Research Ethics Board approved this study.

PHASE I: SCREENING PROCESS AND PILOT INTERVIEWS

Method

To begin the process, we undertook a case identification process, where we contacted agencies that served people with ID on Prince Edward Island and requested their aid in contacting parents of their clients. We sought out as eligible study participants families with at least one parent no younger than age 50, with a son or daughter with ID living at home. We provided agency staff with stamped envelopes containing an information letter, and agency staff addressed and mailed the envelopes. Parents interested in participating in this study then contacted research staff, who screened them via telephone conversation for eligibility. The parents who responded were asked for names of other families who would fit the study criteria, similar to the process employed by Rimmerman and Muraver (2001). Project staff then contacted and screened these additional parents identified. The study was undertaken in the province of Prince Edward Island, Canada, which has a total population of 137,781 people (Vanier Institute of the Family, 2004).

In the screening interviews, the parents were asked for contact information, their age (to determine eligibility), the nature of their son or daughter's ID, and any comments or issues they wished to share. Many did discuss current issues of concern and shared their concerns for the future. Carer responses were recorded by the interviewer on a form. The screening process identified 132 eligible families—while not an exhaustive number, potentially representative of the total number of such families. Of these 132 families, 65.9% ($n = 87$) included a father and mother providing care for a son or daughter with an ID, 30.3% ($n = 40$) included a mother only, and 3.8% ($n = 5$) included a father only.

Of the 132 families, we randomly selected 14 to participate in a pilot interview in order to further identify current and future issues that these families face. The parents were contacted by telephone and invited to participate in a face-to-face interview. Three parents declined to participate in the interviews, resulting in 11 pilot interviews completed. For those who agreed to participate, an appointment was made for an interview in their home. After giving written consent, the interview proceeded with nine open-ended questions, including questions on current living arrangements, care provided by the family, programs and services currently used, future plans for care, and wishes for future care. These pilot interviews ranged from 20 to 30 min in length. In nine of the pilot interviews, the mother participated, and in two interviews, both the mother and father participated.

The first author conducted a thematic analysis of the information provided on the screening forms and the data collected during the pilot interview process to identify current and future issues of importance to the parents. Thematic analysis is a form of pattern recognition within data allowing for themes to emerge directly from the data using inductive coding (Fereday & Muir-Cochrane, 2006). This process involved generating initial codes, searching for themes, reviewing themes, and defining and naming themes that resulted in thematic codes that represented patterned responses within the dataset (Braun & Clarke, 2006). Thematic analysis is particularly useful in understanding influences and motivations related to how people respond to events (Luborsky, 1994), and thus lends itself well to developing a greater understanding of the issues and challenges that parents of sons and daughters with ID face today and in the future. Thematic analysis has been used previously in research on narratives of women's disability and in research with adults with ID (Duggan, Albright, & Lequerica, 2008; Mitchell & Clegg, 2005).

Findings

Background characteristics In the 132 families identified, the mean age of the mothers was 62 (range: 41–91, SE = 0.90), and the mean age of the fathers was 63 years (range: 45–90, SE = 1.05). Although all of the families included at least one parent age 50 or older, in 3.8% of the cases, the mother's age was not reported, and in 28.8% of the cases, the father's age was not reported. In two-thirds of the families, the fathers resided in the home. The mean age of the sons and daughters with ID was 33 (range: 8–59, SE = 0.93); 8.3% ($n = 11$) of the sons and daughters with ID were under age 18. In 85% ($n = 112$) of the families, the sons and daughters lived with their parents, and 15% ($n = 20$) lived in another setting (i.e., group home, long-term care facility). Although many had a single diagnosis such as Down syndrome, others had more than one identifiable disability, or had a general diagnosis such as "mental retardation" or varying degrees of ID. Many also had a concomitant physical disability.

Thematic analysis We identified the following five themes through the thematic analysis of the qualitative data collected during the screening process and pilot interviews (see Table 1 for specific notations from the interviews).

Worry about the future care of son or daughter. As the majority of the sons and daughters in this study lived with their parents, the parents knew that they needed to make some arrangements for the care of their son or daughter in the future. The parents exhibited concerns about their own aging and when a time might come when they would not able to provide care for their son or daughter. They also worried about what would happen after they died. Although many parents did not know what they were going to do, some knew what they hoped would happen. Their hopes included not only physical care, but also an environment where their son or daughter would be accepted and loved. Many parents hoped that other family members would be able to provide care for their son or daughter with ID. Some parents had a tentative plan in place that often included other family members, such as their other children (i.e., adult daughters) providing care in the future. However, not all the families wanted to rely on other family members to provide care, and in some cases, there was no other family member available who could provide care.

Concern about funding for services. Many of the families mentioned concerns about finances. Parents discussed the strain they experienced because of the continuous care required to look after their son or daughter. Many parents suggested that they needed funding for either in-home respite or programs outside of the home. Additional financial concerns identified included not having enough money to meet medical needs, not having money for extras, not being aware of financial entitlements, and the high costs of caring for their son or daughter at home. Concerns about reductions in public forms of financial assistance or low levels of financial assistance provided were also evident.

Having housing and care options. The respondents indicated that appropriate housing for their sons and daughters outside the family home is currently a luxury rather than a right. Only a few families were satisfied with the current housing options for their sons and daughters. They also preferred to have less bureaucracy in order to access housing. Many respondents suggested that new forms of housing programs be developed or that current forms be expanded. Although the families provided many suggestions for the development of appropriate housing, they most frequently mentioned developing "small options homes." Other suggestions for the development of appropriate housing included developing more group homes, creating group homes that are gender specific, providing independent living apartments that are supervised, ensuring that housing does not lump all adults with disabilities together, increasing the availability of private family foster homes, and accommodating the needs of both the parents and their sons and daughters with ID within a retirement facility.

Lack of provider understanding of carer's needs. The respondents referred to a lack of understanding by government personnel, professionals, and the general public. Many of the families felt that in general, the government did not understand their needs, and the government did not provide adequate supports and services in an appropriate way.

Other families felt that personnel in a specific government department or agency providing services neither understood their situation nor provided necessary services. Finally, a lack of understanding by the general public was also noted.

TABLE 1
Illustrative quotes by theme

Theme	Illustrative quotes
Theme 1: Worry about the future care of son or daughter	*Where we are older, all of our friends are older, you know, and my brothers and my husband's brothers and sisters are retiring as well, so it's a really scary situation, and I don't want to plunk our son in a group home.*
	I guess it would worry me that he would always be treated with love and looked after. I wouldn't want anyone to be abusive to him. That's all that would be my concern 'cause he can't speak up for himself and there is nobody to speak for him.
	Our daughter is quite concerned about him. She is hoping that she can put money aside for him if he needs it. And she said that she hopes too that she would be able to house him if he ever needs it when she is older. If anything happens to us, she will look after him.
	I would have to say that I wouldn't have another family member look after her. She would have to go to a group home.
	Because I am 55, and my husband will be 58 next month, I don't know what we are going to do. We have a daughter who is 30 and lives in [another city]. She is working full-time. There is no way I would want her to do this. I don't know what I am going to do with our son.
Theme 2: Concern about services funding	*We need more respite care. There should be more money to hire people to care for our daughter. We just get so tired.*
	I wish there was some place to take my son when I wanted to go out. It costs a lot for someone to come in. I really need some time to myself.
	I would love to see a lump sum put out that said this is what you have this year for the respite . . . for summer camps.
	More financial assistance for people who keep their children at home. Start taking into account [that] it takes a lot of money to keep someone like our son. I am talking about when a person becomes an adult, but that doesn't seem to be recognized by government. If he was to go and live on his own, it would be great, you know, they would cover it, but if you stay at home, it's kind of your tough luck.
	You know, our combined salary is higher than the level where you can actually get help . . . but you know, we are just a little bit higher, but it is still not enough.
	If I received the same financial help as the foster families, then my child could stay at home.
Theme 3: Having housing and care options	*There needs to be more small options group homes. We were lucky they could take our son.*
	I wish there was more housing that they can access without having to go through a whole bunch of paperwork and finding out if there is anything available for this or if they require it.
	Some type of housing has to be established for mild to moderately delayed adults.
	Housing is our big concern. Our daughter wants to live independently, but there is no supervised housing.
Theme 4: Lack of provider understanding of carer needs	*They don't understand what we need.*
	The government just takes from us. They need to open their eyes. We need help. We lost our home, everything.
	There is not enough help from Social Services. They need to be more of an advocate to protect people like our son.
	From time to time, we had people who were very compassionate and caring who seemed to understand. But, we have had others that didn't seem to care one bit, and that's distressing. I think that the department involved needs to somehow better train their personnel so they have a better understanding of what kind of people, and what is needed and required, and what frustration that the parents and the caregivers feel.
	We are very upset at the lack of understanding in people. They don't try to understand my daughter and the things she does.
Theme 5: Helping son or daughter become a productive and active member of society	*The education system is really very poor for these children when they are young. It prepares them for nothing.*
	I would like to see more programs set up for when the kids get out of school. More employment and transportation to get there.
	I believe there should be more activities for the adult/child to do. More opportunities to socialize with others.
	We do a lot with our son, but we are his mother and father, and I would love for him to have somebody in his late teens, early 20s, to take him out bowling, to McDonalds, or see a movie, so he doesn't have to go with his parents all the time, sort of a buddy.
	They have helped her get some training and they helped her get a job. She got a nice little job now at Co-op, so she has really been lucky in that way. They have been really, really good to her . . . she is very lucky to have the jobs that she has and the Special Olympics, she goes bowling and curling.

Helping son or daughter become a productive and active member of society. Several subthemes emerged within the context of encouraging persons with ID to be productive, including the provision of appropriate educational, employment, and social opportunities. In addition, transportation emerged as a factor that can enable or inhibit any of these activities. Those families that did have a positive experience with education, employment, or social activities felt very fortunate, and they indicated that this was not the norm.

In addition to the thematic analysis illustrated above, we also identified specific issues of concern for these families and forms of housing and support programs that the parents discussed during the screening process and pilot interviews. In the next phase of this study, we collected additional data through in-depth interviewing in order to determine what the most pressing issues were and the most preferable future housing and support options.

PHASE II: IN-DEPTH INTERVIEWS

Method

From the 132 families identified, we then randomly selected 85 families who did not participate in a pilot interview and asked them to participate in the in-depth interview portion of the study. The research coordinator contacted each family by telephone. Following three attempts, 13 could not be contacted during the data collection period, and an additional 39 declined to participate, for a response rate of 40% ($n = 33$). The reasons for nonresponse included not having enough time to participate, currently not experiencing any problems and/or not wanting to cause problems, experiencing personal illness or the illness of a family member, experiencing a recent death of a family member, not feeling up to it, and not having any interest in the study. For those who agreed to participate in the in-depth interviews, a face-to-face interview occurred in their home. Six trained research assistants completed the interviews and also tape-recorded and transcribed the qualitative data verbatim. The interviews lasted approximately 1 hour each. While either parent was welcome to participate, only mothers of a son or daughter with ID chose to participate in the in-depth interviews.

The background data collected in the in-depth interviews included information on age, number of sons and daughters, marital status, educational level, and income. We used four quantitative measures to evaluate subjective well-being in a separate component of the study, and these results are published elsewhere (Weeks, Bryanton, Kozma, & Nilsson, 2008). Based on the results that emerged from the screening process and the pilot interview data, we identified 17 specific issues of concern for these families. The mothers who participated in the in-depth interviews rated these issues on a continuum from whether they were not at all an issue for the family (1) to whether they were an extremely important issue (5). In addition, the mothers ranked their preferences for housing and support programs they would like to be available to their son or daughter in the future from indicating the most preferable program (1) to indicating the least preferable program (7). Like the issues identified, the housing and support programs also were identified by the parents who participated in the screening process and pilot interview data. The interviewers recorded the responses to the closed-ended questions. SPSS was used for statistical analysis.

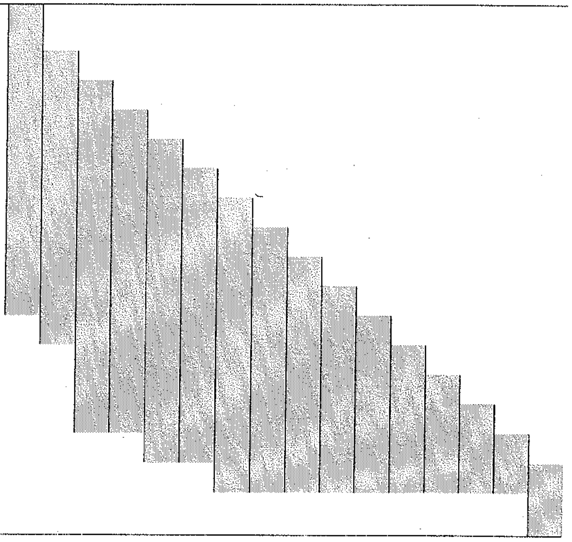
TABLE 2
Characteristics of the mothers who completed in-depth interviews

Characteristic	*n*	%
Age		
43–64	17	51.5
65–74	15	45.5
75–84	—	—
85+	1	3.0
Number of offspring		
1–2	5	15.2
3–4	15	45.5
5–6	7	21.2
7+	5	15.1
Missing	1	3.0
Marital status		
Married or common law	21	63.7
Widowed	9	27.3
Divorced or separated	3	9.1
Never married	—	—
Educational level		
University degree or beyond	3	9.1
Some training beyond grade 12	3	9.1
High school diploma	5	15.2
Less than grade 12	18	54.5
Missing	4	12.1
Extent to which income meets the family's needs		
Very well	1	3.0
Adequately	6	18.2
With some difficulty	14	42.4
Not very well	4	12.1
Totally inadequately	5	15.2
Missing	3	9.1

Findings

Background characteristics For the mothers who participated in the in-depth interviews, we collected additional background information (see Table 2). The mean age of the mothers was 62.9 (range = 43–87, SE = 1.58). Most were married or living in a common-law relationship (63.6%) or widowed (27.3%). More than half of the mothers did not graduate from high school (54.5%), and 18.2% had training beyond high school. Only 21.2% of the mothers felt that their income adequately met or exceeded their needs, and 27.3% of the mothers responded that their family's income did not meet their needs very well or was totally inadequately.

TABLE 3
Ratings of concerns for sons and daughters with intellectual disabilities

Concern	**Mean**	**SE**	**Duncan's ranges**[a]
The government does not understand the family's situation	3.94	0.23	
Uncertain who will provide care after parents die	3.88	0.26	
Not being able to provide care in the future	3.7	0.26	
Physical needs will not be met	3.7	0.24	
Abuse of child may occur	3.58	0.28	
Money for adequate respite services	3.58	0.25	
Inappropriate placement being made before parents die	3.55	0.29	
Social and emotional needs will not be met	3.48	0.25	
Money for occasional or unexpected expenses	3.48	0.26	
Money for basic needs	3.45	0.22	
Money for medical needs	3.30	0.26	
The public does not understand the family's situation	3.24	0.29	
Appropriate transportation is not available	3.21	0.27	
Professionals do not understand the family's situation	3.12	0.29	
Appropriate social opportunities are not available	3.09	0.27	
Appropriate employment opportunities are not available	2.97	0.30	
Appropriate educational opportunities are not available	2.48	0.28	

[a] Vertical bars connect concerns whose means do not differ significantly at $\alpha = 0.05$; SE: Standard Error

Using statistics developed by the Vanier Institute of the Family (2004) on Canadian families, we compared the women in the sample with the population of the province as a whole. Compared with the population of the province of Prince Edward Island, similar proportions of the women in the sample were married, common law, divorced, or separated. However, many more women in the sample were widowed (27.3% vs. 6.9%), and while none of the women in the sample was never married, over one-quarter of the population as a whole were never-married. Compared with the population of the province as a whole, the women in the sample had lower education levels. For example, while only 18.2% of the women in the sample continued their education beyond high school, 51% of the whole population of the province did so. Given that the sample includes only women who are middle-aged and older, these results for marital status were not surprising. However, as only 9% of the population of the province as a whole is deemed low income, it appears that the women in the sample faced far greater financial problems than the general population.

The mothers participating in the in-depth interviews described their son and daughter's general diagnoses as "mental challenges," "developmental delays," or "a slow learner" ($n = 18$). Specific diagnoses were Down syndrome ($n = 8$), Angelman's syndrome, autism, Apitz C syndrome, or mytonic dystrophy ($n = 7$). Fourteen mothers also described the degree of the ID as mild or moderate ($n = 10$) or severe ($n = 4$). Most ($n = 30$, 90.9%) of the sons and daughters lived with the mothers in the family home, and they ranged in age from 11 to 53 (M = 32, SE = 2.06).

Parental concerns about the future The ratings of the 17 issues of concern to the mothers who participated in the in-depth interviews are located in Table 3. It is noteworthy that for most of the items, the mean scores indicated that these issues were located between "somewhat of an issue" (score of 3) and "very much an issue" (score of 4). Analysis of variance results indicate that the mean ratings differed significantly ($F = 16_{(512)}$; $\alpha < 0.05$).

As illustrated in Table 3, significant differences between the items are indicated using Duncan's ranges, a multiple comparison procedure used to compare differences between sets of means. This procedure is especially useful in this analysis, as many of the mean ratings fall close to each, and it is important not to overestimate the meaning of a higher or lower ranking that is not statistically significant. For example, although the top 10 concerns have different mean ratings, they do not differ significantly from each other. This analysis allows us to determine that in this sample, the concern that government personnel do not understand the family's situation is rated as a significantly higher concern than the public or professionals understanding the family's situation. Also, access to appropriate employment and educational opportunities were the issues of least concern for these mothers.

Housing and care options We identified seven specific forms of housing and care options from the screening process and pilot interview data that the mothers indicated they would like to see available for their sons and daughters in the future. The rankings of these options by the mothers who participated in the in-depth interviews are presented in Table 4. Friedman's test indicated that the rankings of the housing and care options differed significantly ($\alpha < 0.05$).

TABLE 4
Ranking of preferences for housing and care options

Type of option	Mean
Small, supervised homes with four or fewer residents	3.29
Facilities that care for both the parents and children	3.53
Other	3.59
Gender-specific group homes	4.38
Supervised independent-living apartments	4.66
Facilities that do not lump all adults together regardless of disability	5.31
Group homes with both genders	5.45
Private foster family homes	5.67

Responses range from 1, indicating the most preferable program, to 7, indicating the least preferable program

The most preferred types of housing and care options that the mothers would like to have access to in the future were "small options homes" and services that provide care to both seniors and their sons and daughters with ID. Many of the participants indicated that an "other" option not in the list was desirable in the future. These other options included family members providing care ($n = 12$), providing funding for a family member to provide care at home ($n = 3$), receiving care in a nursing home ($n = 2$), and living in a home for three or fewer residents with appropriately trained staff ($n = 1$). Also highly desired were gender-specific group homes and supervised independent living apartments.

DISCUSSION

In this study, through a thematic analysis of data collected through a case identification and screening process and pilot interviews, we identified key themes and specific issues of concern that older parents of sons and daughters with ID had currently and for the future. Then, through analyzing data collected in in-depth interviews, we used quantitative methods to determine the degree of their concern about issues, housing, and care. This combination of qualitative and quantitative data provides both an inclusive view of the situation of these parents, as well as specific information for developing supports and services.

To frame our interpretation of the results, it is useful to describe the types of services and supports available to older parents in the province of Prince Edward Island, Canada. There are a variety of limited services and supports available to older parents who have sons and daughters with ID. Financial assistance programs provide quite low levels of funding, and issues with the current system include a lack of indexing of benefits for several years and income caps. Parents can receive tax benefits through a Registered Disability Savings Program. Respite and day programs are available on a limited basis, and staffing for respite is a particular problem. Independence is encouraged through employment assistance programs, job coaching, transitioning from school to the community, and inclusive postsecondary programs. Organized social and recreational activities are available, such as participating in the Special Olympics.

Meeting the social and emotional needs of people with ID and providing social opportunities were rated as more important issues for the participants in this study than employment or educational opportunities. Jokinen and Brown (2003) also found that one key concern about the future is access to appropriate social connections for their adult children with ID. Many parents in our study had adult children older than the age at which people are typically enrolled in a formal educational program. Thus, a younger sample of parents would potentially yield different results. Also, the province appears to currently focus more on training and career building opportunities rather than social opportunities for people with ID, and a greater balance between these two types of activities is warranted.

While approximately two-thirds of the families screened had both a father and mother in the household, few fathers chose to participate in any stage of this study, and no fathers participated in the in-depth interviews. This is consistent with other research that observed that fathers are less likely to be primary carers of sons and daughters with ID than are mothers (Chou et al., 2007; Heller et al., 2007; McConkey, 2005), and that this may influence their participation in research. We did find that in almost 4% of the families screened, only a father was present to provide care to a son or daughter with ID. While this is a very small proportion of the families screened, more research is needed on this subgroup of parents.

The results of our study add to the current knowledge of issues of concern for older parents continuing to provide care for their sons or daughters with ID, most of whom provided care at home. Many of the mothers who participated in the in-depth interviews were unhappy with their interactions with the government, and our results indicate that this was a greater concern than interactions with professionals. The participants may have distinguished the difference between the government that develops policies and allocates resources and the professionals who deliver services. Our research supports results of other researchers who identified problematic issues that older parents experienced in their interactions with the service system, including lack of trust, difficulty finding helpful contact people, and emotional barriers from fighting the service system (Heller & Caldwell, 2006; Rapanaro, Bartu, & Lee, 2008). It is evident that increased cooperation among service systems is needed in order to more effectively support caregiving families (Clark, 2007).

While our results helped to identify the diversity of housing and care options that are preferred by older parents of sons and daughters with ID, we did not determine whether these parents accessed these services (Botsford & Rule, 2004; MacLellan et al., 2002; McConkey, 2005). For example, consistent with other studies, our results pointed to the importance of respite care for aging parents of sons and daughters with ID (Barron et al., 2006; Freeman, Griffiths, Krauss, & Seltzer, 1999). However, our results also suggest that it is not only the availability of respite care that is important, but also having access to the necessary funds to purchase respite care. Services, such as respite, that can strengthen the capacity of parents to continue providing care are prudent and practical, especially in jurisdictions where there is limited or no publicly supported programs and services (Ansello & Janicki, 2000).

The parents' preference for "small options homes" for the care of their son or daughter in the future is noteworthy. In Prince Edward Island, "small options homes" are supervised group homes with a limited number of residents, generally four persons or less. Possibly, the parents in this study felt that these homes provided higher levels of protection, permanency, and the home-like environments often sought out by parents (Bigby, 2000). In addition, a highly preferable future housing and care option is one that can provide care for both aging parents and adult children with ID, thus further emphasizing the lifelong strong bonds between many older parents and their sons and daughters with ID. Our results suggest that further cooperative living residential care options that meet the needs of these two generation groups should be developed—perhaps using the assisted living facilities model. However, the development of this type of service is not currently promoted due in part to concerns about the adequacies of nursing facilities for people with ID, due to a lack of cross-training staff to work with both people with disabilities and older adults, insufficient staffing levels, and a lack of an appropriate outlet for social and recreational activities (Bigby, Webber, Bowers, & McKenzie-Green, 2008; Janicki & Ansello, 2000; Thompson, Ryrie, & Wright, 2004). The mothers' preferences for supervised independent apartments are also noteworthy, and may reflect a preference that is related to their son or daughter's degree of impairment.

Several limitations of this study should be mentioned. We analyzed data from older parents of sons and daughters with ID without dividing them into subgroups. As Haley and Perkins (2004) suggest, more information is needed about subgroups of older parents, such as those in different age groups or older parents with offspring with specific needs. This study included a relatively small number of parents of sons and daughters with ID, which precluded such parsing. The results of this study, howsoever preliminary, have important implications for future research, practice, and policy in Prince Edward Island, as the results provide insight into the needs and preferences of these families. While limited, the results also can apply in other jurisdictions where the supports available to these types of families are narrow.

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