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To cite this article:

Rachelle D. Hole, Tim Stainton & Leah Wilson (2013) Ageing Adults with Intellectual Disabilities: Self-advocates' and Family Members' Perspectives about the Future, *Australian Social Work*, 66:4, 571-589, DOI:10.1080/0312407X.2012.689307

To link to this article: <http://dx.doi.org/10.1080/0312407X.2012.689307>

Ageing Adults with Intellectual Disabilities: Self-advocates' and Family Members' Perspectives about the Future

Rachelle D. Hole¹

School of Social Work, University of British Columbia, Centre for Inclusion and Citizenship;

Tim Stainton

School of Social Work, University of British Columbia, Centre for Inclusion and Citizenship

Leah Wilson

Department of Educational & Counselling Psychology, and Special Education, University of British Columbia

Abstract

Although the numbers of ageing adults with intellectual disabilities are increasing, current systems are ill-prepared to meet the unique needs of this population and research is needed to direct policies and practices aimed at supporting ageing adults with intellectual disabilities. This article presents the qualitative findings of research conducted in British Columbia (BC), Canada, which explored the future perspectives of 11 ageing adults with intellectual disabilities and 11 family members. Future concerns of the adults with intellectual disabilities included concerns for their ageing parents, for their future living arrangements, and about loneliness. Family members concerns centred on ensuring the future security of their loved one with an intellectual disability, addressing legal issues and financial security, and promoting future choice and self-determination. The results point to the importance of early and intentional planning that supports and balances the needs and desires of both ageing adults with intellectual disabilities and family members.

Keywords: Ageing; Intellectual Disability; Supports and Services

As with many high income countries (e.g., United Kingdom [UK], Australia, United States [US]), the population of Canada is ageing. In 2006, 13.7% of the Canadian population was aged 65 or older; by 2026, it is estimated that 20% of Canadians will have reached the age 65 or greater (Statistics Canada, 2007). Similarly, dramatic changes in life expectancy for individuals with intellectual disabilities have occurred in the last 50 years (Bigby, 2002), and the life expectancy of individuals with a disability continues to rise as health and social conditions improve (e.g., Bigby & Haveman, 2010; Janicki, 2009; Lawrence & Roush, 2008). In Canada in 2006 (population 31,612,897), there were approximately 47,290 adults between the ages of 45-64 years and 7,260 adults over the age of 65 years living with intellectual disabilities (Participation and Activity Limitation Study, 2006). It is expected that this population will double in the next 25 years (Canadian Housing & Mortgage Corporation, 2006). These changing demographics and the paucity of existing research (particularly in the Canadian context) emphasize the urgent need for ageing and intellectual disabilities research.

Researchers interested in ageing and intellectual disabilities have identified numerous areas needing attention. Thus, although not an exhaustive list, research is needed that focuses on identifying the needs and concerns of ageing adults with intellectual disabilities (Bigby et al., 2008; McCausland, Guerin, Tyrrell et al., 2010); on investigating the best practices for supporting individuals and family

¹ Correspondence to: Dr Rachelle Hole, University of British Columbia - School of Social Work, 3333 University Way, Kelowna, British Columbia V1V 1V7, Canada. Tel: +1-250-807 8741. Email: rachelle.hole@ubc.ca

members in future planning for the future (Jokinen, 2006; Werner, Edwards, Baum, Brown, Brown, & Isaacs, 2009); and, on how best to support family caregivers, especially ageing family caregivers (Clark, 2007; Roeher, 2003; Weeks, Nilsson, Bryanton & Kozma, 2009). This is particularly so because family members are the main source of support for almost 80% of adults with intellectual disabilities (Canadian Housing & Mortgage Corporation, 2006), and approximately 50-60% of adults with intellectual disabilities live with family carers (Weeks et al., 2009). Thus, with increasing numbers of adults with intellectual disabilities living longer, these individuals and their families who support them, most often ageing parents, are encountering numerous transition issues (Canadian Housing & Mortgage Corporation, 2006).

Future planning is one such prominent issue discussed at length in the literature on ageing adults with intellectual disabilities (Bigby 1996; 2000; Heller, Caldwell, & Factor, 2007; Weeks et al., 2009). Although planning for the future is a task faced by all who age, future planning is particularly important for adults with intellectual disabilities and their families and involves planning for future living arrangements, financial planning, future vocational and recreational desires, and decision-making and trusteeship issues. However, complications to future planning exist.

Although ageing parents express concern about their adult child's future (e.g., Brown, Anund, Fung, et al., 2003), research demonstrates that the majority of families have not engaged in concrete permanency planning (e.g., Gilbert, Lankshear, & Petersen, 2008). This is a critical concern because without adequate plans and supports in place, unfortunate situations may materialize such as emergency placement in inappropriate settings and inadequate financial and legal safeguards (Gilbert et al., 2008; Heller & Caldwell, 2006).

Another challenge to these pertinent transition issues is structural where the systems meant to support ageing adults with intellectual disabilities are not well prepared to do so (Ansello & Coggle, 2004; Bigby, 2002; 2010; Lin, Wu, Lin, et al., 2011; Llewellyn, McConnell, Gething, et al., 2010; Putnam, 2004). Ageing individuals and their ageing family members most typically receive supports and services from specialised community living services, which, historically, have not had a great deal of experience in supporting seniors. Similarly, generic seniors' supports have not traditionally been inclusive of people with intellectual disabilities (Bigby, 2002; Rice & Robb, 2004).

In provinces like British Columbia (BC), the responsibility for ageing and intellectual disability reside in separate government Ministries operating independently; meaning that structurally the potential is strong for individuals to become caught between systems with each claiming the other is responsible (Cleaver, Hunter, & Ouellette-Kuntz, 2009; Stainton et al., 2006). Moreover, disability supports are not usually funded by the ageing system, which limits the options for "ageing in place" (Bigby, 2010). The above issues contribute to an inefficient and frequently ineffective support system and hinder individuals' and families' abilities to effectively plan for the future. Given these structural issues, significant demands for new disability and ageing related services and enhancement of existing services are indicated (Bigby, 2010; Lawrence & Roush, 2008); and, questions loom as to how to ensure positive and successful ageing for adults with intellectual disabilities and how to best assemble the most appropriate array of services to address their needs.

In an effort to better understand the needs, hopes, and desires of ageing adults with intellectual disabilities and family members of adults with intellectual disabilities, we undertook a qualitative study to explore the perspectives of individuals with intellectual disabilities (referred to subsequently as self-advocates) and family members. These findings are part of a larger mixed-methods research project aimed at investigating the current state of practice with regards to community living supports and services in BC. Services to seniors was one of four key areas of inquiry of the larger project and the focus of this paper.

Method

Descriptive qualitative methods (Sandelowski, 2010) were used to explore the perspectives of self-advocates age 50+ years and family members of individuals with intellectual disabilities about the future. The research question guiding the inquiry was, “What are participants’ plans, hopes, and concerns regarding future supports and services?” Ethics approval for this research was granted by the University of British Columbia Behavioural Research Ethics Board.

Sampling and Recruitment

Using convenience sampling, individuals were recruited from across BC. For the topic of services to seniors, the inclusion criteria were: (a) an individual who receives, or who is eligible to receive, services from the Crown Agency responsible for community living supports and services in BC or a family member of an individual with intellectual disabilities who is in receipt of, or eligible to receive, services from the Crown Agency; and, (b) an individual age 50+ years or individuals with a family member with intellectual disabilities age 50+ years. Persons under formal Guardianship or Committee were excluded.

Community organisations supporting self-advocates and family members were asked to post and distribute project information. Individuals were invited to contact the research team either directly or through a representative to request additional information or arrange participation. Upon contacting the team, information about the project including the consent form and the interview guide (all in plain language) were provided to interested individuals. A self-advocate with years of professional experience consulting provided input and guidance on all plain language project documents. Providing project information in plain language were important aspects pertaining to informed consent. Self-advocates were encouraged to have a trusted person assist them in reviewing the information prior to agreeing to participate in the research.

Participants included 22 individuals: 11 self-advocates and 11 family members. Although we interviewed both self-advocates and family members, the self-advocate participants were not related to the family member participants. Although level of disability was not a formal criterion for sampling, the resulting sample of self-advocates had mild to moderate disabilities and all 11 used verbal communication.

Procedures

As is common in qualitative traditions, data collection and data analysis occurred concurrently (Richards, 2005). For feasibility reasons, participants were given the option of participating in group interviews or individual interviews. Group interviews enhanced opportunity for participation from across BC; however, some preferred individual interviews. Interviews with self-advocates and family members were conducted separately. Three group interviews with family members ($N= 2$, $N= 2$, and $N= 4$) and two group interviews with self-advocates ($N= 4$ and $N= 3$) were held. Four individual interviews with self-advocates and three individual interviews with family members were conducted.

Semistructured interview guides were employed ensuring that the same broad topics were covered across interviews while allowing for flexibility to explore the participants’ experiences and perspectives (Kvale, 2008). The interview guides were developed in consultation with the self-advocate consultant.

As the part of the larger study focusing on current practices in BC, the first part of the interview for family members and for self-advocates asked about current services and supports: for example, what is working and what is not working. For self-advocates, the interviews were anchored in their day-to-day lives: for example, what kinds of things do you like to do during the day? Who helps you do that? Are

there things you wish you could do that you are not able to do? For the topic services to seniors, self-advocates were asked about the future: participants were asked about “retirement”, about what they look forward to, and about concerns for the future? The self-advocate consultant, along with researchers (TS and RH) who have a background in community living, developed probes and suggestions for alternate wording to assist in communicating these more abstract ideas. Family members for the topic on seniors were asked two additional questions: “What programs, services, or options would you like to see available for your family member?” and, “What needs to happen for these desires to be realised?”

The interview guides were pilot tested with a focus group of self-advocates and a focus group of family members prior to engaging in data collection. Participants gave consent prior to each interview and each session was digitally recorded and later transcribed verbatim.

Thematic analysis (Braun & Clarke, 2006) was used to compare, contrast, and categorise the data into themes (both within and across transcripts). The process involved the identification of themes through careful reading and rereading of the data. The data were coded, organised, and reorganised several times leading to the development of an initial coding framework. The research team met to evaluate the coding framework and to synthesise the categories and concepts into themes. NVivo^{QSR} was used to manage the data and facilitate data analysis.

The team held analytic meetings to discuss and monitor coding consistency and thus to address the analytic validity of identified themes (Morse & Richards, 2002). In addition, the research team met to ensure that the findings were internally consistent and supported by the data. Data were compared and findings across group interviews and individual interviews were consistent. Emergent themes are supported by direct quotes from the participants as to enable readers to evaluate the interpretations. All identifying information has either been removed or changed to ensure participants’ confidentiality.

Findings

Both self-advocates and family members participated in this research. The findings from each group will be presented separately beginning with the findings from the interviews with self-advocates.

Voices of Self-Advocates

Future Plans and Hopes

The findings of this study reflect a diversity of views with respect to ageing adults’ interests, future plans, and hopes. Participants shared their varied interests with respect to activities, which included: traveling, going for coffee, going shopping, attending church, volunteering, working, playing bingo, photography, participating in arts and crafts, playing cards, and visiting with friends and family.

When asked about retirement, the majority of self-advocates expressed their desire to continue participating in activities they currently enjoy. Participants talked about their desire to retire and to be a “senior”, while emphasising particular leisure activities they would enjoy. For many, retirement was associated with opportunities to engage in other activities such as travel and to participate in leisure activities. In fact, one participant saw retirement and associated travel as providing him with the time to think about what kind of living arrangement he desired and how he could make that happen. However, others expressed the desire to keep working. For example, one man shared, “It doesn’t really fit in right now. I don’t really want to retire. I’d rather be doing what I’m doing, keep going... as long as I can even when I’m retired” (Participant #2). Another woman stated:

I'd rather keep working until it's about 60 or 65, eh? Because I think work is more important. [R: Why is work important to you?] Because it helps other people and you're more reliable for other people, and it has, and it makes you feel good. That's what we all feel when we're working. (Participant #3)

The diversity of views with respect to future plans and desires points to the importance of assessing each individual's needs and wishes when planning with them for their future.

Future Concerns

When asking participants about their future concerns several themes emerged. These included concerns relating to relationships and security particularly about ageing parents, living arrangements, and loneliness. Concerns about ageing parents reflected self-advocates' unease with their own future as well as worries for their parents' wellbeing. For example, participant #10 expressed, "if my dad dies, what will the future be for me?" Another participant shared her concern about her elderly parents and her desire to provide care to them:

right now my parents are getting old and I worry about that constantly; and I might get upset about this, but anyway, it's that they're getting old and being able to be there for them, and it worries me that I'm not able to do as much as I could or someone with a car say, for example, like I'd like to be able to go and pick them up and take them grocery shopping and take them to doctors' appointments but I can't do that so I feel I want to. I'm not a very good daughter. (Participant #5)

This participant discussed how she wanted to play a more significant role in the lives of her parents as they age; however, she was unable to provide the kind of support she wants to.

Discussions about living arrangements were also spoken about in the context of future concerns. One participant shared his frustration about the lack of choice he had following the death of his mother. Repeatedly, he brought up his dissatisfaction with his current living arrangement and expressed concern that he would not be able to move. He was dissatisfied that he had to move to a different neighbourhood from where he and his mother had lived:

And one thing is my mom died of a heart attack...it was hard for me to take...I didn't have any choice [I had to move]...so I found it was too far for me. I couldn't get to the doctor; I couldn't get to the dentist. It was just terrible. (Participant #1)

Another participant spoke of how living arrangements meant that spending time together was difficult:

With my parents, and that, we, we don't see each other... we see each other around, twice a month if we can and I think it's important ... I think it's important that they're there for me and I'm there for them because they're getting old and it's, you know, it's hard to get old. And I find living alone in Coquitlam hard when

they live in Vancouver; so, I don't get to see them that often.
(Participant #5)

Finally, loneliness was an issue that participants spoke to with respect to ageing and not being able to get out as often. One participant shared:

I wish I could do more. Like, I want to be doing more so I wouldn't feel so, like I'm not all alone. I feel sometimes, like during the day when everybody is working, I feel I should be doing something but I'm not. (Participant #6)

In spite of the future concerns expressed by self-advocates, only one self-advocate (participant #5) indicated that she was actively engaged in planning for her future by creating a list of life preferences so that such information was articulated and clear should she be unable to communicate those wishes in the future.

Voices of Family Members

Family members participating in this research overwhelmingly expressed a "lack of peace" and "concern" with respect to the future:

I'm really concerned. I'm 63 and she's 18. So, there's a huge difference and I will be gone for many years of her life. I'm the only one left. So, it's a real source of concern for me, for somebody to watch out for her when I'm gone. (Participant #12)

Another participant shared, "I've been thinking about the future and have the feeling of uncertainty about it" (participant #13). In fact, planning for the future was a prominent theme for family members.

Most participants spoke of the need or importance of later life planning; however, only three families had engaged in such planning at the time of this research. Those who were engaged in future planning spoke of a support person, a champion, who facilitated planning and accessing resources. For example, one mother had a support worker who assisted her:

It's very complex... I had to redo my will after my husband died and I had to make provision for Jane; and so, there again, my resource was Frank. He gave me a list, you know he lets you make the decision. He gives you a choice... He's fantastic! (Participant #20)

And, two participants spoke of how a crisis highlighted the need for future planning. One mother shared:

I guess what brought it to the forefront would be when my husband got ill. The first time was not bad. He was in the hospital from the heart attack... that lasted two weeks. Three months later he went in and he was in the hospital for six weeks, and then you begin to see, that, gee, you're not invincible after all and that in the future

you're going to need more help than you're getting. (Participant #19)

Family members who were not engaged in future planning indicated several factors that contributed to their lack of future planning. Some individuals spoke of years of advocacy and described a sense of feeling burnt out: "I can't take on anymore than I've got" (participant #15). Others shared their belief that family members would "step up when the time came" (participant #12). And, many family members pointed to formal and informal barriers that resulted in a "disconnection" from services and supports thereby influencing their lack of engagement in future planning.

The following section describes the theme "proactive planning for the future"; presenting the important dimensions of future planning and discussing the complexities of the contexts within which this future planning occurs.

Proactive Planning for the Future

Repeatedly, family members expressed the importance of proactive future planning. For these family members, there was recognition of the need to create some kind of plan to provide stability in the face of future changes. In fact, the need for intentional planning was articulated as a response to concerns about the future. For example, one parent expressed:

Everybody is concerned what's going to happen when we're no longer around, right? And our group, the parents who have kept their kids at home, I mean they're in their 60s, 70s, and 80s and ... their children are still at home with them. (Participant #18)

Furthermore, there was recognition that the issue was of growing significance and that planning should be preemptive rather than a crisis response. A sibling shared:

There's so many that have elderly parents and they're just hanging on not knowing what's going to become of their loved one. Yeah, my dad is 80 some[thing] and my mum is going to retire at 65 at the end of this year, and they'd like to see something in place for John before they pass on. (Participant #22)

Another participant stated,

[I've seen] elderly parents, parents like in their 70s, 80s, with Down's Syndrome children that were in their late 30s and 40s. And I [am] concerned because I thought, "What happens to that person when their parents pass away?" (Participant #18)

The following key points were emphasised regarding proactive future planning: the importance for secure and stable living arrangements, the need for attending to legal issues, the importance of financial security, and the value of choice and self-determination.

Numerous family members emphasised the need for stability with respect to future living arrangements that went beyond the family home. This was particularly salient for ageing parents whose

adult child was living at home. Parents spoke of such living situations as precarious: “things could change at any moment.” A sibling explained:

We needed to get going because my sister has, she’s 40, 41 and still living at home and I had ageing parents; so the key for me was for me to be able to move her into a living arrangement, and it was very difficult. (Participant #22)

And, transition planning was one important element of intentional planning:

This is my single biggest concern that Jane not be left to drift... I think that by going to a respite and breaking that tie to get her to realise that she can exist without mum, without dad, that she can continue to live a good life. And I think respite would give her that... confidence that, “Gee, I can sleep in another bed beside my own and still be comfortable.” I would like to see her established ... somewhere where she feels comfortable, where she feels secure in her place, and yes, I’m there to back her up. (Participant #13)

Another parent stated, “He’s now in a semi-independent living situation. We’re getting on in years and it was essential for us that the cord was broken and that he has to learn to survive himself in the community with assistance” (Participant #16)

One strategy families promoted involved using respite as a resource to facilitate transitions for ageing adults with intellectual disabilities who had been living in the family home. In the quote above by Jane’s mother, the parent was coming to realise that this situation could not work forever; respite was a means of providing Jane the opportunity to build her confidence apart from mom and dad. Finally, family members shared that they wanted to be around to help and support their family member transition into a new living arrangement. Families wanted to see their loved one settled into a long-term, stable, living situation.

Another dimension of proactive planning concerned the need to attend to legal issues, particularly the importance of ensuring that ageing adults with intellectual disabilities had an advocate and that her or his legal rights were protected. One family member had obtained a court appointed advocate to ensure that there would be someone available to speak for her loved one after she herself passed; another family member had recently pursued formalising a representation agreement; and several family members spoke of the importance of microboards for future planning. Microboards are comprised of individuals (e.g., family members and friends) who come together to create a nonprofit society to address the support needs of an individual. Microboards are designed around principles of person-centred planning, empowerment, and customised approaches to support (see: Vela Microboard Association, <http://www.microboard.org/>). Microboards can assist in ensuring security for loved ones as well as facilitate future planning. As one parent explained, “Well, from our point of view its strictly an administrative, financial thing... hopefully for the future, the microboard, when we’re gone, will provide the support services for our son” (Participant #16).

Related to addressing legal issues, many family members spoke of the importance of addressing their family member’s financial future. For two participants, concern for their loved one’s financial future was addressed through microboards, which can manage self-advocates’ funding and benefits as well as trusts and other monies willed. One family member had a microboard and a representation

agreement in place. Despite many participants not having a formal plan “in place”, most participants in this study acknowledged the importance of financial security for their loved one and the need for some kind of financial plan. For example, one mother shared:

I would like a way of establishing a business plan or setting up some kind of financial arrangement that would see her, you know, possibly being able to have a little extra money to, you know, buy some extra things or go out for dinner, movies, that type of stuff.
(Participant #17)

Finally, the importance of choice and self-determination was another dimension of proactive future planning. Participants explained that it was important for choice and self-determination to remain a feature of ageing adults’ lives. According to family members, when ageing adults were able to exert independence and choice in the face of age-related changes or crises, they were better able to live the lives they desired. One parent and her adult child with intellectual disabilities were registered with an online registry for personal planning tools (e.g., Representation Agreements or Living Wills), which outlines preferences for the future. The Registry is a way that third parties (e.g., hospitals, banks) can find out who has legal authority to act on behalf of the registered individual (see <http://www.nidus.ca>). Finally, family members highlighted the importance for opportunities for meaningful socialisation activities for their loved one and the value of connections with others.

The Complexities of the Planning Context

When discussing intentional future planning, participants spoke of and highlighted the complexities of the context that impact the planning process – both informal and formal. Informally, participants spoke of how social networks impacted the planning process and, formally, they spoke of how complexities in system structures (e.g., supports and services) impacted the planning process.

Informal

With respect to the planning process, the importance and complexities of social networks were emphasised. Many of the family members described the “dissolution of networks” that occurs impacting planning for the future: “As you get older, my support system kinda dissolved.” Another participant described:

as you get older a lot of these people will pass and a lot of them move away and your support system kind of does almost eradicate and there’s not much you can do about it, it’s all very...Life goes on and you just seem to be stuck here and life goes on for the people who are leaving. Life takes them elsewhere. (Participant #13)

Participants also described the complexities of family networks. Some participants discussed how they imagined that siblings would step in and assume the role of caretaker for their sibling with an intellectual disability, while others noted that they did not want to place that burden on the sibling. For example, one participant stated, “we have a daughter who helps me out but she can’t be responsible for her” (Participant #18). Similarly, another participant explained:

I just don't think it's fair to them. I think most families growing up with a handicapped child, that sibling has to give and give and give when they were a child. They give in a lot of loving ways and it's never changed the relationship between the two of them. They have an excellent relationship and I think that's really important too... I don't know want that falling on her, I really don't. I don't think that's fair. (Participant #13)

Other participants spoke about the important role of family for the future and their family's willingness to embrace this role. One participant shared, "because he has a brother and a sister, they've always made it very clear from the time they were quite young that he was going to be their responsibility as we got older. They're quite incredible kids" (participant #16). This participants' wife added:

We could drop dead at any time or get hit by a car or whatever. I know that Katy will take care of the family but I also know she may have her own family; so it's nice to know we have so many kids and especially the two girls who I think maybe because they're girls that they would probably take care of him the best. (Participant #17)

Formal Factors

In addition to the informal factors influencing how participants approached the future, participants also spoke of the impact of formal factors. These factors included: funding, lack of formal supports, and frustrations with systemic issues. Many family members talked about their concerns related to government funding – "Would this funding still be here? Would there be cuts to funding? What will this mean for my family member?" As one participant exclaimed, "Money is being cut back everywhere" (participant #13). Government cutbacks caused strain:

We're into a position now with community living and the funding of our programs through our association, we had to fundraise like mad to make ends meet and this is something here too because we always had adequate funds. Now you're, you know, close to the line all the time so... it's getting more difficult. (Participant #13)

Related to funding issues, availability of formal supports was another stress: these included concerns over waitlists, lack of available and appropriate respite, and staffing issues – high turnover among support staff. These concerns were particularly salient in times of emergency. One mother shared the following story:

Two or three years ago my husband had a very serious heart attack and respite in Clarkstown does not exist, and you phone the Ministry office, and they say, "Well I'm sorry. We haven't got anybody available"... and it makes you feel like you're wasting your time. I went through the whole thing with the Ministry and getting approved for three days a month but there's never anyone to give me respite. So, what good did it do? (Participant #19)

Another family member stated, “[finding support workers is] a terrific problem... It’s an extremely difficult task” (Participant #13). Difficulties in finding quality staff and “continuity of care” for their loved one was further exacerbated by economic factors. For example, one mother shared that their support workers were leaving and explained the worry this caused:

I’m very worried... So, we will have a relief caregiver ‘till we find new ones, which is going to be very difficult because the market place is such that it’s very difficult to find people that will work in this field when they can earn \$30 an hour as an apprentice carpenter. (Participant #18)

Staffing for respite was a particularly salient problem across participants.

Finally, with respect to formal factors, family members spoke about experiencing frustrations when interacting with the social care system(s) intended to provide services and support. Family members discussed frustrations with having to deal with multiple systems, lack of accessible information about supports and services, and concerns about future services. One participant shared:

I feel that individuals who are receiving a disability benefit or who are eligible to receive a disability benefit, I should put it that way, should only have to deal with one government bureaucracy. They should not have to deal with the Ministry of Employment and Income Assistance. (Participant #18)

Another family member shared her frustrations working with the staff of the Crown Agency responsible for services. She described, “The staff we dealt with had very limited knowledge of certain disabilities and those who did were ineffective within the organisation and stifled by the bureaucracy of the current structure” (participant #13). Another participant explained the difficulty navigating the service delivery system:

if you were to just even phone the local office, just the first contact you make there is a challenge for any of us to wade through the voicemail options that are given on the phone..., their forms, none of them are worded appropriately too. For people with limited understanding or comprehension, all those things, it’s just very poor and it’s a complicated Ministry...for anybody to deal with. (Participant #12)

In summary, the family members all spoke of the value and importance of proactive planning. Although the majority expressed concern and frustration when discussing future planning for their loved ones, the aim of this planning was motivated by the desire to ensure a good, safe, and satisfying future for their family member.

Discussion

Thematic analysis of the interview data revealed a number of themes pertaining to self-advocates' and family members' thoughts about the future. These results add to the current knowledge relating to future issues and concerns of ageing self-advocates and family members. One distinctive aspect of this current study is the inclusion of both self-advocate and family member participants. In a broad sense, the findings from both groups support the results of other researchers (e.g., Buys, Boulton-Lewis, Tedman-Jones, et al., 2008) highlighting that this population faces many of the similar issues as the general "able-bodied" population. One such issue that is arguably of greater intensity for this population is the importance of future planning.

Future planning has been studied extensively in the field of intellectual disabilities and ageing, highlighting its significance (e.g., Dillenburger & McKerr, 2010; Griffiths & Unger, 1994; Heller & Caldwell, 2006; Heller & Factor, 2001). This literature underscores important aspects of the process of future planning, such as family member communication that occurs early in adulthood (Griffiths & Unger, 1994), access to support networks (Heller & Kramer, 2009), and availability of supports and services to guide families during this process (Heller & Factor, 1993). Many scholars have noted that families often refrain from actively engaging in future planning processes, a trend reflecting the absence of explicit planning despite extensive anxiety associated with the uncertain future of their loved one (Davys, Mitchell, & Hays, 2010; Griffiths & Unger, 1994; Heller & Kramer, 2009). Findings from the current research echo this paradox, with parents expressing fear about the future quality of life, safety and security of their loved one, and simultaneously refraining from engaging in formal future planning. In addition, the notion of "transfer trauma", reflecting the emergency residential relocation of ageing adults (e.g., due to the unexpected death of a parent) in the absence of a formal permanency plan, has also been discussed in the literature (see Griffiths & Unger, 2004; Heller & Factor, 1988). Parents in the current study acknowledged this possibility and articulated the need for proactive or intentional planning regarding their adult child's future (e.g., organising legal affairs, formalising residential arrangements); however, they also reported feeling ill-equipped to address this need.

Family members' ambiguity and confusion is a common theme in scholarly writing about intellectual disabilities and future planning; as a result, interventions have been designed to address the gaps and systematically guide individuals and families in this process (e.g., *The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities*; DeBrine, Caldwell, Factor, & Heller, 2003 as cited in Heller & Caldwell). Research investigating the efficacy of such interventions has demonstrated positive results, specifically demonstrating gains in facilitating self-determination in the lives of ageing adults, decreasing the burden on caregivers, and articulating concrete plans for the future (Heller & Caldwell, 2006). The potential for the utilisation of empirically and practically supported resources to contribute to the quality of life of ageing individuals and their families is an area that warrants further exploration and investigation.

The findings of the current study highlight some of the issues facing ageing self-advocates and family members pertaining to their futures. Of note, when comparing the two groups of participants, an important difference is revealed. Self-advocates in the present study emphasised the importance and value of their present day-to-day leisure activities when asked about their future whereas family members stressed the importance of future planning. This may be a reflection of the cohort of adults with intellectual disabilities in this study (e.g., thoughts and experiences of work, daily activities, and retirement would reflect the access to supports and services of this generation); however, it is important to note that other studies (e.g., Buys et al., 2008; Clark, 2007; Judge et al., 2010) found that social

opportunities were rated as more important issues for participants in these studies than employment or educational opportunities.

The importance of social and leisure opportunities to participants' wellbeing as they age has potential implications for professionals working with families in future planning. If one takes seriously the wishes and desires of self-advocates, professionals should advocate for and facilitate self-advocates' participation in the design and delivery of supports and services (Duffy, 2010). This recommendation for planning is in line with current practices that promote personalisation and person-centred planning (e.g., Sowerby, 2010), emphasising self-directed support and involve the use of individualised funding, peer and family support teams, and user-led organisations (Duffy, 2010). This direction for practice is not intended to produce a false dichotomy between self-advocate and family members wishes but, rather, to emphasise a family-centred approach, which sees both the self-advocate and family members as an inter-related system requiring a balanced planning approach (Bigby, Ozanne, & Gordon, 2002; Llewellyn et al., 2010).

Another practice issue relates to the self-advocates' expressed concerns regarding relationships (particularly ageing parents), security and living arrangements, and loneliness. Crawford (2004) found that self-advocates concerns about the future related to: issues of isolation; loneliness; no one being there to listen; no one with authority to speak on their behalf; and, lack of relationships. Relationships have implications for many fundamental aspects of life, which highlights the importance of including relationship and network building into plans for the future. Thus, one focus of intervention might be on strengthening and building supportive networks (Ennis & West, 2010; Erickson, 1984).

Personal network development complements current policy and practice in many countries (e.g., Australia, Canada, US, UK) towards personalisation (Sowerby, 2010). In BC, social network development is promoted by the Crown Agency responsible for supports and services. In fact, personal network development is seen as one strategy for addressing experiences of loneliness in communities, and for strengthening safeguards and addressing issues of security (Community Living British Columbia, 2009). One organisation advancing social network facilitation in BC is the Plan Institute for Caring Citizenship (see <http://institute.plan.ca>). Drawing on a personalisation framework, practice in network development emphasises the service-user (self-advocate and her/his family): the service-user(s) is at the centre of the planning.

Network development would involve a systematic assessment of strengths and assets of the self-advocate, family system, and environment and a plan for promoting meaningful choices, with the clients having the authority to choose (Rapp et al., 2005). Such network development needs to focus on both informal and formal networks. This is supported by family members in the current study who spoke about the dissolution of their personal networks and their disconnection with formal supports and services. For these participants, the complexities of navigating these systems were impediments to engaging in future planning; a valuable consideration given the importance placed on intentional future planning by family members.

These findings reflect the current Canadian landscape where the increasing lifespan of ageing adults and their unique needs are emerging in a context where the social care architecture – programs, services, systems, and policies – are fragmented and lagging in response to growing demographic changes. Similar to previous research, participants highlighted the problematic issues interacting with the service system including difficulties finding helpful contact people (Weeks et al., 2009), lack of accessible information to assist with planning (Heller et al., 2007), and challenges and concerns with continuity and stability of funding. These formal factors impeding proactive planning underscore the calls of previous researchers (e.g., Ansello & Cogle, 2000; Bigby, 2002) for the need for system

integration and intersystem collaboration as well as a strategy to make explicit the options available when planning for one's loved one.

Limitations of the Study

Given the qualitative nature of the study and the geographic location of the research in BC, the findings of this study cannot be generalised. However, the findings of the present study complement and are consistent with the findings of research conducted in other geographic areas on ageing and intellectual disability: for example, Australia (Bigby, 2002), Scotland (Judge, 2010), Eastern Canada (Weeks et al., 2009), and the US (Jokinen, 2006). Despite a relatively small sample, the results point to the importance of early, intentional planning that supports and balances the needs and desires of ageing adults with intellectual disabilities and family members. It is clear that systemic collaboration and intentional planning across systems is necessary to address the reality of the changing demographic landscape of ageing adults with intellectual disabilities. Finally, although beyond the scope of this research, an examination of the complexities of family and social networks may provide a useful direction for future research, particularly a focus on the gendered nature of caring networks. Such research may have valuable implications for interventions aimed at personal network development and "future planning".

Conclusion

Although not representative of all ageing adults with intellectual disabilities and their family members, the findings from this research highlight the complex interaction of systems (intra- and interpersonal, community-level services, governmental agencies) in the awareness and identification of issues related to future planning. Both ageing self-advocate and family member participants expressed concern about one another's wellbeing in the future. These worries were rooted in an uncertainty about supports and lack of transparent, proactive, and intentional planning. It seems that these future fears and a lack of formal guidance serves to immobilise families; thus impeding planning and, subsequently, resulting in crisis management efforts. Such efforts have the potential to place stress and strain on the family, ageing adults, and the wider system that is not prepared for the increasing numbers of this ageing population.

As the life expectancy for individuals with intellectual disabilities increases, support and planning at the policy and systems level needs to flexibly respond to this growing demographic. It is likely that the uncertainty identified by participants in this study parallels that of the broader systemic authority as they are faced with uncharted territory. Systems and community-based supports must work with the priorities of ageing adults and their family members to ensure adequate future planning and facilitate quality of life.

A variety of priorities have been clearly articulated by participants in this study. It is clear that many ageing adults desire to be active, engaged members of the community as they pursue leisure and work interests into old age. Family members want to know that their ageing adult will have a comfortable and safe place to live, financial security, and continued opportunities for self-determination and choice. Listening to the voices of those individuals who face the reality of getting older in systems not designed to support them is fundamental to advancing quality service provision, and quality of life, for ageing adults with intellectual disabilities and their families.

Acknowledgements

We would like to thank the self-advocates and family members who agreed to participate in this project. This project was supported by the Centre for Inclusion and Citizenship and was funded by the British Columbia Ministry of Children and Family Development and Community Living British Columbia. We

would also like to thank the reviewers for *Australian Social Work* for their time and insightful comments.

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