



**Supports for Seniors
with Developmental Disabilities
in B.C.:**

An Exploration of Family Member and Self Advocate Experiences

Community Living Research Project

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This report was prepared by the *Community Living Research Project* based at the School of Social Work, University of British Columbia. This document is part of a larger research project exploring the Community Living supports and services available locally, provincially, nationally, and internationally for adults with developmental disabilities.

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Introduction and Methodology

In the late spring and summer of 2006, the Community Living Research Project conducted focus groups and interviews with 35 Self Advocates and 70 family members throughout the province of British Columbia (i.e. Vancouver Island, Lower Mainland, Northern BC, Interior). These interviews centred on four broad topic areas:

1. Young Adult Transition from High School to Adult Life
2. Residential Alternatives
3. Non-residential Supports (e.g. day supports and activities)
4. Services for Seniors

Broadly speaking, the goal of the focus groups and individual interviews was to elicit feedback from people with disabilities and their families and networks regarding programs and services to adults with developmental disabilities. More specifically, the purposes were: 1) To explore how individuals with developmental disabilities and their families experience their current services, supports and the options available to them; 2) To explore what individuals with developmental disabilities and /or family members would like to see in terms of services/supports/options available; and, 3) To assist in the development of a survey for a subsequent phase of this study.

Focus groups and individuals were separated by topic area and by participant type (i.e. family member or Self Advocate). This report focuses on the findings based on the topic of Young Adult Transition and is one part of a larger report that summarizes the findings of the research as a whole (see Adult Community Living Services in B.C.: An Exploration of Family Member and Self Advocate Experiences). Criteria for participation in the Services for Seniors focus group/interview was: Self Advocates over the age of 50 or family members with a family member over the age of 50

participated in a services for seniors focus group/interview. A total of 22 individuals participated in the seniors specific focus groups (family members = 11, Self Advocates = 11). However, themes related to seniors were discussed across focus group topics and relevant findings are included in this report.

Each focus group/interview made use of an interview guide that had both general and topic specific questions. In addition, Self Advocate interview guides asked different questions than the family member interview guides however, both sets of guides aimed to address the same overarching areas.

Data Analysis

Interview and focus groups were audio-taped and then transcribed (i.e. audiotapes were typed out into printed texts). The transcribed interviews and focus group interviews were entered into a computer software system. The software enabled both the organization of a large amount of data and facilitated comprehensive exploration of themes. Using thematic analysis (Braun & Clarke, 2006) – comparing, contrasting, and categorizing the data into themes - the research team was able to look at both similarities and differences across participants' stories. Exploring the data beyond commonalities in themes ultimately provided a more detailed, rich and accurate picture of participants' experiences with and hopes for the adult Community Living support systems.

Report Layout

This report provides a summary of the themes extracted from the stories shared by participants. Findings are organized by sub-categories:

- A. What is working? What is effective?
- B. What is not working? What is ineffective?
- C. Barriers
- D. Gaps
- E. Desires/Aspirations
- F. Services for Seniors Specific Themes

Services for Seniors: A Brief Review of the Literature

In Canada, there are approximately 44,770 adults between the ages of 45-64 years and 11,080 adults over the age of 65 years living with a developmental disability (Participation and Activity Limitation Study, 2001). Research on adults with developmental disabilities consistently asserts that the life expectancy of individuals with a disability continues to rise as health and social conditions continue to improve (Delorme, 1999; Heller, 1999; Rice & Robb, 2004). This means that supports and services for seniors with developmental disabilities and their families has become an important issue. The American Association on Mental Retardation explains that, although the age related concerns are the same for all adults, they are complicated in the lives of those with developmental disabilities; this is because "...on the whole, they are more dependent on caregivers... [furthermore] they typically have less income, fewer opportunities to make choices, and less knowledge of potential options than do other adults in the general population." (p. 2-3).

Janicki (1999) articulated that one of the challenges facing older adults with developmental disabilities is the problem "...inherent in growing older in a system that has not accommodated older people previously" (p. 291). Aging and disability service providers have reported that their services were inadequate to meet the needs of the population of aging

adults with developmental disabilities (Sparks et al., 2000). In order to increase service capacity in this area, service providers identified key recommendations centring on training, identifying strategies to provide counselling support to this aging population, and enhancing service provider collaboration.

Best practices for supporting individuals with developmental disabilities centres on active choice making and the incorporation of personal preferences in planning for the future (Wadsworth et al., 1995). Ashman and Suttie (1995) assert that choice and decision-making is often not included in the lives of aging adults with disabilities. The National Advisory Council on Aging (2004) explained that the lack of decision-making opportunities for these individuals "...can create unnecessary dependency among those who do have the capacity for self-determination." (p. 9). Older adults with a developmental disability is a growing population which currently requires, and will continue to require, consistent efforts toward supporting active engagement, meaningful relationships and interactions, and an overall higher quality of life.

A. What is working? What is effective?

Family members were asked to reflect on their experience of those supports and services their family and/or family member has received, either currently or in the past, in terms of what was helpful or what worked well. Family members were also asked to discuss any later life planning that had taken place and how they had gone about such planning. Similarly, Self Advocates were asked to talk about those aspects of their lives that they enjoyed, looked forward to or were important to them. A summary of participants' responses is provided below.

Autonomy and Self-determination

The importance of autonomy and self-determination for their adult family members was mentioned in relation to aging parents and crisis situations. In crisis situations, participants explained that it was important for autonomy and choice to remain a feature of aging adults' lives. According to family members, when aging adults were able to exert independence and choice in the face of age related changes or crisis, they were better able to live the lives they desired.

Opportunities to Deal with Loss or Grief

One Self Advocate explained how he lost his mother recently and how this loss drastically changed his life. However, now he has a new ritual to deal with the loss of his mother and to remember her. Every week he visits his mother's favourite bench in a local park. This man made it clear that his new weekly tribute was very important in his life.

Proactive Planning

Participants repeatedly emphasized the importance of proactive planning with respect to aging. One family member discussed her experience sitting on a microboard for another Self Advocate in the community. She noted that through this microboard, money had been set aside for emergency situations to ensure necessary supports for the Self Advocate. This is an example of proactive, rather than reactive, planning for the future. Another family member talked of wanting to plan for her child while she was still healthy and could support any life transitions - proactive planning to assist with life transitions. Furthermore, an aging Self

Advocate 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. This Self Advocate also reported wanting some help to formally outline this list of preferences down on paper.

B. What is not working? What are ineffective supports?

In the context of aging parents/caregivers as well as aging Self Advocates, family members were asked to discuss those things that were ineffective in supporting aging adults. Similarly, older Self Advocates were asked to discuss aspects of their lives they wished were different. A summary of participant responses is provided below.

Death, Loss and Associated Changes

Dealing with the death of family and of parents was an experience one Self Advocate discussed. He discussed how the death of his primary caregiver, his mother, resulted in a change in his living situation in which he had no choice. This new living environment was outside of this Self Advocate's neighbourhood and far away from his doctor and dentist which he viewed as an inconvenience and a limit to his freedom. He stated, "*...I didn't have any choice.....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.*"

C. Barriers

Barriers are those things that get in the way of successful and effective support that enables an adult to live the life he or she desires to live. Barriers may be structural, such as lack of funding or waitlists, interpersonal,

such as relationships with others or lack thereof, or attitudinal, such as beliefs about abilities or available supports. Specific to services for seniors, barriers get in the way of continued support that maintains connections to the community and contributes to overall quality of life.

Nature of Networks - Dissolution

One family member noted that it was difficult to plan for the future when there was an absence or lack of relatives. This was because members of the family play an important support role over the life course and an absence of these supports can translate into uncertain future planning. Additionally, there was a trend toward the dissolution of networks as families and individuals age. People were dying or becoming ill which meant they were likely not able to play the same kind of support role they once did. In addition, parents were pulling away from the system and agencies that they may have been actively involved with in earlier years because they were no longer able to expend the same kind of energy due to their own issues related to aging.

D. Gaps

Family members were asked to think about and share their concerns for the future with regard to the lives and support of their family member with a disability. Similarly, Self Advocates were asked to think about and discuss their worries for the future. A summary of participant responses is provided below.

Respite Needed as Health Conditions Change

Respite was discussed as necessary in the context of aging parents when situations of illness arose. When a caregiver became ill due to an age-related issue, temporary care was often needed for the adult child who lived at home. However, families discussed how such care was often not readily available in a time of crisis and the onus for finding suitable respite care was frequently on the family. This could be further complicated when an adult had very specific needs which required someone with particular training (e.g. seizures).

Respite as a Transition Tool

The need for respite was identified in some focus groups with family members. Respite was discussed as a support that could assist in the healthy and necessary separation of parents and adult children. For example, one 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."*

In another case, the adult child lived in the family home and the parent was coming to realize that this would not be a living situation that could work forever. This parent saw respite as a means of providing her daughter with the opportunity to build her confidence apart from mom and dad. Living out of the family home, even if for a short time, was believed to offer an adult child the experience of being okay and comfortable in a different living arrangement. Ultimately, such an

experience was discussed as a way to ease the transition from the family home into an alternate living situation. This parent stated,

"...I think that by going to respite and breaking that tie to get her to realize 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 besides my own and still be comfortable."

Need for Alternative Living Options (long term, not respite)

There was also recognition on the part of some family members that having their adult child living at home as the parent aged was not a desirable situation. There was some talk of the precariousness of such a living situation when parents were so old and things could change at any moment. Some parents acknowledged that they were not as young as they used to be. There were also some anticipatory feelings of additional burnout as parents aged; for example, one mother stated,

"...I just don't have the energy to pull it altogether right now so that's going to have to go on the back burner till my husband's health gets [better] and my mother-in-law gets sorted out but these are real life issues hey? Especially with aging parents, I'm not even that aged yet you know, but holy cow, I just see it coming."

E. Desires/Aspirations

Family members were asked to think about and share their hopes and desires for the future with regard to the lives and support of their aging family member with a disability. Similarly, Self Advocates were asked to think about and discuss their hopes and plans for the future. A summary of participant responses is provided below.

Concern and Worry about the Future - Lack of Peace

There was some discussion about obtaining a "feeling of certainty" about the future life, and particularly future living arrangements, for a family member. One parent wanted her daughter to start the transition to a new living arrangement while she, the parent, was still capable and alive.

"I would like to see her established some place where she could come home for the weekend, she could come home for holidays and she'd be established somewhere where she feels comfortable, where she feels secure in her place and yes, I'm there to back her up."

Another parent stated,

"I'm really concerned. I'm sixty three and she's eighteen so there's a huge difference and I will be gone for many years of her life and I'm the only one left so it is a real source of concern for me, for somebody to watch out for her when I'm gone."

Parents discussed their feelings of "worry" about what the future would look like in this regard. Associated with this sense of concern and worry for the future was the idea of wanting to have some reassurance that things would be okay in the lives of the adult children once the parents are no longer around to take care of these things. In reading the experiences of these parents, there was a clear sense of a *lack of peace* around their feelings for the future.

F. Services for Seniors Specific Themes

This section of the report includes themes from the data that are specific to services for seniors and do not fit in the previous categories.

Later life planning

Some family members were aware of the need or importance of later life planning however, not all families and individuals had engaged in such planning.

Proactive Planning

One family member reported wanting to begin the transition in living arrangements for her child while she (the parent) was still able to act in a supportive role during this transition; the parent believed it was important for her child to begin to mentally prepare for a different living situation in which she would be out of the family home. This parent wanted to build her child's confidence and belief in the possibility of a good life without mom and dad (she viewed respite as a key player in this transition). This family member also believed it was important to plan while she (the parent) was still mentally and physically healthy (the other focus group participant agreed).

Another family member talked about how the microboard members were getting together the next day to revisit the previous PATH and create a new one that reflected new dreams and a new vision.

A different type of planning took place in one family. In this case the mother purchased various items her son might need in the future when she might not be around to obtain these items for her son. She stated,

"I'm always buying ahead because I think I might not be here. Like I bought him a new ski suit at the January sales because I thought he'll need one within two or three years and I might

*not be here to buy it for him and I'm always thinking that way;
I have to stock pile for him."*

The need to plan for some came as a result of having later life issues highlighted when a parent became ill due to age-related changes.

Resources Accessed

Some parents discussed the various resources they have accessed to assist in the change process associated with aging. One parent had looked into having a court appointed individual to advocate on behalf of her child when she was no longer able to do so. Another family talked about the role the microboard played in later life planning. Finally, one parent, and her child, was registered in the NIDUS registry which outlined preferences.

Conclusion

This report organized and summarized the thoughts and experiences of Self Advocates and family members throughout B.C. who participated in this research. Family members and Self Advocates had much to contribute to what is known about how young adults with developmental disabilities are supported. While the nature of qualitative research does not allow us to say with certainty that the opinions expressed in this report reflect a majority or dominant opinion, they do provide a rich reflection of the diverse array of experiences, aspirations and opinions of the self advocates and families who participated in the research. As such, this research provides valuable insights into the way individuals with developmental disabilities and their families are supported currently and the way individuals and families hope to be supported in the future.

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