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

An Exploration of Family Member and Self Advocate Experiences

A Plain Language Summary Report

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<u>Reading this report</u>

This paper is a plain language report adapted from a full academic/government report called "Supports for Seniors with Developmental Disabilities in B.C.: An Exploration of Family Member and Self-advocate Experiences" produced by the Community Living Research Project.

To help people read this plain language report some words and phrases have been defined. Definitions are in brackets (example) and follow the word or phrase. Some words and phrases are underlined with a star at the end of the word (for example – definitions*). Words that are underlined can also be found in the "Glossary" at the end of the report. There are some quotes from people who took part in this research. These quotes are in boxes throughout the report. Please note that in this report, "adult" refers to adults with developmental disabilities. If you need more help reading this paper, please ask a friend.

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Introduction

In the spring and summer of 2006, the Community Living Research Project held group interviews with 35 adults (Self Advocates) and 70 family members throughout the province of British Columbia. Interviews were held in:

- the Lower Mainland,
- the Interior,
- Vancouver Island,
- the North, and
- Powell River.

The research also involved phone interviews with family members who lived in <u>remote</u>* (far off places) areas of the province. The goal of the interviews was to get feedback from people with disabilities and their families about programs and services for adults.

Participants were asked to share their experiences with community living supports in four topic areas. Those areas were

(1) Young adults leaving high school and going into adulthood,

(2) <u>Residential options</u>* (i.e. living arrangements),

(3) <u>Non-residential supports</u>* (e.g. day programs, work), and

(4) Services for seniors.

Interviews were recorded, typed, and looked at using computer software. The results of the study are organized in this report by topic area in the following way:

- **A. What is working? What is helpful?**
- **B. What is not working? What is unhelpful?**
- **C. Barriers (things that get in the way)**
- **D. Gaps**
- **E. Desires/Aspirations (hopes and dreams)**

Seniors with Developmental Disabilities

In Canada, there are about 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.[1] Some people are not known to <u>formal service providers</u>* (agencies or organizations that help and support individuals with developmental disabilities and their families). There are different ideas about the age at which a person is called a "senior". For these reasons, it is hard to know exactly how many aging adults with developmental disabilities live in British Columbia or Canada.

The <u>life expectancy</u>* (how long someone is expected to live) of individuals with a disability continues to increase as health and social conditions continue to get better.[2] Supports and services for seniors with developmental disabilities and their families has become an important issue.

People with and without disabilities share many concerns about aging. However, aging with a developmental disability is often complicated because generally they:

- Are more dependent on caregivers,
- Generally have less income (money),
- Have fewer opportunities to make choices, and
- Have less knowledge of possible options.[3]

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[1] (Participation and Activity Limitation Study, 2001)
[2] (Delorme, 1999; Heller, 1999; Rice & Robb, 2004; Salvatori et al., 1998)
[3] (The American Association on Mental Retardation, p. 2-3)

Many adults with developmental disabilities want to continue to participate in meaningful activities as they get older.[4] However, much of the activities older adults participate in are leisure-related (for example, watching television, relaxing, reading, spending time alone).[5]

This means that supports and services for seniors with developmental disabilities and their families has become an important issue. The American Association of Intellectual and Developmental Disabilities) 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).

A. __What is working? What is helpful/useful?__

Family members were asked to think about and talk about their experience of those supports that have been helpful and useful. Family members were also asked to talk about any later life planning* (plans for when people get older) that they had done with and for their family member. Adults were asked to talk about those parts of their lives that they enjoyed, looked forward to or were important to them.

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[4] (Bigby, 2004)
[5] (Salvatori et al., 2003)

Autonomy and Self-determination (independence & making your own decisions)

It was important for adults to have some independence and opportunities for decision making even during crisis situations. In crisis situations, people who took part in this research explained that it was important for autonomy (independence) and choice to stay a part of aging adults' lives. According to family members, when aging adults were able to be independent and make their own choices, they were better able to live the lives they wanted.

Opportunities to Deal with Loss or Grief (sadness)

One adult explained how his mother died and how this loss changed his life. Now he has a new ritual (routine or tradition) to deal with the loss of his mother and to remember her. Every week he visits his mother's favourite bench in a nearby park. This man made it clear that this new ritual was very important in his life.

Proactive Planning (early planning)

Many family members said how important it was to proactively plan* (plan before or early) for getting older. One parent talked of wanting to plan for her adult child while she was still healthy and could help with transitions (changes, e.g. moving to a new place). This is an example of proactive planning*. An older adult was planning for her future by making a list of things that were important in her life. She was doing this in case she would be unable to let people know of her wants later on.

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

Family members were also asked to talk about those things that were unhelpful in supporting aging adults. Older adults were asked to talk about parts of their lives they wished were different. This is what people said.

Death, Loss and Associated Changes

One adult talked about the death of family and parents. He said that the death of his mom, the person who helped him the most, meant that he had to move. He did not have a choice. The home he moved to was in a different neighbourhood. Also, he moved far away from his doctor and dentist which meant it was difficult to be independent. He said, *"...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

For this report on services for seniors, barriers (obstacles) get in the way of support that keeps connections to the community and adds to quality of life* (overall enjoyment of one's life).

Networks (groups of people) fall apart over time

One family member said it was hard to plan for the future when there were not many relatives (family). This was because members of the family play an important support role throughout one's life. When there are no family members it can be

difficult to plan for the future. Also, networks tend to fall apart as families and individuals age. People were dying or becoming sick which meant they were not able to offer as much support to the adult and the family. Some parents were pulling away from agencies that they may be been involved with in earlier years. This was because parents no longer had enough energy because of their own issues related to aging.

D. <u>Gaps</u>

Family members were asked to talk about their concerns for the future of the lives and support needs of their family member with a disability. Adults were also asked to talk about their worries for the future. This is what people said.

Respite* (a break) is needed as People's Health Changes

Some family members said <u>respite</u>* was a must as parents age and become ill. When a caregiver became sick because of an age-related issue, temporary (short term) care was often needed for the adult child who lived at home. However, families talked about respite not being available in a time of crisis (emergency). Also, families were often responsible for finding someone to give respite. This was more difficult when an adult had very specific needs and needed someone with specific training (e.g. training to support someone who has seizures).

Respite as a Transition Tool (respite helps adults move out of the home)

Some family members talked about respite as a support that could help adult children move out of their parents' home gradually (slowly). One parent said, *"He's now in a semi-independent living situation. We're getting on in years and it was essential (necessary) for us that…(he)…learn to survive himself in the community with assistance."*

In another example, an adult child lived in the family home and the parent realized it could not work forever. This parent thought <u>respite</u>* would be a way to help her daughter build her confidence (belief in herself) away from mom and dad. One parent believed that living out of the family home, even for a short time, gave her daughter the experience of being okay and comfortable in a different living arrangement. This was a way to ease (help slowly) the transition (move) from the family home into a different living situation. This parent said,

> *"...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 different types of long term living options

Some family members realized that having their adult child living at home as the parent got older was not a good situation. It is a worry to have adults live at home with parents because aging parents' health can change at any moment. This makes this living arrangement unstable in the long term for adults. Parents also thought that they would not have as much energy as they used to as they got older. One mother said,

> "...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 (hopes and dreams)

Family members were asked to talk about their hopes and wants for the future of their aging family member with a disability. Adults were also asked to talk about their hopes and plans for the future. This is what people said.

Concern and Worry about the Future

Many family members talked about wanting to feel confident (strong and positive) about the future for their adult family member. One parent wanted her daughter to start the move to a new living arrangement while she, the parent, was still alive.

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

Another parent said,

"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 talked about their feelings of "worry" about what the future would look like. Family members wanted to have some reassurance (guarantee) that things would be okay in the lives of the adult children once the parents are no longer around.

F. Services for Seniors Specific Themes (ideas)

This part of the report includes themes that are only about services for seniors and do not fit in the other areas.

Later life planning (plans for when people get older)

Some family members knew it was important to plan for old age. However, not all families and individuals had taken part in such planning.

Early Planning

One family member said she wanted to begin the transition to a new living arrangement for her child while she (the parent) was still able to help her during the move. This parent believed it was important for her child to begin to prepare for a different living situation outside of the family home. This parent wanted to build her child's belief in the possibility of a good life without mom and dad.

Another family member talked about how the microboard (planning group) members were getting together the next day to look at an earlier plan. They were going to revise (edit) the plan and create a new one that reflected (showed) new dreams.

A different type of planning took place in one family. In this case, the mother bought different things her son might need in the future when she might not be around to buy these things for her son. She said,

> *"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."*

<u>Supports Accessed</u>

Some parents talked about some supports they made use of to help as things change when people get older. One parent looked into having a legal representative to advocate for her child when she, the parent, was no longer able to do so. Another parent, and her child, was registered in the NIDUS registry which is a computer database that records people's plans for their care/support.

Conclusion

The information in this report shares some of the stories, opinions, and hopes of family members and adults throughout B.C. who participated in this research. This type of research is not meant to be true of everyone's experience. However, the information in this report gives useful and important information about how adults and families are supported and about how they hope to be supported in the future.

Glossary

Formal service providers: are agencies or organizations that help and support individuals with developmental disabilities and their families.

Later life planning: is making plans for when people get older.

Life expectancy: is how long someone is expected to live.

Non-residential supports: are things that people do during the day and night. For example, day programs, work.

Proactively plan: is to plan before someone gets older or becomes a senior.

Quality of life: is overall enjoyment of one's life.

Respite: is a break from supporting a family member.

Residential options: are different types of places where people might live. For example, group home, apartment, with a family.