Residential Alternatives in B.C.:

An Exploration of Family Members and Self Advocate Experiences

A Plain Language Report

This review 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.

A special thank you to Barb Goode for her assistance on creating this plain language report.

Reading this report

This paper is a plain language report adapted from a full academic/government report called "Residential Alternatives 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 remote* (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) Residential options* (i.e. living arrangements),

(3) Non-residential supports* (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)

Residential Options

People who took part in this research talked about many types of living situations for adults. People also said that there were not enough options. Here are some examples of where adults who took part in this research lived:

- rented apartment
- living in one's own apartment with support from Community Living Services
- apartment living in a support complex or living in an apartment building with other people living in their own suites (this might be subsidized (cheap) housing)
- apartment living with a "typical*" (a person without a disability) roommate
- apartment program in which adults take turns living in an apartment with a worker for support - slowly helping people move out on their own
- adult owning their own home (not renting) and living with a spouse (married partner)
- church organized 24 hour home care
- group home
- living with parents (for some, there were no other options)
- in a private home with another family who were paid to give support.

Changes in a person's living situation cause changes in a person's life. And sometimes people move because there are changes in a person's life.

A. <u>What is working? What is helpful/useful?</u>

Family members were asked to think and talk about their experiences with supports that have been helpful in the area of <u>living arrangements</u>* (where a person lives). Adults were asked to talk about what parts of their <u>living arrangement</u>* they liked. This is what people said.

Accessibility (easy to get to the service)

Many people said that living close to services/supports, or on a bus route, was a helpful thing about where they lived. People said that a <u>living arrangement</u>* that is close to transportation, friends, and other supports helps adults feel happy and independent (able to do things on their own).

Caring people

Many family members said that caring people make supports helpful. This often involved taking that extra step to help an adult or family. Support staff who understand people's feelings, return phone calls, and treat adults and families with respect were seen as caring people.

For instance, one participant described a care worker as *"she's not doing this just for the money, she cares, she has some sort of feeling for it, so she wants to see the changes."* Another family member said that more caring people are needed; *"there is good people in all of the associations there's just not enough of them."*

Communication

Support staff talking openly and clearly with family members and adults was something participants said was helpful. People also said it was helpful when support staff listen to families. One parent said, *"…finally there was somebody who was listening to them, not telling them what they could have or what they couldn't have."*

Another family member said,

> *"I have demanded that if he says something they listen to him but it means he's always listened to and if we can accommodate* (adapt to or adjust) *what he likes and wants to do, then we do it and sometimes we can't and that's life, you know, but he has to be heard."*

Expertise (skill) and service provider training

Another helpful thing family members talked about was having someone who was an expert in supporting persons with disabilities. Family members wanted to deal with staff who had training and skills. Some family members also said it was helpful to have workers trained specifically for their family member. Sometimes parts of the training was provided by the family. This would also help to make sure the worker was compatible (well matched) with the adult and the family.

Many family members believed that experts have a better idea of what is needed and how those needs can be met. Some family members talked about the training the whole family had. For these families the experiences (events) were positive (good) because it brought the family closer together. One parent said,

> "*We took that emergency management training so that if we had to do certain things we could do it and the kids took it too so that was good, it kind of made them feel part of it as well which was nice.*"

Support of family members

Some people got a lot of support from family members and found this kind of support very helpful.

Personal space

Adults and family members talked about how having personal space where one lives is important and helpful. For example, a benefit (a plus) of living in your own home is that you can organize and decorate your space in a way that you want.

One parent said, *"Sam* is now in his own place. He has that pride* ((feels good about him/herself)) *of 'it's my place'."*

One adult said, *"I talked to dad after my mom died and decide I don't like group homes and it was time for me to move on to be independent, getting my own house or...getting an apartment downstairs."*

B. <u>What is not working? What is unhelpful?</u>

Family members were asked to talk about things about their family member's living arrangement that were not helpful. Adults were asked to talk about those things they did not like about where they lived. This is what people said.

Planning Takes Time

Family members said that organizing where someone will live takes a long time because of planning and waitlists. Because it takes so much time and people have to wait, this is unhelpful.

<u>Interpersonal dynamics</u> (the way people talk to and spend time with other people) Sometimes a person's roommate changes a lot and this can be hard. Sometimes people do not get along and this can cause problems.

One participant said the staff was "nagging". She said, *"It's not them personally, it's just the nagging me to be doing stuff that I don't need to be nagged about because I already know I'm supposed to do it."*

Safety concerns

In some communities (towns), violence and vandalism (destroying property) were problems that made adults feel uncomfortable about where they lived.

Some adults reported living in an old, run down apartment. Adults wished there were more affordable (not too expensive) options that would give them a clean, safe, and new home.

Not Enough Personal Space

Personal space was important to some adults. Some felt their home did not give them enough space. One participant stated,

> *"After a long day of doing chores, I need the staff to leave me alone so I can have some time to myself, to relax and unwind and I just need some alone time. I wanna get married and as I said, no kids, just me, my husband and a cat or two in our own place where we actually own the house and staff aren't around every day to nag us to do this and do that. I already have a mom who nags me, I don't need anybody else nagging me."*

One individual talked about how his family member needs 24 hour support but that he also enjoys some time alone. This raises the question, how can people who need 24 hour care and supervision enjoy some time alone and some personal space and still be safe? Safety was a big worry talked about by most family members.

Things that get in the way of independence & self-determination* (making your own choices)

When you live alone it can be hard to get to certain supports/services. This can make it hard for adults to be independent. Also, when you move out of your area because of things out of your control (e.g. family member death) then getting to supports in your area can be hard. This can mean a loss of friendships.

Burnout

Most family members said that it takes a lot of energy to care for a person with a disability. As a result, burnout can happen both for families and family care providers. Some family members said that family care is not always the best situation for adults needing a lot of support.

C. <u>Barriers</u>

Barriers are those things that get in the way of living in a home that meets the needs and wants of the adult. This is what people said.

Philosophy (attitudes and views)

Family members had different beliefs about how adults should be supported to live their lives. For example, one parent argued that it was important for parents to care for their own children within their family's own home. The participant added that formal support should be given so that this can be possible. One parent said, "*…with the proper supports there, I think most parents can care for their child in the home and through the school years.*"

Some family members said that sometimes their beliefs were different from support workers, doctors, and service administrators (program supervisors). Some participants had conversations with support workers who acted as though they knew better than parents because they had done a training course.

Not enough money and other resources

Family members also said that not enough money and not enough supports was a big problem. Some families believed that overworked staff with too much to do was part of this problem. Some people believed that some areas of the province got more money from government than other areas. Small towns in the province were thought to have the least amount of government money.

Lack of continuity (things do not stay the same)

Family members said that support staff are always changing and this can be hard for families and adults to deal with. Many times families said they were not told when these changes were taking place.

Family member beliefs and wants

The beliefs family members had about the abilities of their family member influenced how options were looked at and how decisions were made. For example, some family members believed their family member could only be supported in the family home. These beliefs got in the way of looking at living options. One parent said, *"There's so many concerns, you know, with his meds and his appointments and his seizures and everything that once he's away under somebody else's care it's like, you know, you feel lost and out of control I guess."*

One parent wanted her daughter to continue living at home. *"I would like her to, this sounds selfish but I would like her to stay with me."*

Funding (money) availability

Many family members believed that money for support was hard to find and get. Many people also thought that the way government gave money to people was unfair with some people getting more than others.

Many families felt that the money they got from government could be taken away at any time. This was stressful for families.

D. <u>Gaps</u>

This section is about those parts of <u>residential supports</u>* (where a person lives and what services they get in their home) that family members thought were missing or were needed. Adults were asked to talk about what they wanted their <u>living arrangements</u>* to look like.

Most family members wanted <u>individualized support options</u>* (ways to be supported that meet the individual needs of the person) in the area of living

arrangements. Some people believed there was not any government funding (money) to make individualized options available.

Family members said that there are not many emergency living options.

When families are finding, hiring, and firing their own staff, it can be hard because there are not many trained staff people.

Some people wanted more group homes.

For adults, living with a spouse (husband or wife) can mean tax and benefits issues. Some adults wanted more information about how living with a partner affects the taxes and benefits they receive.

E. __Desires/Aspirations__ (hopes and dreams)

Family members and adults were asked to talk about their life hopes, dreams, and plans for the future.

Family members' vision

Family members wanted their adult family member to live in a safe, secure home. Many family members wanted living situations that:

- Had proper supervision,
- Helped the adult have some responsibility,
- Could change to best met the needs of the person and,
- Helped adults be independent.

Individualized support options

Most family members wanted individualized support options* in the area of living arrangements. However, many family members did not see this as possible. Some

people believed that there was no government funding (money) to give individualized options.   Another family member said that the government is not listening to the needs and wants of individuals and families.

Living options that are close to friends

Family members wanted their adult to live close to his/her friends so that he/she would not be lonely.

A separate home lets parents have a life of their own

For some parents it was important for their family member to live outside of the family home. This was because it made it possible for parents to have a life of their own. One parent explained,

> "...we really want to have a life of ourselves too. It's very hard for us for all these years, we don't have our private life, a life on our own because everywhere we go we take Lisa* along. We have no social life."

Other living options that people wanted

Some family members wanted home sharing (or family model homes) options.

One family member wanted to buy the house next door to hers, so that her daughter could live there. This way she would have her own space but also be close by. Another family wanted to buy a home with a suite in the basement so their family member could have his own place within the family home and be able to take part in family activities (such as meals).

Some families talked about hopes and plans to buy a home for a couple of adults to live in together with support.   Other families thought about pulling their money together to rent a duplex (two houses joined together) and share support needs

and costs. Some families were thinking about buying land to build an apartment complex on.

Created Communities

Many family members talked about their hopes to create a community for individuals with disabilities. Some people wanted a group of homes, in the one area, for both adults and their family members to live together. In this example different families could get together and share meals and activities. One family member said,

> *"...if it were in an apartment block then she's surrounded by people that are her peers, she's surrounded* (has people around her) *by her own community, just like seniors have seniors communities, you know, why can't our folks have their own community? She'd be supported by her peers, she'd have friends right around her and she'd have her support network right there and I think that would be a really good place for her to be."*

Other family members talked about a community for both adults with developmental and physical disabilities to live together so they would be able to support each other.

Some people saw these kinds of communities as a way to build friendships and networks.

Another part of the separate community idea is stability (things stay the same). Family members explained that when you have your own apartment, if a support worker leaves, you stay in your own home. This means less disruption (problems) for adults. Family members also liked the safety of this type of living.

Affordable (cheap) housing

Some people who took part in this research also wanted affordable housing. In some cases, cheap housing was often run down and old. In some cases this was underlined subsidized housing* (houses that are cheaper because the government pays for part of it). People wanted homes that were newer and cleaner.

Personal Space

Adults talked about a picture for the future that involved moving out of their parents' home and into their own place or a place with a roommate. Adults also wanted to be more independent in their own place. This would give them more control over their lives and help them be able to do the things they wanted, such as have friends over.

Adults wanted:

- to live with people their own age
- to live with their boyfriend (if they had one)
- to live in their own place (not necessarily one that they owned)
- to own their own place, not rent
- to get support in areas they need it (e.g. money matters).

One older adult (50+ years) said she wanted to live on her own in her own place. But, she was told by her family members that she was not responsible enough to manage. At the time of the interview, she lived in a home sharing situation with her own suite in the basement. She knew that it was not *her* place and there were restrictions (limits) on how she could organize her home and her time. She wanted her own backyard with a garden to be able to grow her own flowers. She also wanted to have her own fridge and be able to put whatever she wanted in it.

F. Themes (ideas) about living arrangements

Living in the family home

Some adults said they liked living with their parents in the family home. But one adult said that it was boring to live at home with her parents and that she spent too much time with her parents. This was a young woman in her early twenties who wanted to spend time with and live with people her own age. However, some parents explained that not everyone is ready to move out once they turn 19.

Some parents said that having your child live at home and having support staff come into the home means a loss of privacy (time alone) for the family.

Renting an apartment

Renting an apartment with a "typical" (without a disability) friend was described as a good experience for both the person with the disability as well as the "typical" roommate.

Many adults talked about how important it was to own an apartment rather than rent one.

Many family members and adults talked about being lonely. When an adult lives alone, he or she can feel lonely and sad because there is not a lot of support. Also, there is often no one working to connect the adult to his or her community.

Pri-care, Home Sharing/Family Care/Model Homes, Foster Care

The difference between pri-care, home sharing, family care homes, and foster care is unclear in general and in the stories of individuals and families. At times it was hard to figure out what type of living arrangement an individual was talking about.

One family member said,

> "...family care homes, which is foster care, and nobody gave up their whole life just to have their sons and daughters put into foster care and just moved from one to another to another because it's never the individual's home, it's always the other person's home that they're in."

Many parents said family care homes were an unstable living option. Once a family decides they are no longer interested or able to provide support to an individual, then the adult often must move to a new home.

> "The difficulty with family care is the fact that it doesn't offer the same stability in terms of location, better stability in terms of treatment because in an ideal situation a person becomes part of that family, a family member or treated as family and people with whom he is involved set up a loving relationship with their child. And that's the perfect situation but ten years down the line, their needs change and (the son) would be looking for some place else and we recognize (see) that as a problem."

Families and individuals have had both positive (good) and negative (bad) experiences with these types of living arrangements.

Monitoring (checking in on) was another issue family members had with home sharing. Family members were concerned about the lack (not much) of monitoring that takes place in home sharing. One family shared stories she heard from people about providers making a lot of money by supporting an adult; "...people have said, 'well, I paid off my mortgage in five years'." This was a worry for some family members.

Home sharing was also seen as a better fit for some adults because they were more individualized (meeting the needs of the individual). One adult who lives in a home

sharing arrangement described his living situation as a "happy home". Also, home sharing allows for more "freedom" and the adult can spend time doing things on their own.

For one family, buying a home and then finding a family to rent and move into the home to provide the "family care" was an option. This would give the adult the opportunity to be in charge of the hiring and firing of the care person/family. Also, he or she would not have to move.

Owning a home

In one example, an adult lived at home with her parent who was going to move out at some point leaving the adult in the familiar (well-known) home rather than cause disruption (trouble). Another family built a home for their family member and the participant said that her family member has such pride (pleasure and happiness) in having her own home.

Group Homes

Although some family members believed that group homes were a good living situation for their family member, some people did not.

Some family members believed that there were too many people living in one group home.

Some family members also thought that there was not enough of attention on life skills building in group homes. And finally, some group homes were not connected to the internet which means staff and adults might miss out on some information.

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 how they hope to be supported in the future.

Glossary

Individualized support options: are ways adults are supported so that the individual needs of the person are met.

Living arrangements: is where a person lives. There are many types of living arrangements such as group homes, apartments, and family homes.

Residential supports: can be both where a person lives and what services they get in their home (e.g. meal support, help with money).

Self-determination: is when people make their own decisions and choices.

Subsidized housing: are houses that are cheaper because the government pays for part of the rent.

Typical person: is someone without a disability.