



Non-residential Supports in B.C.

An Exploration of Family Member and Self Advocate Experiences

A Plain Language Summary 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.

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Reading this report

This paper is a plain language report adapted from a full academic/government report called "Non-residential Supports 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 find out 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* (e.g. 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)**

Non-residential Supports

This research looks at all kinds of day activities that are a part of adult's lives or a wanted part of adult's lives. This report summarizes (goes over):

- day activities,
- what makes day activities useful/helpful,
- what makes day activities unhelpful,
- things that get in the way of helpful day supports, and
- hopes and dreams for how adults are supported in their day-to-day life.

Adults and their families talked about a number of activities that adults enjoy. For example, sports, classes, and other leisure activities. Many people explained that the benefit of activities was that they make it possible to spend time with others. Adults said they needed to see their friends, meet other people, and build relationships with people. This was also important to family members.

For those adults who attended day programs, most went to the program 4-5 days each week. The types of activities available in the day programs mentioned by participants included:

- Volunteer work
- Playing games
- Arts and crafts
- Going out and doing things in the community
- Shopping
- Skills content (life skills - cooking, work skills)
- Learning opportunities (e.g. reading, math, geography, computers)
- Sight seeing
- Music
- Sign language
- Shredding
- Swimming

- Social events (dinners, dances)
- Dog walking
- Deliveries
- Performing (shows).

In some of the smaller communities (towns) of the province, day programs were not an option. Instead, drop-in programs with a limit to the number of people who could be there, were available. Such programs were often limited in length, activities, and size. These programs had limited hours and activities. This was disappointing and frustrating for many families.

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

Family members and adults were asked to talk about what parts of day supports are, or have been, helpful.

Same age workers

Some family members explained that having age appropriate workers was helpful because it was more of a friendship than a working relationship. For instance, one participant said, *“what really works is the age appropriate workers. It's so fabulous because he's got buddies, they're not workers, they're buddies.”*

Caring people

Many family members said that caring people make supports more 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.

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 listened 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 and they could do.*"

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 part 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 were positive because it brought the family closer together.

Continuity (things being the same for a long time)

People said that having the same worker, being in the same program, or having the same job for a number of years was helpful. Having the same support workers can make it easier to build and continue relationships with support workers. Family members thought it was important for adults to have continuity with staff; as one participant said, "*My daughter is always questioning. Well, if I'm not going to be there who is going to be there? You know, she wants to know that she's secure.*"

Having the same program and employment allowed some adults to become used to their surroundings, the people, and the activities.

Acceptance

One family member stated, "...the day program is totally successful. It accepts his needs and everyone in the program." Many family members thought that it was important for adults to be known to other people in the community. For some, this helped adults be accepted and find jobs.

Personally meaningful activities* (activities that are important to me)

Many people said it was important for adult to do activities that were important to them. This helps people feel good. Many people said it is important to ask adults what they want to do and then help them do this.

Family members and adults stated that doing activities with friends was important because it helped people not feel so lonely. One adult explained, "*I think that's the biggest thing I enjoy is seeing the people I usually hang out with, going to have a good time, as long as you're having fun.*"

Day Programs Offer Structure

Many family members thought that day programs gave adults some structure to their day. One family member said,

"...they like routine and this is what the programs give them. They give them a reason to live, there's something to get up and go to everyday. It's just like the difference you feel between having a job and not having a job."

Champions* Enable Access to Service

Champions* were those people or agencies who played a big part in helping families and adults get services. Family members talked about the way these individuals "fought" for their child and family. Champions* were seen as creative people with advocating skills.

Also, champions* were charming people who worked well with people and adults. One parent explained the role a champion* played in the life of her family member:

"...there was a young woman who was really liked by the students. She was in high school, and she was fantastic with them, but they all loved her and even our granddaughter. It was her that our granddaughter wanted to be with and as soon as that person is gone or steps away, that group falls apart because those kids are not really there for the reason of being with Lisa or doing things with Lisa."*

Having connections

Family members thought it was important to be connected with people who had a lot of helpful information. Many people also thought that it was helpful to be connected to other people in the same kind of life situation; for example, other families who have a family member with a disability or who have a family member in the same program.

Support of family members

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

Relationships with Friends

Family members and adults talked a lot about the importance of having friends that are not staff members. When adults were asked what makes their friends important, they said, *"I can call them and we can talk about things and we can see each other and it's nice to be able to see friends, or just pick up the phone."*

Some family members said it was important to have friends who also had developmental disabilities. These friendships can offer comfort and belonging.

"They want to be together where they feel that they belong. The same as we do. We don't want to be put in situations that we're not comfortable. We like them to be accepted and integrated into typical situations, but it's kind of...you're comfortable with what you know. These are their friends. They can talk to them. They can laugh."

Support for family members

Family members talked about the helpfulness of groups of families who come together to support one another and share ideas and information. As one participant described, *"...really we need to get a parent group so we can start a think tank and maybe a way of helping each other with ideas and maybe swapping off, you know, young adults, helping each other."*

Individualized support with many different types of activities

One family member talked about the one-on-one buddy her son had who gave some day support once a week. She stated that this individualized support was the most important part of her son's week. Another special day support identified by an adult was a vacationing group. This individual was able to go on vacations with other people and support staff. This was an important piece of her life.

Special Olympics

Many people said that Special Olympics was a good and helpful activity. It is also an opportunity for adults to spend time with friends. When asked why the Special Olympics were so positive and important, many said that everybody has fun. One participant stated, *"It doesn't matter where you are, you just go out to have fun."* Another family member said, *"...the enjoyment of most of that is just the contact with someone else other than family."*

People also thought Special Olympics was positive because it did not cost anything to participate. Family members said that in some towns, there were not

many programs and the Special Olympics were the only activity. The Special Olympics were also seen as giving travel opportunities to those who would not normally get to travel.

Some family members talked about the fact that Special Olympics is a segregated activity* (it is only for people with disabilities). In comparing the Special Olympics to typical activities one participant said,

"...well [she] bowled her year with quote normal children and they never counted her score, 'cause why should her score take everybody else's down. But when you bowl with your peers one day a week, boy! You win trophies, you're on cloud nine."

Options after high school

One parent talked about how small towns did not have many integrated options* (choices for adults to be included with all types of adults) for young adults once they leave high school. In some cases, segregated options that operate (run or function) within the larger community help these young people to participate in "typical" activities (community activities for people without a disability). This was an example of how a segregated support worked to make it possible for adults to live a life they wanted to.

Respite* important

Many family members said respite* (a short break for family members) is important because it gives caregivers and the adult a break. Some participants described how grateful they were to have respite.

Day programs offer opportunities to socialize* (spend time with friends)

Day programs gave adults the opportunity to spend time with their friends. One adult stated,

"...I just enjoy going to my day program. It's getting to see the other the people I hang out with, I think that's the biggest thing I enjoy is seeing the people I usually hang out with, going to have a good time."

One family member explained,

"...the socialization is crucial, having a disability is a lonely thing anyway because you're out in the community and you know that you're different, but when she's with her friends she's so comfortable and much less shy, it's a beautiful thing."

For another family member, when her daughter left high school and started a day program, she really began to enjoy herself.

Day programs were seen as an opportunity for people to build friendships in different settings.

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

Family members and adults were asked to talk about what parts of day supports are, or have been, unhelpful.

Structure limits choice

Some family members thought that the structured routine of day programs means that their family members often had little choice in their daily activities.

One size fits all

Some family members thought that there should be different options for people with different levels of functioning. Some participants talked about how their family member could not handle large groups of people. One family member stated,

"I always find it sad that, at the day programs there's very low functioning people and that they're all in there together. And I know that when she comes, the number of low-functioning people making noises, she has a headache every day. And I wonder, is this fair? Is it fair that she has to be there? Listening to these people making their noises and screams and so on. There is really nobody, certainly at that program, that she can really converse [talk] with. It's really tough, it's really tough."

Varied needs among adults

People who participated in this research said that there are many individual differences among adults. This means that programs need to be able to support different people but often programs are not able to do this. Family members thought this was a problem.

Participants stated that they had often had to deal with a "one-size-fits all" mentality. As one participant said, *"...that's their mindset - it's got to be good for the group or it's not good for anybody."* Another participant stated,

"What works for one doesn't always work for the other and that's, I think the difficulty with this whole thing is that it's so individualized and it has to be because there's such a wide range of clientele involved. So you have to try and find a way of addressing both ends of the spectrum [range] without forcing people."

In some cases, participants thought that staff and programs were good overall, but that it was simply a poor fit with their family member.

Participants also shared stories of how their family members had lost services or how activities had been cut. Sometimes the changes were because of funding cuts. One family member argued that it was just easier for the program to treat all clients as the same rather than as individuals. One parent stated, *"[the program]*

often defaults to [does] what the staff would like to do and what is the easiest for everyone."

Other family members said it was tough to find trained staff to support adults with specific support needs.

Participants said their family members did not receive true diagnoses due to the unique (special and different) nature of their disabilities. At times, this meant that people had trouble getting services.

Too many choices

Some family members said that there were so many associations and societies in a region/town and this made it hard to make decisions about the best service choice. The many choices made it difficult to learn about all of the options and then make an educated and informed decision about what would be the best fit for your family member. This family member stated, *"I feel like I'm living in the dark. I don't know whether it's the right place to send her to, is there another choice? But I don't know."*

Access (getting to places)

Access to programs was also hard for some people living in different areas of the same city. One family member stated,

"Location of most facilities for handicapped people are in the East side of town. This is fine for locals there, and may work, for us it doesn't. We don't know of any recreational facility suitable for handicapped people in [the West side of town¹]."

¹ Quote revised to protect the anonymity of participants.

Dissolution (ending) of networks

In talking about networks, many family members indicated that they do not last forever. They simply had too many other things going on (such as a family and children of their own). These family members said that networks are often put together when a person is young and as this person gets older, the network gets smaller. This is because as people get older (e.g., siblings) they begin living their own lives and moved on.

Some family members talked about how neighbours were once part of their network, but with time, they all moved away. It can be difficult to rebuild those networks with new neighbours. As a result, individuals were often left behind. For example, one participant said, *“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.”*

None or not much service provider training

Many family members talked about their experiences and concerns about care worker training or lack thereof. As one participant said,

“...what about training? You got people who have absolutely no training to work with our most vulnerable [at risk] people in our community. And they don't have the training – why? There are some programs available here, but it's, and they're constantly hiring people 'cause they can't keep anybody.”

Family members said that not all agencies required their employees to have official education or training. Many family members said they only wanted to hire trained or experienced workers to support their family member, but it was extremely difficult to find such workers. As one participant argued, training and experience was a must. He said, *“...it's scary to me because we've lived that and he needed people that were trained and experienced and understood that he*

had a neurological [brain] disorder, has a neurological disorder. Just love won't do it."

Many people who participated also said that only taking courses did not mean a person was qualified to support an adult.

Many people thought that limited (not much) training was because there were not many staff and not enough money to train staff. Some family members said it can be serious when staff do not have proper training. As one participant described, *"My daughter came home injured and it was because the staff person that was working with her was unaware of some pretty basic stuff and I felt that that was inexcusable."*

Special Olympics

It is important to note that there were a couple of negative comments about Special Olympics. For example, one participant described a letter she got from organizers asking her not to bring her daughter anymore. The reason she was asked not to come was because her daughter was no longer interested in participating in the activities, but just wanted to spend time with friends. Finally, one participant argued that the Special Olympics were only for a small group of higher functioning people and not the larger group "more disabled" people. This family member also believed that Special Olympics needed too much time from caretakers.

Concerns about respite

When talking about respite*, family members had many concerns about this service. Most participants were concerned about how hard it was to get respite*. A few participants said there were not enough respite* services available. As one family member said,

"I've never heard of anyone that has a good reliable respite system in place. I know none of the parents that I talk to have a good respite system in place and there's a crying need out there for it."

A couple of people said it was hard to find respite workers for specific times, such as on weekends. Another person said funding for respite was not the problem, but finding people to give respite care was the problem.

Some people were also worried about how to make sure respite workers are giving good and proper care.

Family members said respite was available in crisis situations but it was not available to prevent crises by giving families a break.

Things that get in the way of inclusion/integration

Feeling excluded (left out) in different settings was described as hard for many people and some parents believed that the community needs to make the effort to welcome people. For example, one parent said,

"I mean it's fine to want community integration and for them to live in the community but there's so many things that they can't deal with. I mean there's being taken advantage of with hours or shifts being changed and there's a lot of upset with all this stuff and the employer is going well, you know, 'we have the right to do that because we only have to give 24 hours notice' and 'you can't eat, you know you have to buy food at work, you can't bring your food into work.' Well Joe can't afford to eat there everyday that he works, right, because he's on limited income."*

Panic (worry) Planning

Some family members explained that when unhelpful supports are in place, people are often left in panic (worry or fear) situations. Planning for activities and support was a part of the lives of most families. Some planning was panic planning which could happen when families were desperate for services or when crisis situations happened. Making choices in a state of panic can mean that people may choose supports/services that are not a good fit.

C. Barriers

Barriers are those things that get in the way of useful and helpful things that make it possible for an adult to live the life he/she wants to live.

Beliefs about Ability

Some family members were frustrated about the ways their family members were kept from making their own choices because they have a disability. One parent said,

"...why can't they live a life like we live? You know, some people don't have a very good life you know. It's by choice. By the choices they've made or maybe they're uneducated. But these kids, why can't they have a chance like everybody else? Why does their disability have to dictate...I mean they're good kids, but they can't have things."

For some parents it was difficult to trust support staff or trust that their child would be okay out in the community. In some situations, not being able to trust can get in the way of an adult's independence.

Lack of funding and resources

Family members also stated that not enough money and not enough supports was a big problem. Some families believed that staff with too much work to do was part of this problem. Some people believed that some areas of the province got

more money from the 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.

Fear based decision making

Some families talked about decisions that were made based on fear. For example, some families made decisions to stay with a support because they were afraid that if they complained, services might be threatened (in danger of being cut). Another family said that they didn't want to ask for help with their child because they worried he would be removed from the family home.

Barriers to inclusion

Other examples of barriers to inclusion included:

- mobility challenges (wheelchair accessible, walkers),
- lack of effort on the part of the community to include individuals, and
- the way things are organized.

One example of this is the post-secondary education system (e.g. university and college). Classes at university and college were often long which could be hard for some people to sit through.

Belonging

Family members talked about "belonging" (fitting in). Specifically wondering, where can my family member participate and share his/her gifts? Where is the place where my family member can feel comfortable, hopeful for his/her future, listened to and accepted? Some family members said that friendships with other

adults with disabilities are comfortable and a good fit for their family member. In these friendships, some people were better able to feel more free to be themselves and have a good time.

Unrealistic (unlikely) goals of social networks

Many family members viewed natural networks (groups of people) as positive and viewed friends as a place where adults could share their gifts and belong. Some family members felt that making people create networks was unrealistic (unlikely). *"We don't know or feel comfortable with that, it's an intrusion [disturbance]. We don't know how to do it and it feels like an intrusion."* Many of these people felt it was too much trouble to ask other people to help out with their family member.

D. Gaps

This section is about those parts of non-residential (day) supports that family members thought were missing or needed. Adults were asked to discuss what they would like to do more of (e.g. travel, spend time with friends).

Not enough day programs was a worry for some family members.

Adults wanted the following:

- different types of sports,
- different ways to meet people and spend time with friends (e.g. a dance, "guys' night"),
- travel, and
- opportunities to do meaningful activities (volunteering and work).

Adults wanted to do more activities. People did not participate in activities because:

- they did not have enough money,
- the programs were no longer going on,

- not enough support workers.

Respite care was important for many family members. Participants stated that respite was a hard service to access. Many family members said that there was not enough funding (money) for respite services. A number of other people talked about the problems they had when they had to take their family away from the home to get respite services. For example, one parent discussed how her daughter's schedule and routine was disturbed when getting respite outside of the family home. This was a stressful situation for both her daughter and the rest of the family.

Respite offered families some relief here and there but they could not get this service often. Another parent said,

"He doesn't need a home because he's got a home. He doesn't need people to take him to the dentist or the doctor or the physiotherapist because I do all that. I just need him to have some time away from me, partly so I can go to work but also so he has a life that's not totally wrapped up with mine."

Other people said that respite gave caregivers the chance to have time to themselves and have their own life. For example, one parent said, *"you want to be social but you can't be because you have nobody to look after your son or daughter."*

E. Desires/Aspirations

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

Parents realized that it was important for their adult child to have his/her own life. One parent said,

"...[I want my son to] become as independent as possible. I want him to have his own place, his own work, his own roommate, his own life and that. I don't want my other kids living with me till I'm eighty years old and I don't want him living with me till I'm eighty years old. He needs to have a life and we need to have a life and I just wish for him exactly what I wish for my other children. And that's what he should have and I'm going to make damn sure he has it."

Parents also realized that their adult children need to have their own friendships without having parents "hovering" around.

Many parents said it was important for their adult child to have their own life so that the parents could have a life. Having a child with a disability was sometimes described as tiring and limiting to the lives of parents. One mother stated,

"...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, you know, a life of our own because everywhere we go we take Sue along. We have no, no social life because everywhere we go, we take her."*

Family members and adults wanted independence and one way for adults to be independent was by living in their own place. For some adults being independent meant that you do not have to rely on your family all of the time. Some adults made it very clear that they were able to do the things they wanted to do ("I can do it on my own") and would ask for help when they needed it. When talking about her wanted living situation with her boyfriend, one young woman said,

"It wouldn't be renting. It would be our own place with a swimming pool and cats to take care of and no kids...We'd ask for help when we need it of course, but we wouldn't want people coming in every day and stuff."

Adults also wanted to spend time doing activities that they found interesting. Adults wanted to make their own schedules for the day rather than live by other people's schedules.

Many adults and family members also wanted more work options.

One adult explained that if she had more to do, she would not feel as lonely. She said,

"...I'd rather have more to do...I'm feeling sometimes like there's not enough... I don't know how to put it, I wish I could do more, like I want to be doing more during the day when everybody is working. I feel I should be doing something but I'm not. Sometimes, but at night, that's when it really gets to me because I don't like being alone at night and I don't particularly like going out at night on my own."

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

Integrated options: are activity choices for all adults both with and without disabilities.

Personally meaningful activities: are activities that are important to people. For example, working, volunteering, or spending time with friends.

Respite: is a short break for family members.

Segregated activity: is an activity that only people with disabilities participate in.

Socialize: means to spend time with friends.