



# **Residential Alternatives in B.C.:**

## **An Exploration of Family Members and Self Advocate Experiences**

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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**

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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 Residential Alternatives 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 Residential Alternatives focus group/interview was: Self Advocates between the ages of 25-49 or in the case of families, a family member

with a developmental disability with a between the ages of 25-49.<sup>1</sup> A total of 58 individuals participated in the residential alternatives specific focus groups (family members = 39, Self Advocates = 19). However, themes related to residential alternatives 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**

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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.

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<sup>1</sup> Residential alternatives and non-residential supports were joined to form one overall topic area for the purpose of the interviews.

## **Report Layout**

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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. Residential Alternatives Specific Themes

## **Residential Alternatives: A Brief Literature Review**

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Recent trends emphasizing inclusion and self-determination have resulted in a shift in residential attributes reflecting choice, community living, and active participation. With this shift came residential alternatives to group homes such as home sharing and semi-independent living. Research (e.g., Caldwell & Heller, 2003; Emerson, 1999; Emerson, 2004; Emerson et al., 2000; Emerson et al., 2001; Felce et al., 1998; Howe et al., 1998; Parish, Pomeranz-Essley, & Braddock, 2003; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lakin, 2004) has begun to explore these alternatives in terms of cost and quality outcomes and has identified many favourable quality outcomes associated with residential alternatives. However, exploration in this area for adults with severe developmental disabilities is sparse with housing options often limited to institutional environments.

Residential services will be in increasing demand for middle aged adults (baby boom generation), older adults (increased life expectancy), and young adults with severe disabilities (increased survival rates). Thus, this area of support requires both serious exploration and an increase in the

availability a multitude of options to meet the needs of this unique and diverse population. An awareness and understanding of the favourable and unfavourable quality of life outcomes enables for planning that serves to capitalize on the favourable and minimize, or create additional supports to respond to, the unfavourable. In general, research has found that residential options that (1) resemble family homes, (2) are located in communities where individuals have a social network, and, (3) have well-organized and directed levels of support promote quality of life.

The themes presented in this section are both topic specific and general points identified by participants that are not specific to but are relevant to residential alternatives; thus, this topic area and the non-residential supports topic area will have some repetition.

There were a variety of current living situations for Self Advocates identified in this research, however, a general lack of options was also noted. In terms of current living situations, the following were identified (random ordered):

- rented apartment
- living in one's own apartment with support from CLS
- apartment living in a support complex or living in an apartment building with other people living in their own suites
- apartment living with a "typical" roommate
- apartment program in which Self Advocate take turns living in an apartment with a worker support - slowly helping people move out on their own
- Self Advocate owning their own home (not renting) and living with a spouse
- church organized 24 hour residential care

- group home
- living with parents (for some, there were no other options; for one, she had lived at home her entire life - 52 years)
- pri-care.

Changes in living situations both cause and reflect changes in life circumstances. To contextualize the themes presented in this topic area, it is important to note that perspectives about current living situations are variable often reflecting recent experiences or life changes. To clarify, one Self Advocate stated that she liked where she lived but had we asked her the same question the day before, she might have told us a different answer.

#### **A. What is working? What is effective?**

Family members were asked to reflect on their experiences 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 in the area of residential arrangements. Similarly, Self Advocates were asked to talk about aspects of their living arrangement they liked. A summary of participants' responses is provided below.

#### ***Features of Living Arrangements***

##### Accessibility

One factor that was identified as having a positive influence on success in general was accessibility to services and supports. When discussing accessibility, most participants made references to transportation such as bus services. Participants also indicated the importance of being in close proximity to people and resources. When discussing accessibility in terms

of transportation and proximity, participants highlighted how these factors contribute to independence. Finally, one participant described how her/his family member had access to a resource room with a specialized computer, which allowed him/her to access various resources he/she previously could not. Thus, according to participants, the accessibility of a living arrangement also involves enabling an individual to actively engage in his/her community. Overall, according to participants, a living arrangement that is close to transportation, peers, and other resources leads to successful outcomes for adults with developmental disabilities.

### Caring People

When discussing factors thought to influence success, participants frequently referred to caring people. In some cases, participants were able to use specific examples in describing what, in their opinion, qualified as "caring". For example, one participant indicated that his/her family member attended weekly meetings, hosted by a group of volunteers; to this participant it was the dedication of the volunteers that portrayed a caring attitude. Similarly, another participant highlighted an experience in which a social worker regularly called to check in on his/her family member even though new services were not being provided. Thus, regular status checks demonstrated a caring attitude.

The notion of commitment was also expressed by a participant, who described a social worker who would always respond to questions, even though the responses were not always immediate given a heavy caseload. Other participants, both Self Advocates and family members described caring as evidenced by support workers engaging in a variety of activities which provided a closer resemblance to friendship rather than a working relationship.

For many other participants, their descriptions of caring were of a more intangible quality. For instance, one participant simply used the word “empathy” while another said it was an issue of showing clients “respect.” Yet another participant described it as a type of energy; *“they had some really dynamic people leading it, sometimes it’s not about whether it’s segregated or integrated or included, it’s about the energy and the attitude of the person running it.”* Other participants described caring individuals as being there not only to do a job. 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, right, so she wants to see the changes.”* One family member went on to discuss how these caring features were not simply a component of specific programs, but rather something that unique individuals bring to the job, *“I feel my daughter is getting the best possible service right now but it has nothing to do really with CLBC, it has to do with the fact that this person, I’m just lucky she’s good, she’s very, very good.”* Additionally, this participant went on to state that others can learn the special qualities, *“...you can teach, you can train people, you can because it’s a way of thinking...and if you can explain it and show it and be like a mentor you can teach people how to do it and how to work with them the best way possible.”* Such a possibility is promising as one participant argued that more caring people are needed, *“there is good people in all of the associations there’s just not enough of them.”*

### Communication

Participants also highlighted communication as a factor influencing general success. Hands down participants indicated that a lot of communication was preferable. With open lines of communication,

participants argued that everybody involved in providing services and supports knows what is going on and can operate on the same page when supporting an individual. Most importantly, open lines of communication mean fewer surprises in the way an individual is supported.

Along with ongoing and regular communication, family members described other situations in which communication was effective. Some participants appreciated social workers who were willing to listen and discuss matters; *"...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."* One participant also identified communication aimed at finding out the needs, interests, and goals of his/her family member to be effective. Participants indicated that communication was most effective when the different people involved in an individual's support (e.g., teachers, social workers, principal, etc.) all participated.

Finally, one participant alluded to communication as being a right that persons with disabilities deserve,

*"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 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 and Service Provider Training

Another feature of effective support identified by participants was dealing with someone who was an expert in supporting persons with disabilities. Family members did not elaborate specifically on what qualified as

expertise, but rather alluded to expertise through terms such as "trained" and "skilful". Most participants clearly stated that trained and skilled workers are needed to appropriately support persons with disabilities. Participants reported very positive experiences and indicated that the service or care was very helpful when they encountered care workers who were trained. What these participants described were workers who had specific knowledge and experience in dealing with particular disabilities (e.g., autism). In other words, it appears that, in the experience of participating family members, specialized training is more successful compared to more general disability training. Some participants also said it was helpful to have workers trained specifically for their family member. In some cases, the particular aspects of training were provided by the family. This would also help to ensure that the worker was compatible with the Self Advocate and the family.

One participant stated that qualified doctors are especially necessary for people with severe disabilities. The overall sense from family members was that experts simply have a better sense of what is needed and how those needs can be met. One participant indicated that with the expertise comes a "solid" knowledge of what works. Another participant added that in the area of disability care and services, *"there's so many places you can go wrong."*

Finally, some participants also described training that the whole family received. In such cases, the experiences were positive as all members felt they could contribute and family training brought the family closer together. One participant described such an experience. She stated,

*"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."*

## ***Types of Support***

### Support of Family Members

In exploring what is working, some participants said it was the family unit and the associated support that was effective and successful. In some cases, formal resources/services (e.g., respite) were never accessed, because extensive family support ensured somebody was always available to support the Self Advocate.

## ***Outcomes of Living Arrangements***

### Personal Space

Some Self Advocates and family members discussed personal space in living arrangements (e.g. one's own room or own apartment) as an outcome of living arrangements that worked. For example, the benefit of living in your own home is that you can organize and decorate your space in a way that you desire.

Independence was also viewed as an outcome/experience that builds self-esteem and pride in the lives of Self Advocates. *"Sam\* is now in his own place. He has that pride of 'it's my place'."*

### Opportunities to Make Changes

Living arrangements was an area in which some Self Advocates took initiative to make changes. One Self Advocate stated, *"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. What is not working? What are ineffective supports?**

Family members were asked to describe features of their family member's living arrangement that were not helpful or effective. Similarly, Self Advocates were asked to describe those things they did not like about where they lived. The summary of participants' responses to these queries is provided below.

### ***Features of Living Arrangement***

#### Planning Takes Time

Family members explained that arranging living situations is a lengthy process with individuals often waiting a long time for a space to become available. The time consuming nature of both planning and waiting for options is not helpful in ensuring satisfactory and desirable living arrangements.

#### Interpersonal Dynamics

In terms of living with other people, personalities were noted as affecting living situations with people having varying levels of how easy they are to get along with. Family members described changing roommates over time and the lack of continuity associated with some living arrangements.

In addition to clashes with roommates, some Self Advocate participants discussed challenges they had with staff in their residential support. One participant identified the staff as "nagging". She goes on to explain, *"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."* Thus, interpersonal challenges with both roommates and/or staff contribute to an ineffective residential support.

### Safety Concerns

In some communities, violence and vandalism were issues that affected the way Self Advocates and family members felt about where they lived.

Some Self Advocates reported living in an old, run down apartment. This was an undesirable situation for these individuals, and they wished there were more affordable options that would provide a clean, safe, and new living environment.

### Absence of Personal Space

Personal space was important to some Self Advocates and they felt that their current living situation 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 people, I already have a mom who nags me, I don't need anybody else nagging me."*

One individual discussed how his family member requires 24 hour support but that he also enjoys some time alone. This raises the question, how can people who require 24 hour care and supervision enjoy some time alone

and some personal space and still be safe? Safety was a paramount concern identified by most family members and is an important consideration when advocating for personal space.

### ***Outcomes of Living Arrangement***

#### Impediments to Independence and Self-determination

When you live alone, sometimes access to certain supports (such as transportation) can be limited and thus get in the way of self-determination and independence. Similarly, when you move out of your community due to circumstances beyond your control (e.g. family member death) then transportation to access supports and services in the previous community can be a challenge. Such changes can translate into lost connections and a decrease in independence and self-determination.

#### Burnout

Family members consistently noted 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; thus, some participants indicated that family care is not an ideal situation for individuals requiring much care.

### **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 residential

alternatives, barriers get in the way of living in a home that meets the unique needs of the individual.

### ***Philosophy***

A number of participants addressed several issues on a philosophical level. That is, they spoke to matters related to the support of persons with disabilities on a more global and belief based level. One participant argued that it was important for parents to care for their own children within their family's own home. The participant added that support should be provided so that this can be achieved; *"with the proper supports there, I think most parents can care for their child in the home and through the school years."*

Another participant questioned the focus of the current system of care stressing that *"...right now we are focused on crises management, we should be focused on crises prevention."* In order to focus on prevention, better respite and support services were needed for those in private homes.

Some participants identified how their philosophies of care/support for their family members were, at times, in conflict with support workers, doctors, and service administrators. Some participants experienced interactions with support workers who acted as though they knew better than parents because they had completed a training course. In some instances, participants questioned the degree of training one receives during a three month course and compared this to the training and skill that results from living with a person with a disability for years. Finally, some participants indicated that certain services and supports did not

allow for them to engage in their own family processes; *“...when she moved over there we wanted to help her unpack and they said, 'oh no, we'll do that' and I thought, no, you're not going to do that, this is my process so, they weren't making room for my process.”*

### ***Lack of Funding and Resources***

Another major factor associated with ineffective supports was the lack of funding and resources. Numerous accounts of overworked staff were cited as an example of such lacking. Interestingly, many indicated believing that the workers (i.e. social workers/facilitators) assigned to their cases were skilled and qualified people; however, the ultimate barrier to support stemmed from high client to staff ratios making it impossible for workers to meet the needs of their clients.

Participants added further that they did not believe that the limited resources were allocated equally across the various geographical regions of the province. As a result some family members believed that rural communities were greatly under resourced. The lack of funding and resources also placed an added strain on families leading to burnout and the inability to advocate for family members and participate in various programs.

### ***Lack of Continuity***

The lack of continuity in support staff was also implicated as being a general barrier to support. Family members described situations in which *case workers* were constantly being reassigned. For many clients with disabilities, such instabilities are argued to be very difficult to deal with

placing additional stresses on their lives. Aside from changes in *case workers*, family members also described continuous changes to program staff. Adding further to their frustrations, family members reported being unaware of why such changes occurred.

### ***Family Member Beliefs and Wants***

The beliefs of family members about the abilities of their family member were one of the main factors influencing how residential options were explored and how decisions were made. To clarify, some family members believed their family member could only be effectively supported in the family home (for example). Thus, such beliefs prevented or got in the way of an exploration of other residential options. This piece about beliefs can extend to include beliefs about how the health condition of a Self Advocate means a particular type of living situation is not possible. *"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."*

Another factor acting as a barrier had to do with the wants and needs of the family member (i.e. parent, sibling, etc); for example, a Self Advocate may remain in the family home because the parent wants him/her to be with the parent. When asked about future options for her daughter, one parent stated, *"I would like her to, this sounds selfish but I would like her to stay with me."*

### ***Funding Availability***

The availability of funding and associated challenges are barriers to receiving effective residential supports. One participant felt cheated because after receiving funding, he found out that his daughter was entitled to twice as much. Another participant also described frustration at not being able to access funding. In this case, the ministry would not provide funding directly to the family; and, because she lived in a small town, there were few service provider agencies to funnel the money through.

Finally, participants expressed dissatisfaction at what they felt was funding discrimination against those who wanted to keep their family members at home rather than putting them in group homes. As one participant said, *“the impression we get as parents, right or wrongly, I think it’s rightly, is that there’d be a lot more funding for them if we lost custody of them.”* Similarly, another participant said,

*“...there’s still a discrepancy between the amounts of dollars that go towards a young person who is a ward of the ministry or in a family care home or a group home as opposed to the ones who stay in their family home.”*

### ***Funding Rules and Associated Stress and Fear***

Participants alluded to the stress and fear created by government rules regarding funding. A couple of participants explained that, as parents, they are not allowed to receive money for the care of their family members. These participants concluded that the concern was that parents were not supposed to benefit financially from their disabled

children. This rule served as a barrier to accessing funding. Another person raised concern about the government's process to ensure that people with disabilities receiving funding meet the eligibility requirements. This involves a review process that places stress on families who fear losing funding even though their family members' conditions are chronic.

#### **D. Gaps**

This category refers to those aspects of residential support and living arrangements that were missing or those issues that were not addressed as identified by family members. Self Advocates were asked to discuss what they would like to see in terms of living arrangements as well as where they might like to live. Findings related to gaps are summarized below.

Overall, most participating family members wanted individualized support options in the area of living arrangements. Some people believed that there is no available government funding to provide such individualized options; instead, they believed that block funding was the only option.

The lack of emergency living situations was noted by some family members.

When families are locating, hiring, and firing their own staff, it can be difficult due to limited available and qualified staff.

There was also a desire by some for more group homes.

For Self Advocates, living with a spouse can mean tax and benefits issues. There was a desire for more information about what the implications were for such issues when Self Advocates live with their spouse or partner.

### **E. Desires/Aspirations**

Family members and Self Advocates were asked to describe their hopes for the future in terms of where they might like to live and what features of the living arrangement they desire. This section begins by summarizing what Self Advocates said about what they wanted for their current lives and then moves to a discussion of both family members' and Self Advocates' hopes and desires for the future with regard to living arrangements.

#### ***Desired Aspects of My Current Life***

This theme captures Self Advocates' desires for changes or additions to their current routines. For example, many Self Advocate participants expressed interest in gaining independence and having more control over the nuances of their daily lives. Overall, references were made either directly or indirectly to desires for flexibility that would not require them to conform to *set* schedules, but rather enable a schedule of their own.

#### ***Family Members' Vision***

Family members stressed the desire for their adult family member to live in a safe, stable environment. While a myriad of arrangements were described, they all seemed to highlight the capacity to provide necessary supervision, instill a sense of responsibility in their family member, and yet, allow for flexibility and the fostering of independence. It was also stressed

that these environments would be monitored with those responsible for the arrangements (e.g. service providers) accountable for the protection and well-being of their family member. Ideally, emphasis was placed on providing the opportunity for the adult to have ownership of homes/apartments in order for them to establish equity and financial security.

### ***Individualized Support Options***

Overall, most family members expressed the desire for individualized support options in the area of living arrangements. However, many family members did not see this as a possible reality. Some people believed that there is no available government funding to provide individualized options. Another family member stated that the government is not listening to the needs and wants of individuals and families.

### ***Safe Living Environments***

Safety was another large component in desired living situations. Some communities and areas of town were seen as safer than others. One family member explained that where her family member lives, there have been several break and enters. Family members wanted to know their family member was safe. This also meant that family members wanted to be able to trust the staff in particular living situations.

### ***Living Options in Close Proximity to Peers***

Family members wanted their individual to live in close proximity to his/her peers to facilitate social interactions. In addition, having day supports

close to the living situations of individuals was viewed as a desirable arrangement.

### ***A Separate Home Enables Lives of One's Own***

For some families, the desire for a living situation for their family member outside of the family home was important so that the parents could begin to have a life of their own. One parent explained,

*"...we really want to have 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 Desirable Living Arrangements***

Home sharing (or family model homes) was identified by some family members as a desirable living situation.

One family member hoped to buy the house next door to hers, which already had valuable modifications (such as a wheelchair ramp), and have her daughter move into this place next door. In this situation, a care person could live in a suite in the home so that care was available when needed but independence and stability for the Self Advocate was maintained. Similarly, another family wanted to purchase a home with a suite in the basement so their family member could have his own place within the family home and still be able to participate in family activities (such as meals).

Some families discussed hopes and plans to buy a home in which a couple of Self Advocates could live together semi-independently with support coming into the home. In the same way, other families explored the option of pooling resources to rent a duplex and combine support needs and costs. Some families were thinking about purchasing land on which to build an apartment complex. And in another situation, microboards joined together to form a co-op and the co-op currently manages the living situation for several Self Advocates.

### Created Communities

Many family members discussed their desire for the creation of a community for individuals with developmental disabilities. Such a community was described in different ways. For example, for some, a separate community meant a cluster of independent living suites in which the Self Advocate and family members could reside with the presence of a communal space for activities and some meals. One family member stated,

*"...if it were in an apartment block then she's surrounded by people that are her peers, she's surrounded 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."*

Another conceptualization of a desired separate living community was described as having both individuals with developmental and physical disabilities live together so they would be able to support each other.

For some family members, a separate community was not viewed as segregating individuals with disabilities; rather, it was viewed as an option that enhanced opportunities for social interaction and network building. For others, they understood that what they were describing was a segregated setting; however, the rationale for such an option was,

*"... inclusion is wonderful to a point but it doesn't work all the way. It might for really high functioning people but for the lower functioning people, it just doesn't work so I think that this apartment idea is a really, really nice idea because it provides them with their own residence but there would be support on site."*

Another component of the apartment block or separate community concept is that of stability. Family members explained that when you have your own apartment, if a support worker leaves, you still remain in your own home and the disruption to your life is minimal. Safety and security was another desirable feature family members attached to such arrangements. Overall, separate living situations were seen as enabling independence while maintaining stability and security over time.

One participant explained that the difference between an institution and a care facility (as a version of a created community) is that in the former individuals were not allowed to leave and in the latter, individuals would be able to come and go as they please.

### Co-op Living

A co-op (typical) was viewed as a desirable living situation for a parent and her daughter. If her daughter could have her own suite in the co-op with another individual, then she would be able to be independent, be in

close proximity to her family, be in an affordable option, and access occasional short term support from other co-op members.

### ***Affordable Housing***

Affordable housing was also desired. Such a desire was noted both by family members and Self Advocates. Some Self Advocates indicated that affordable housing in their community was often run down and old. As a result, there was a desire for newer and cleaner affordable living options. One Self Advocate stated, *"It's pretty sad, my place is."* Affordable housing options with built in supports was another feature family members desired with regard to living arrangements.

### ***Personal Space***

Self Advocates generally described a vision for the future that involved moving out of their parents' home and into their own place or one with a roommate. Self Advocates also described wanting to become more independent which would allow them to have more control over their lives and enable them to do the things they wanted, such as having friends over.

Generally speaking, Self Advocates wanted:

- to live with people their own age
- to live with their boyfriend (if they currently had one or not)
- 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. financial matters).

One Self Advocate, who was in her 50s, stated that she wanted to live on her own in her own place however, she was told by her family members that she was not responsible enough to manage. At the time of the interview, she resided in a family care home situation in which she had her own suite in the basement; however, she recognized that it was not *her* place and there were particular restrictions on how she could organize her place and her time. She wanted her own backyard with a garden to be able to grow her own flowers; and, she wanted to have her own fridge and be able to put whatever she wanted in it.

Having one's own place was the dominant domain in which independence was discussed both for parents and Self Advocates. In one's own place, the adult was then viewed as independent with opportunities to make choices. One parent explained how her son enjoyed looking through flyers to choose items he would like to put in his own place.

For one Self Advocate, living arrangements also referred to a reflection about where in the province he might like to live; in this case, where to live was not only about the type of living situation.

## **F. Residential Alternatives Specific Themes**

### ***Living in the Family Home***

Some Self Advocates noted that they liked living with their parents in the family home. However, in one case, a Self Advocate indicated 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 indicated that having your child live at home and having support staff come into the family home means a loss of privacy for the family. Another challenge to having your child live in the family home is that obtaining a home that has the necessary supports for a child with disabilities may cost more than purchasing a home for the rest of the members of the family.

### ***Renting an Apartment***

Renting an apartment with a "typical" peer was described as a beneficial experience for both the person with the disability as well as the "typical" roommate.

Many Self Advocates made the clear distinction between *renting* an apartment or home versus *owning* an apartment or home. All participants who made reference to renting and owning indicated that owning was the preferable option.

Being isolated and lonely were issues many Self Advocates and family members discussed. In independent living situations some individuals can feel lonely and depressed because there is limited support and formal efforts to connect individuals to community and participation in community activities are lacking.

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

The distinction between pri-care (PC), home sharing (HS), family care homes (FCH), and foster care (FC) is unclear in general and particularly in the stories of individuals and families. At times it was difficult to distinguish the type of living arrangement to which an individual was referring. One participant identified the overlap and explained her frustration with this type of arrangement. She stated,

*"...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."*

This quote also highlights a point raised by many parents; there is a lack of stability associated with family care homes. Once a family decides they are no longer interested and/or able to provide support to an individual, then the living situation of the individual is disrupted and he/she 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 that as a problem."*

Families and individuals have had both positive and negative experiences with PC/HS/FCHs/FC. Some families explained they had heard "horror stories" about pre-care situations. Additionally, one family member noted that foster home families do not have the same type of investment in the individual as one's *natural* family. Another family member had difficulty understanding why the government will pay another family to care for your family member. Similarly, one parent remarked, "*...what family really would want to give up their kid to another family unless they were desperate?*" Yet, another family member wondered how having her family member go and live with a stranger is beneficial. Interestingly, however, one family member viewed home sharing as offering the security of a family life.

Care provider burnout was identified by some family members as a result of having a "family care" provider provide 24 hour care to your family member. Group homes were seen by some as a better fit for individuals who require 24 hour care as the changes in staff work to protect against burn out.

Monitoring, or lack thereof, was another issue associated with home sharing. Family members were particularly concerned about the lack of monitoring that takes place in home sharing. Important parts of monitoring included running background checks as well as having training for care providers. One family shared stories she heard from people about pre-care providers making a lot of money off of supporting an individual with a disability; "*...people have said, 'well, I paid off my mortgage in five years'.*" This was a concern for some family members as financial reasons are not in line with the principles of family model homes.

Home sharing was also seen as a better fit for some individuals because they were more individualized. In some experiences with group homes, families found the residents to be less active than their family member and thus, such settings were not an ideal fit. One mom stated,

*"Well, I didn't feel he was ready to live away from a family environment so the family environment has worked well. They're an active family, Jack\* is a very active young man and so he gets taken to baseball and he just gets taken along with all their family activities. And he enjoys that, he's been into rugby and soccer and baseball, sometimes on the sidelines but participating as a spectator and a cheerleader. And they've got a boat and they're always doing projects so that particular family is always busy and that suits Jack well because now that there's just [husband] and myself here at home we're not as busy."*

One Self Advocate who currently lives in a home sharing arrangement describes his living situation as a "happy home". In addition, home sharing allows for more "freedom" and the Self Advocate can spend time doing things on their own. Living in a home sharing placement enables Self Advocates to meet new people through the care providers. One Self Advocate indicated that he liked meeting people this way.

For one family, buying a home and then locating a family to rent and move into the home to provide the "family care" would enable the Self Advocate to be in charge of the hiring and firing of the care person/family; ultimately maintaining a stable living situation.

In some situations included in this type of living arrangement, Self Advocates lived with other individuals with developmental disabilities in the foster home. This is another piece of family model homes/foster homes in that, in many cases, there is not just one person in need of care/support living in the home.

The issue of the living arrangement and belonging was also discussed. One parent explained how her son was clear about where he belonged and where he was just visiting. Her son lived with another family but he knew he wasn't a part of that family and wanted to be at home with his own family or in a place of his own.

*"This model is no panacea, and is dependent on many other factors being in place, none of which are at this point secure. We need to continue to urge CLBC to the promised choice."*

### ***Owning a Home***

In one situation, the individual lived at home with her parent whose plan was to move out at some point leaving the adult child to remain in the familiar home rather than cause disruption. Similarly, another family built a home for their family member and the participant remarked that her family member has such pride in having her own home.

### ***Group Homes***

Although some family members believed that group homes were a desirable living situation for their family member, much of the discussion about the features and outcomes of group home living centred on the negative.

Firstly, some family member participants believed that there were too many people living in one group home. Group homes were also not a good fit for some; the group home option is often outside of the community in which the family resides, and the individual resided previously, which leads to a loss of connections and regression in behaviour.

Some family members also stated that there was a lack of emphasis on life skills building in group homes. And finally, some group homes were not connected to the internet which means they miss out on some information.

## **Conclusion**

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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.

## References

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- Caldwell, J., & Heller, T. (May 2003). Management of respite and personal assistance services in a consumer-directed family support programme. [Electronic version]. *Journal of Intellectual Disability Research*, 47(4-5), 352.
- Emerson, E. (2004). Cluster housing for adults with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 29(3), 187-197.  
Residential Options for Adults with Developmental Disabilities/57
- Emerson, E. (1999). Residential supports for people with intellectual disabilities: Questions and challenges from the UK. *Journal of Intellectual and Developmental Disability*, 24(4), 309-319.
- Emerson, E. & Hatton, C. (1998). Residential provision for people with intellectual disabilities in England, Wales and Scotland. *Journal of Applied Research in Intellectual Disabilities*, 11, 1-14.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., & Hallam, A., et al. (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, 106(5), 401-415.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., & Hallam, A., et al. (2000). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation*, 105(2), 81-102.

- Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., & Hallam, A., et al. (2000). The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities. *Journal of Intellectual & Developmental Disability, 25*(4), 263-279.
- Felce, D., & Emerson, E. (2005). Community Living: Costs, outcomes, and economies of scale: Findings from U.K. research. In R. J. Stancliffe, & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 45-62). Baltimore, MD: Paul H. Brookes Publishing Co.
- Felce, D., Lowe, K., Perry, J., Baxter, H., Jonesna, E., & Hallam, A., et al. (1998). Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: Processes, outcomes and costs. *Journal of Intellectual Disability Research, 42*(5), 390-408.
- Howe, J., Horner, R. H., & Newton, J. S. (1998). Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation, 36*(1), 1.
- Parish, S. L., Pomeranz-Essley, A., & Braddock, D. (2003). Family support in the United States: Financing trends and emerging initiatives. [Electronic version]. *Mental Retardation, 41*(3), 174-187.
- Stancliffe, R. J. (2005). Semi-independent living and group homes in Australia. In R. J. Stancliffe, & K. C. Lakin (Eds.), *Costs and outcomes*

*of community services for people with intellectual disabilities* (pp. 129-150). Baltimore, MD: Paul H. Brookes Publishing Co.

Stancliffe, R. J. (2002). Provision of residential services for people with intellectual disability in Australia: An international comparison. *Journal of Intellectual and Developmental Disability, 27*(2), 117-124.

Stancliffe, R. J., & Lakin, C. (2004). Costs and outcomes of community services for persons with intellectual and developmental disabilities. [Electronic version]. *Policy Research Brief, 14*(1), 1. Retrieved February, 2006, from Institute on Community Integration, University of Minnesota (<http://ici.umn.edu>) database.

Stancliffe, R. J., & Lakin, K. C. (2005). Context and issues in research on expenditures and outcomes of community supports. In R. J. Stancliffe, & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 1-22). Baltimore, MD: Paul H. Brookes Publishing Co.

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual & Developmental Disability, 25*(4), 281-305.