

Adult Community Living Supports in British Columbia:
An Exploration of Family Member and Self Advocate Experiences

Community Living Research Project

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

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Executive Summary

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 (total participants = 105). Specifically, interviews and focus groups were held in the Lower Mainland, the Interior, Vancouver Island, the North, and Powell River. Phone interviews were also conducted to enable families in remote areas of the province to participate in the research. 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 for adults with developmental disabilities.

Focus Groups and Interviews

**35 Self Advocates
70 Family Members**

**Total participants:
105**

Participants were invited to share their thoughts about and experiences with community living supports in four specific topic areas; those areas were (1) young adults transitioning from high school, (2) residential options, (3) non-residential supports, and (4) services for seniors. Interviews were digitally recorded, transcribed, and analyzed using computer software (NVivo 7). The results of this study are organized in this report by topic area in the following way:

- A. What is working? What is effective?**
- B. What is not working? What is ineffective?**
- C. Barriers**
- D. Gaps**
- E. Desires/Aspirations**

With regard to those things that are effective, participants discussed communication between families and service providers, families and CLBC (including facilitators), service providers and CLBC as a required element of effective supports. Contrastingly, when asked to identify those aspects of community living supports that were ineffective, a lack or absence of communication between all stakeholders (i.e. families, individuals, service providers, CLBC) was stated by participants. Not surprisingly, many of those features identified as creating effective supports when present were also noted as ineffective when lacking or absent.

Other features of effective supports included: expertise and service provider training, continuity in support staff (i.e. low turn over rates), caring people in support positions, individualized planning and supports to enable such planning, opportunities to participate in meaningful activities, acceptance, creative planning, and accessibility. Some specific types of support that participants reported as effective included: support for family members (from other families and in the form of formalized supports), respite, relationships with peers, Special Olympics, and microboards.

"I think my future is getting brighter, I've got a lot of people supporting me, which I never had before...I don't know what's gonna happen in the future but I will make the best of it and I think I'm happy, I like people, I like my friends."

When participants were asked to discuss those supports, or aspects of supports, that were ineffective, issues such as lack of flexibility within programming (e.g. one size fits all mentality), lack of coordination within and across systems and supports, lack of clarity, on the part of families and support staff, around accessing particular supports, funding and financial limitations, lengthy and time consuming planning practices, and a lack of creativity and innovation in supports were cited.

Overall, lack of continuity in both support staff (i.e. facilitators and other front line staff) and supports accessed was identified by participants as a barrier to support, ultimately getting in the way of enabling an adult to live the life (s)he desires to live. With continuous changes to support staff, planning for the present and future becomes problematic because those people involved in and/or facilitating the planning do not know the Self Advocate and his/her family. This lack of continuity gets in the way of forming relationships and a sense of consistency and stability in the lives of Self Advocates.

"My concern was that the social workers have changed so frequently that they didn't really know her and you're doing a meeting about her future."

Other barriers to support reported by families and Self Advocates included: limited knowledge of available support options, lack of funding, conflicting philosophies, disconnection between support systems, challenges in person and system interaction, beliefs about a Self Advocate's ability, decision-making based on fear, lack of a sense belonging - isolation, and transportation issues.

Gaps were defined as aspects of support that were missing or were not addressed. Gaps in support as identified by participants were often topic specific. For example, one gap that many family members discussed was the isolation experienced by some young adult Self Advocates following high school exit. A gap specific to residential options was the lack of emergency living situations as well as the lack of individualized living options. Similarly, with regard to non-residential supports, participants reported a lack of individualized day support options. Gaps were emphasized in the Northern regions of the province as well as in some smaller communities. Some families discussed how many needed supports and services were absent in their community due to either the geographical location and/or the small size of their community. In addition, the lack of available respite support was cited by many families as a gap in support. This was particularly important for families with an aging caregiver. Changes in health status often means changes in ability to support a Self Advocate in which case, some families were looking to respite as a transition tool in helping the adult adjust to a new living situation. Counselling support was also identified as a general gap in the way individuals with developmental disabilities and their families are supported.

Desires and aspirations refer to those supports, or features of supports, family members and Self Advocates would like to see exist as options in the future. Generally speaking, both family members and Self Advocates described a desire for a future that includes choice and personal space, individualized living and support options, multiple relationships with people in the community, employment, and safety. Many families had fears for the future of their family member. Some parents and Self Advocates asked, "who will care for my family member/me when I'm/my parents are no longer able to?"

"There's so many that have elderly parents and that they're just hanging on not knowing what's going to become of their loved one...they'd like to see something in place for their loved one before they pass on."

This summary report also includes topic specific themes based on participant responses. Themes specific to transition included: Self Advocate post-transition activities (e.g. college, day program, social outings), a recognition of the change in status from child to adult, parental recognition of the change in relationship with their now young adult, and a desire for more information about possible next steps.

In the residential options specific themes, families and Self Advocates debated the pros and cons of living in the family home, in one's own apartment, in pri-care, in a group home, and owning one's home.

"It wouldn't be renting, it would be our own place. We'd ask for help when we need it of course but we wouldn't want people coming in every day and stuff."

Overall, Self Advocates spoke of the importance of having personal space and the desire to own rather than rent a home.

The need to plan and a discussion of how to be proactive in planning for later life were themes in the services for seniors topic area. In some cases, families had taken explicit steps to plan for the future care and support of their family

member. In other cases, parents had an awareness of the need to plan but had not yet engaged in later life planning.

Many family member participants spoke of their experiences with and hopes for CLBC. Family member participants reported a general uncertainty and unease in relation to CLBC. For some, this had to do with a lack of information about how CLBC would support individuals and families – would it be different than the Ministry of Children and Family Development? Would it be the same, worse, or better? The overall tone of the discussions about CLBC was negative with families expressing disbelief in the vision for CLBC and families sharing unsatisfactory experiences with CLBC thus far. At the point of this research, many families stated they were waiting for CLBC to follow through on the promises and vision shared at its inception.

"The vision that they were showing us of CLBC I want that vision to become real because its nowhere near real right now, right now it's just a total mess and it's just totally frustrating for parents."

Parents also identified hopes for CLBC and this new system. Broadly speaking, participants desired: accountability and monitoring, improved communication with family members, support staff, service providers, and other systems, individually tailored supports, and the recognition, and subsequent addressing, of gaps in support.

This report organizes and summarizes the thoughts and experiences of Self Advocates and family members throughout BC who participated in this research. The information shared provides insight 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.

Introduction and Methodology

In the late spring and summer of 2006, the Community Living Research Project conducted focus groups and interviews with 35 Self Advocates and 70 family members throughout the province of British Columbia (i.e. Vancouver Island, Lower Mainland, Northern BC, Interior) (see Table 1). 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.

Table 1.
Number of Participants Interviewed for Each Topic Area

Participant Group	Interview Topic			Total/Respondent Group
	Transition	Residential Alternatives & Non-residential Supports	Services for Seniors	
Family Members	19	39	11	69
Self Advocates	5	19	11	35
Total/ Topic	24	58	22	105

Focus groups and individuals were separated by topic area and by participant type (i.e. family member or Self Advocate). Criteria for focus group/interview allocation was as follows:

- Self Advocates between the ages of 19-24 or family members of a Self Advocate who was between the ages of 19-24 participated in a transition focus group/individual interview.
- Self Advocates between the ages of 25-49 or family members with a family member between the ages of 25-49 participated in a residential alternatives and non-residential alternatives focus group/interview.¹
- Self Advocates over the age of 50 or family members with a family member over the age of 50 participated in a services for seniors focus group/interview.

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

Data Analysis

Interview and focus groups were audio-taped and then transcribed (i.e. audiotapes were typed out into printed texts). The transcribed interviews and focus group interviews were entered into a computer software system. The software enabled both the organization of a large amount of data and facilitated comprehensive exploration of themes. Using

¹ Residential alternatives and non-residential supports were joined to form one overall topic area for the purpose of the interviews. Findings from each topic area are separated out in distinct sections of this report.

thematic analysis (Braun & Clarke, 2006) – comparing, contrasting, and categorizing the data into themes - the research team was able to look at both similarities and differences across participants' stories. Exploring the data beyond commonalities in themes ultimately provided a more detailed, rich and accurate picture of participants' experiences with and hopes for the adult Community Living support systems.

Report Layout

This report provides a summary of the themes extracted from the stories shared by the 105 participants. Findings are organized by topic area (Transition from High School, Residential Alternatives, Non-residential Supports, Services for Seniors, Community Living BC, General) and then further 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. Topic Specific Themes
- G. Recommendations based on findings

Due to the interconnected nature of the way individuals and families access supports and services, some themes apply to more than one topic area and, thus, may be included in each relevant section. However, the description of the theme will only be included in the section in which the theme is first identified. Subsequent notations of the themes will refer the reader to the page of the initial theme reference.

Young Adult Transition from High School

"Transition", in the context of the Community Living Research Project, refers to the move from high school to adult life that takes place for young people between the ages of 18-24. "Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships" (Division of Career Development and Transition as cited in Halpern, 1994, p. 117).

As young people prepare to exit secondary school, they are confronted with new aspects of their lives to contemplate. Issues such as employment, post-secondary education or training, living arrangements, and financial responsibilities become important areas for consideration as young people enter adulthood. Transition as it pertains to the lives of young adults encapsulates life adjustments and new experiences as these individuals move from school environments to independent living and working (Wehman, 2001). Leaving school behind to enter the adult world can present challenges for all individuals; for students with disabilities and their families, these challenges may be even more salient (Beresford, 2004; Wehman & Revell, 1997).

A. What is working? What is effective?

Family members were asked to reflect on their experience of the transition process in terms of what was helpful during this time; however, much of the experiences and stories shared about the high school transition

focused on those aspects that were not helpful. Thus, the collection of helpful and effective supports is minimal.

Transition Supports

Some family members identified specific supports/services they accessed during transition that were helpful. Such supports included: participating in a transition group for young adults and parents, accessing an extra year of school to allow for better planning or an opportunity for maturity, and organizing an overlap in services. The transition group provided a place for parents to connect and discuss transition related issues and access group support. The young adult aspect of the group enabled young people to connect with peers and build relationships. An extra year of school allowed some young adults to transition slowly into post-school life and activities while maintaining the connection to and the support received through the school system. Experiencing an overlap in services was also often organized in conjunction with an extra school year which allowed the young adult to continue to receive school-based supports as he/she prepared to access post school services. However, there was also a worry on the part of some parents that some transition options/ supports were just keeping the young people occupied and were not providing any tangible benefits.

Creative Options

Some parents have worked with service providers to get creative about how a young person in transition can be supported. This has involved persistence on the part of the family member. One parent stated,

"...he's not the kind of person who easily fits into a hole of any shape. He needs to create his own. So, just having somebody

there who was really good at planning, who wouldn't necessarily spoof you, but would sit down with us with information at different times along the way, to help us grow and lean into it and send us in direction."

Another family with a transitioning young adult created an individualized support option by creating a business for their child based on his interests. Their attitude was - how can we make it happen?

B. What is not working? What is ineffective?

Family members were asked to discuss their experience of the transition process in terms of what was challenging or difficult. Across transition interviews and focus groups, the responses related to this category dominated discussions about transition. Overall, family members used the following words and phrases to describe their experience of transition:

- *"Very scary"*
- Feelings of *"powerlessness"*
- *"Bumpy transition"*
- *"Everything stops"*
- *"It's too much all at once"*
- *"Floundered"* at time of transition.

Lack of Consistency/Continuity

One challenge and barrier to planning identified by family members was the lack of continuity with one social worker/facilitator over time. Family members discussed their confusion and frustration regarding support worker changes over the years and at transition. For some, having different support workers over the years meant that transition planning often involved a support worker who was not familiar with the young

person for whom the planning was taking place. One parent stated, *"...there was a specific meeting for her. It was okay but my concern there is that the social workers have changed so frequently that they didn't really know her and you're doing a meeting about her future."*

In British Columbia, when a young person with a developmental disability turns 19, they must switch from child to adult services, with different eligibility criteria and support options. This usually means that the child support worker who was involved with the young person prior to turning 19 is no longer involved. As a result, previous support relationships (i.e. with a social worker) experience a disruption at a time in which many other life areas are undergoing transition. Family members reported that this lack of continuity was problematic because there was no longer one person associated with the service system who was responsible for guiding the young person and his/her family into this new life stage and new service system.

In addition, some parents talked about a period of limbo experienced when their child was on the cusp of turning 19. Some parents in this study explained that as their child approached 19 years of age, thus preparing to leave the child service system, the child social worker began to pass the "case" off. During this period in which the case was transferred, the social worker was no longer supporting the young person and yet the adult service system did not assume support until the child reaches 19 years. This demonstrates how, at a time of extreme confusion and change, young people and families are left alone to navigate the transition from child to adult and child services to adult services. Many parents explained that this experience of limbo made the transition from high school challenging and frustrating.

Lack of Coordination between/ Lack of Communication among Systems

Related to the theme of 'lack of consistency/continuity', family members identified the disconnect and miscommunication between support systems as another aspect of the transition experience that was ineffective. Firstly, different systems were not communicating with one another. Communication between systems is hindered by an absence of a common language and a common mandate. One parent highlights this challenge. She stated, "...we were kind of at a bureaucratic stalemate...the two policies wouldn't mesh."

This lack of communication was further evidenced by the minimal or absent information available to parents about one system from personnel in a different but related system. For example, some parents reported that school personnel were not aware of the services available following school exit. Similarly, family members identified a disconnect in awareness of those services/supports offered in the child systems and the adult systems by social workers/facilitators belonging to the respective systems. This lack of awareness acted as a barrier to a smooth transition bridging life pre and post school exit for these young people.

Some parents also wanted some assistance with paperwork and other details to help them navigate these systems but such assistance was lacking or absent. These challenges act as barriers to effective transition planning.

Panic Planning

Another theme that was prevalent in family members' stories of the transition experience was panic planning. This is reactive planning that takes place at the last minute, leaving minimal choice often between

undesirable supports or no support at all. Panic planning is often accompanied by fear – usually the fear of having no support at all and, thus, you take whatever you can get. In some cases, transition planning was taking place at the end of the final school year (June). Such late planning meetings created situations of panic planning for some young people and their families. One family member stated, *"...the transitioning doesn't seem to happen until all of a sudden, in a panic, the school says, 'well, you know, they can't come back to school in September' And this is June when it should have started a year prior when they were eighteen."*

Engaging in panic planning may result in accessing supports allowing for some initial relief for a parent/family (such as obtaining permission for an extra year of school); however, over time, some parents wondered if the current support was the best fit for their child. They wondered, what else is out there? Is there something that could be a better fit? However, at the time of planning, the parent was unable to ask these questions because they were in a panic situation. For some families, the fear of having nothing (no supports) in place for your child may mean you are more likely to accept something that might not be the best fit.

Another perspective on planning is that even when formal, person-centred planning takes place, poor outcomes can still result. For example, one parent stated,

"...we started this process in grade ten or eleven like we apparently were supposed to so that everything would be in place when they finished school, but it was the Ministry that couldn't, didn't pull it together. We did the planning session. We did the assessment. The social worker made the

recommendation for funding and that's where everything stalled because there again, the funding wasn't available."

In this example, proactive planning took place, however, due to a lack of resources, a situation of panic still resulted. Thus, examples from the participants demonstrated that proactive planning might not guarantee desired outcomes.

One family member noted that planning can be challenging for systems because what people need are individualized rather than block support/services. Similarly, another family member stated, "*...there's always that discrepancy between his needs and the rigidity of the system as it exists.*"

C. Barriers

Barriers are those things that get in the way of successful and effective support that enables a young person 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 transition, barriers get in the way of a successful transition from high school to adult life for young people and their families.

Disruption to Services at Transition

One of the main barriers to transition for the participants in this study was structural and has been identified as 'disruption to services at transition'. Most parents discussed the interruption to current services received during this time of transition. This young adult transition takes place on multiple

dimensions and an understanding of these dimensions facilitates the complete exploration of the disruption to services.

To clarify, there is: (a) the transition from high school, (b) the transition from child services, (c) the transition into a new support system (or not, depending on eligibility criteria), and (d) the transition into a new life stage. For example, some parents reported a loss of services at 19 followed by a period of *"limbo"* in which the young adult was not receiving supports, and families were waiting to find out what options would be available to them. This may mean waiting to hear from CLBC about the kind of funding that would be available; it may also mean waiting to hear if their son or daughter was able to stay in the school system for an extra year. In many cases, this waiting translated into panic planning as decisions were often provided at the last minute. Transition from child services and from high school is further complicated by the fact that many young people will no longer have the same social worker/facilitator. Thus, young people are leaving school and entering a new arena of life as well as entering a new relationship with a different facilitator. This is a time of change on many levels and all at once.

The experience of transition for young people and their families can be described as the black hole.

"When all of these individuals leave school there's just a hole, they hit a brick wall, there is nothing, absolutely nothing suitable out there for them and they're left swimming around in this deep water adrift and it's so sad."

Some parents who have children who are preparing to transition, or are in the process of transitioning, from high school reported being concerned

about a drop in services once their child turns 19. For some parents, these concerns were based on hearing stories of other families who had already experienced the transition and subsequently, experienced a disruption to services. Parents described the experience of the transition as a time in which *"so much stops...it's a complete cut off."* Similarly, some parents were worried that there would be an absence of activities available for their children once they left high school. One parent stated, *"I think my son will live to be a ripe old age given the genes he has and I'm concerned that I don't want him to sit and watch TV for the rest of his life."*

Limited Knowledge of Options

A lack of awareness/knowledge of the options and opportunities available in the community and the support system acts as a barrier to transition and to transition planning. What are the options? Many parents stated they did not know about the post-school options for their son or daughter. This was complicated by the fact that some parents reported that social workers/facilitators and the school system were not aware of the many options available for the young person to pursue. Furthermore, personnel in these two systems were disconnected from one another meaning that one system did not have information on the other. When personnel (e.g., social workers/facilitators, principals, etc.) did have some information about a support or service, one parent explained that it was a scary way to "place" her child, going on the opinion of one person rather than having that knowledge first hand. However, many parents also acknowledged that they didn't have the time to research and learn about all of the options in the community; such research was viewed as extremely time consuming.

When speaking to Self Advocates about the planning process, some identified having ideas about how they would like to spend their time following school exit while others reported having no idea.

Deficit Marketing

Another idea associated with panic planning is that of "deficit marketing;" in this context, deficit marketing means to "market by negative descriptors".² For example, one parent discussed how they had to paint a negative picture of their family and son in order to get crisis support because they were not able to get any other kind of support. This was a challenging experience for the family. Deficit marketing goes against the principles of person-centred planning which is supposed to focus on the strengths, abilities, hopes, desires, and needs of the young person. The implication is that structural factors create a contradiction between the Community Living values of person-centred supports, self-determination and autonomy and the actions some families and individuals feel they must do to get service.

Giving Up/ No Faith in the System

Parents discussed their interactions with CLBC and social workers/facilitators during transition; generally speaking, parents had poor experiences with this system. Family members referenced experiences regarding a lack of follow through on plans or promises. In addition, families stated they were tired of waiting to hear from CLBC. Waiting for a response from the system caused problems and, at times, resulted in necessity or panic planning rather than proactive, choice-based planning. Some parents discussed how they were repeatedly told by

² (VCU Webcast, 2004)
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government workers that the dreams and/or plans they have for their child are unrealistic. One parent wondered who the government listens to when they make decisions. She stated, "...they don't listen to parents and they don't listen to people with disabilities, I don't know who they do [listen to]." As a result, some people spoke of how they had given up on the ministry/social workers/bureaucracy because they had been let down repeatedly.

D. Gaps

This category refers to those aspects of the transition process that were missing or those issues that were not addressed. Gaps are linked with Desires/Aspirations in that what parents hoped and wished were a part of the transition experience identifies gaps in the way young people and their families are supported.

Isolation Following School Exit

Isolation, the fear of and the need to protect against it, is not a transition specific theme but rather was present throughout participant stories across adulthood. However, it seems to be of particular concern at the time of transition as young people are leaving the school setting and services and supports change. Some parents discussed the "great" programs their children were able to access prior to turning 19; however, upon reaching the age of "adult" status, they were no longer able to enjoy the same services. For many young people, such programs created ongoing opportunities to form peer relationships; however, the organized support made available to such teen groups was not available post 19 years and the potential for these context specific relationships to deteriorate increased. The idea of "fighting the isolation" emerged from

the data as well as the "fear of isolation". Some parents have worked together to create ongoing supports for their transitioning young adults; these efforts enabled the young people to continue to connect with their peers and get out in the community.

Associated with isolation is the notion of belonging - where do I belong? This time of transition further complicates the already prevalent issue of belonging as these young people go from being children to adults once they reach age 19. They no longer belong in the school system but are not necessarily ready to access adult supports. Having a place to belong during and after transition was identified as important by participants. Belonging could be demonstrated through the absence of labels defining these young people; by having programs that fit the young people's needs and not the other way around; and, by recognizing the individual needs of the person.

The following quote is echoed in the stories of many other parents; *"She's trying to find a place where she can be. There's just very, very little support. She's 19, she doesn't want to sit in a room with 40, 50 year olds that have nothing in common with her."* This quote highlights the issue of poor person-and-environment fit as a feature of belonging. Prior to the transition many young people are in school with their peers and some are accessing teen groups outside of the school. Once they have finished school, some families found there were few opportunities to access such same age peer groups.

E. Desires/Aspirations

For the organizational purposes of this report, desires/aspirations in the context of transition refer to those features of the transition experience that family members believe will improve the experience.

Desired Supports

Many parents identified specific supports they would like to see be a part of the transition process. One parent indicated there was no support from social workers with regard to "psycho-social issues" during the transition which she believed was a needed service at this time. Another parent wished there was a transition coordinator who was responsible for being aware of supports in the community, including the wider community, and then connecting individuals and families to such supports. Similarly, one family member explained that she was looking to the government to provide assistance to individuals and families in the form of organizational or structural support. Specifically, this parent identified either providing a space in which a program could operate or providing a strategic planner who would be available to families as needed. She made the distinction between this kind of assistance and direct or individualized funding.

Creative, Deliberate Planning

When reflecting on how the transition experience could be improved, family members noted some very straight forward ideas. One parent wanted to experience a "*proper planning process*" such as PATH with someone who was a "*creative out of the box thinker,*" who had some planning skills, and who could provide useful information.

List of Supports with Key Features for Replication

Some parents reported that having access to a list of all Community Living supports in an area broken down by region and level of support provided would be useful in enabling effective transition plans. Such a resource would facilitate planning based on an awareness of all options and choices rather than planning that involved limited options due to a lack of knowledge and/or a lack of time to research all options available in the community. Similarly, one parent reported that it would be helpful to have access to a list identifying good things that agencies or programs are doing so that these good things could be incorporated into other programs. Generally, both of these suggestions speak to how having access to a comprehensive resource outlining programs and positive features would assist in the transition experience.

Building on this idea of a list of supports, some parents discussed how a transition coordinator would be useful for connecting young people to the available supports. The transition coordinator would be a position dedicated to the identification of relevant community supports and the connection of young people to such supports.

Service Overlap

Related to the experience of a disruption to services at transition is one family member's suggestion to have some supports and services overlap. This overlap might allow for a smoother transition that is not characterized by a complete drop in services and an entirely new team supporting the young person. Many families discussed how often they were told that there were no available supports and no available funding. Some families attempted to pursue other options to maximize the limited supports available during transition. For example, after initially being told there was no money and no space, one family accessed support by working

creatively with a community agency and the young person's school to develop some sort of transitioning partnership. This partnership enabled the agency to support this young person while the school and assigned student assistant provided a level of continuity for the young person as he transitioned from a familiar setting to a new one.

One parent echoed the idea of overlap and emphasized the person-centred-planning approach that is necessary. She stated, *"The school system has been doing really good in getting onto the point where they are but we need ongoing programs that fit the kids not the kids fitting into the programs."*

Psycho-socio-emotional Support

Some families indicated they would like some emotional support during transition. This extends beyond planning support to include counselling for the entire family - working beyond a focus on the transitioning young adult. In addition, some parents wished they had someone who would check in on the family from time to time to see how things were going and revise the plan if needed. One parent made it clear that she did not need to have her hand held all the way along but knowing that someone would be checking in would be helpful.

Sustainable Funding

One parent spoke at length about the need for sustainable funding in improving the transition process. Such funding allows for stable and secure planning that does not dissolve at the end of a year. This parent wanted a commitment from government ministries to make sustainable funding available.

F. Transition Specific Themes

This section of the report includes themes from the data that are specific to the transition from high school and do not fit in the previous categories.

Post-Transition Activities

Young adults engage in a variety of activities and endeavours post-transition. The pursuits identified by Self Advocates and family members included:

- Day programs
- Vocational day programs
- Volunteer work
- College program (e.g. Capilano College, Vancouver Community College)
- Activities with friends
- Special Olympics
- An extra year in high school
- Support groups
- Activities with family
- Creative pursuits (e.g. pottery, music)

In some communities, particularly small communities, there was a reported lack of options for post-transition activities. For example, one family member reported,

"...those individuals that look after our children or young adults don't have any training. So, therefore, they don't really know what kind of programs to run or how to run the

programs, which just makes sense right? If you don't have any training, then you don't know."

A common theme among of Self Advocates and family members for post-transition activities was the desire for more work opportunities. However, participants shared that such opportunities were often limited or were opportunities specific to the interests of the young adult were not available.

Young Adult Experience of Transition

Young adult Self Advocates had a variety of thoughts and reflections based on their experience of leaving high school. Themes specific to this experience included: feelings about transition (how did the young adult feel about leaving high school), change in status/relationship (a recognition of how their relationships with certain people changed as they prepared to leave high school), and next steps (young adults' thoughts about what comes after high school).

Feelings about transition

When young Self Advocates were asked to share their thoughts on their experience of leaving high school, many did not elaborate beyond stating that it was "*hard*" or it was good. It was a hard experience because these young people were leaving behind friends and teachers. One family member stated that her daughter was afraid of school ending because she would miss the contact with people other than her family. According to participating young adults, leaving high school was a good experience because it meant there would be more time to participate in other, more interesting activities; similarly, it would mean the absence of

those undesirable features associated with school (e.g. early mornings, tests).

Change in status/relationship

One young person described his transition from high school as one of *"freedom"*, feeling more *"adult like"*, *"capable"*, and *"responsible"*.

Similar to that of a change in status is the change in relationships some Self Advocates described when reflecting on leaving high school. Relationships with peers and teachers were ending or changing and for some Self Advocates; this was a difficult part of the transition. One young woman stated, *"Made lots of friends, including the teachers, so saying goodbye to them was difficult."*

Next Steps

When invited to think about the transition experience and share their thoughts about what they wanted to do after high school, some young Self Advocates reported knowing what they wanted to do and others said they had "no clue". The desire for more information about what was coming after high school was mentioned by a young male participant. Another young person who was currently in a day program wanted to go to university after finishing high school. Other young adults identified wanting to access work opportunities. These work experiences were directly related to the interests of these individuals. However, a couple of young people cited barriers that got in the way of accessing such opportunities. For example, one young woman experienced a lack of options/opportunities due to living in a small community. Instead, she worked a limited number of hours in a position unrelated to her interests and volunteered in a position that is in line with her interests. Another

young woman wanted to work in the kitchen of a restaurant but, due to a recent health issue, she no longer had the mobility to be a cook in a restaurant.

Another component of 'next steps' following school exit was building connections with peers in the community. One family member indicated that her daughter really enjoys having contact external to her immediate family and has found Special Olympics to be a great avenue for building and maintaining connections with the larger community.

Residential Alternatives

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 favourable. In general, research has found that residential options that (1) resemble family homes, (2) are located in communities where individual 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 Advocates 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 are 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 case load. 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.

Non-residential Supports

Non-residential supports comprise those activities taking place during both the day and the evening, such as day programs, work opportunities, and social activities. A review of the literature on day supports, services, and activities for adults with developmental disabilities found much of the literature to be dominated by research on work-related supports and activities (e.g., microfinance, job coaching, supported employment); there was a lack of research on other types of day supports.

People with developmental disabilities experience persisting low levels of employment (CAACL, 2006). Supported employment has emerged as a major approach for addressing this issue, an approach that is fairly well established in Canada and other jurisdictions (Neufeldt, Sandys, Fuchs, Paris, & Logan, 2000). However, while there have been improvements in implementation of supported employment in recent years, in the U.S. context segregated employment outstrips its continued growth (Olney & Kennedy, 2001).

A range of systemic factors create disincentives to the employment of people with developmental disabilities. These include provincial income programs that penalize people for earning above capped limits and difficulties that people with developmental disabilities face in qualifying for ongoing employment supports under generic and specialized labour market programs and services.

The market orientation that has been driving agencies in the developmental disability sector in recent years has led to a 'commodification' of disability and competition among agencies for clients who are easier rather than harder to serve.

In exploring non-residential supports for adults with developmental disabilities, the present research sought to probe beyond employment options to capture the range of day activities that are a part of, or are a desired part of, the lives of these adults. This section provides a summary of day activities, what makes day activities effective and also ineffective, factors that get in the way of enabling effective day supports, and desires and aspirations for how adults are supported in their day-to-day life.

The themes presented in this section are both topic specific and general points identified by participants that are relevant to non-residential supports; thus, this topic area and the residential alternatives topic area will have some repetition.

Self Advocates and their families described a number of activities that Self Advocates enjoy, such as sports, classes, and other leisure activities. The most common stated benefit of participating in activities in general was that they provide a means to socialize with others. Self Advocates expressed a need to see their friends, meet other people, and build relationships with individuals. This was also important to family members, as many expressed they were happy when their family member was able to get out and enjoy the company of others. Other beneficial activities were those that were educational, skill building, interesting, and individualized.

For those Self Advocates who attended day programs, most went to the program 4-5 days per week. The assortment of activities available in the day programs discussed by participants included:

- Volunteer work
- Playing games
- Recreation
- Arts and crafts
- Community activities
- 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 regions of the province, day programs were not an option; instead, small capacity drop-in programs were available. Such programs were often limited in duration, activities, and size. Many families in these regions expressed dissatisfaction with such limitations and desired additional supports in their communities.

A. What is working? What is effective?

Family members were asked to reflect on their experience of those non-residential 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. Similarly, Self Advocates were asked to talk about those aspects of their lives that they enjoyed, looked forward to, or were important to them. A summary of participants responses are provided below.

"...the key to Bill's success with his workers is that I have demanded that if he says something they listen to him. Now it doesn't mean that Bill gets everything he wants but it means*

he's always listened to and if we can accommodate what we, 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."

Features of Non-residential Support

Age Appropriate workers

A couple of participants spoke specifically about how the age of their family member's worker can have an impact on the relationship. They highlighted a benefit of having age appropriate workers was that the relationship reflected 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."* The participant further elaborated that such a relationship cannot be built on the skill or qualifications of the worker. She described another one of her son's workers who was skilled and did a very good job, but he was older; and, it was obvious when he and her son were out that he was a worker which impacted the nature of their interaction and their experience out in the community.

Caring People

This theme crossed topic areas and thus exists in many sections throughout this report. For a full description of this theme, please refer to page 38 of this report.

Communication

This theme crossed topic areas and thus exists in many sections throughout this report. For a full description of this theme, please refer to page 39 of this report.

Expertise and Service Provider Training

This theme crossed topic areas and thus exists in many sections throughout this report. For a full description of this theme, please refer to page 40 of this report.

Continuity

Participants identified continuity as an important factor influencing success. Continuity was discussed in a number of different contexts, such as having the same support worker, being in the same program, or having the same job for a number of years. In all cases, participants spoke positively about continuity. In terms of having the same support workers, participants stated that their family member was able to build and maintain relationships with support workers. Family members believed it was important for persons with disabilities 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."* Another participant felt that because she had the same social worker who was present when they developed the initial life plan, few changes had to be made over the years. Other participants indicated that dealing with the same people led to less frustration. For example, one participant said, *"...struggling with different staff and with different executive directors and different this and that and it's like banging your head against the wall."* Finally, by having continuity with respect to programs and employment, participants argued it allowed

their family members to become familiar with surroundings, people, and activities.

Acceptance

Another important aspect of successful day programs was acceptance. One family member stated, *"...the day program is totally successful. It accepts his needs and everyone in the program."*

Many family members spoke of the importance of having their young person out in the community participating in various activities and getting to know people. It was the belief of many that when people know you, opportunities (such as friendships and employment) are more readily available and accessible. For some, living in a small community was identified as an advantage in getting to know people. One parent spoke of the great success her family had experienced through her daughter's participation in a community recreation program. This program was for *all* young people and operated with supportive staff (some with specific training, others without). Such an opportunity meant that her daughter was known to other people in the community and people began stepping in and saying they wanted to be a part of her daughter's life. She stated, *"...it brings in your local ones [people] who bring in other supports because they see who is part of the community and they don't feel threatened."* In addition, this parent believed people who become involved with an individual in such a way are doing so because of choice, not due to obligation.

Attempts to create inclusive opportunities characterized by acceptance and opportunities to establish friendships with people in the community have not always produced inclusive results. Sometimes, programs with

the best intentions and goals are unable to facilitate positive outcomes due to situational factors (such as a small community with a small population or lack of organization).

Personally Meaningful Activities

Participants clearly stated that engaging in activities with personal meaning for Self Advocates is an important factor influencing success. Personally meaningful activities were discussed on three levels. First, participants described successful services and supports in terms of the personal and emotional impact they have on individuals. For instance, participants highlighted programs that made their family members “feel really special” or valued, or helped to build self-esteem, by allowing the individual to feel he/she is a contributing member of the community. Second, family members identified meaningful activities as those that meet Self Advocates' personal interests. For many, these programs went beyond life skills training and included things such as general education, music, and art. Participants explained that these meaningful activities can be achieved by asking Self Advocates what they want to do and then supporting them to pursue such activities.

The third focus of this theme was on opportunities for socialization. Specifically, participants identified the importance of being able to socialize and, how, for many Self Advocates, this is the most important aspect of any program. For example, one parent said, “...for my daughter, going to college is as much about education as it is about being with her friends because that’s what the other kids are doing too right?” One Self Advocate 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.” Other participants argued that

socialization is needed to combat the constant isolation that adults with developmental disabilities face. Family members related socialization to isolation in the following ways: *"it's a big thing to fight the isolation"* and *"the socialization is crucial to keep them from being isolated and becoming depressed."*

Day Programs Offer Structure

Many family members discussed the importance of the structure that was available through day programs. For some, family members explained how structure enables enjoyment;

"...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."

Types of Support

Champions Enable Access to Service

Champions were those people or agencies identified by families as playing a significant role in accessing necessary supports/services; agencies, direct care workers, and non-direct care workers were noted as people filling these roles. Family members spoke of the way these individuals "fought" for their child and family. Champions were seen as creative, or able to work creatively, "vocal" individuals who worked to ensure the child and family received the supports needed while

recognizing that the family needed to be in control of the child's life as opposed to the service provider or government.

In addition, champions were charismatic individuals who worked well with people and Self Advocates and acted as the glue holding support groups/networks together. One parent explained the role a champion played in the network of support for 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

Participants identified the value and benefit of having connections. In two cases, participants spoke about having connections with individuals working in the disability services who made them aware of services and helped families to obtain them. The remaining participants spoke about the need to foster connections with people from the community who have similar experiences. Specific benefits discussed with such connections included sharing knowledge and information as well as facilitating community inclusion.

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.

Relationships with Friends

When discussing the most important and beneficial relationships in the lives of Self Advocates, many participants highlighted the significance of friends. Participants were very specific in terms of what constituted friends in these relationships. While family members were grateful for *friendly* relationships between Self Advocates and care aids/workers, they stressed that friendships with peers were the most important. For instance, one participant described how wonderful the relationship between her daughter and her aid was, *"...but when she got in with her peers, she really started to blossom socially."* Another participant expressed that services and programs were not a substitute for peer relationships: *"...your kids grow up with a load of peers and then if they're gonna go into something like pri-care or something like that, they lose all that context. So they need a social life."*

When Self Advocates were asked about the important people in their life, they often described friends. And when asked what makes their friends important, they answered by describing what would make anyone's friends important; *"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 stressed the importance of peer relationships with other people with developmental disabilities as these friendships offer comfort and belonging.

"They want to be together where they feel that they belong. The same as-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. Nobody's kind of looking at them weird because maybe they're not, you know, you can't understand what they're saying or they're not saying the proper thing or their laugh is a different laugh, whatever."

When describing their family members' networks, some participants identified people other than family members or friends who were important in these networks. A couple of participants described church groups, while another participant described neighbours. Yet another participant talked about the Best Buddies program out of the University of British Columbia in which university students buddy up with Self Advocates who are attending the University.

Support for Family Members

Another type of network that was discussed was that of parents who provided support for family members. Often these networks were described as forming from a group of people with similar experiences (i.e. caring for or supporting individuals with disabilities). These networks served a number of functions, such as providing emotional support and even helping to provide care for adults with disabilities. Participants also identified these networks as having the potential to be a great source for disseminating 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.” Another participant also argued that parent networks were responsible for causing much needed change; “It’s always been the parents that have changed things that are bad, it hasn’t been done by the government.”

Individualized Support with Diverse Activities

One family member described the one-on-one buddy her son had who provided some day support once a week. She stated that this individualized support was the most important part of her son's week. Another unique day support identified by a Self Advocate was a vacationing group. This individual was able to go on vacations with other people and support staff and this was an important piece of her life. One Self Advocate attended a summer camp program in years past and her mother stated that this program was a great opportunity for her daughter because there was diversity in activities and the group leaders were dynamic, energized, and had a great attitude.

In addition to receiving individualized support through some day supports, day programs were identified as an avenue for ongoing learning and education; such learning may centre on life skills or world topics (e.g. geography).

Special Olympics

When talking about beneficial activities, many participants mentioned the Special Olympics. The majority of participants spoke very positively about the events. When asked why the Special Olympics were so positive and important, many simply stated that everybody has fun. As one participant explained, *“It doesn’t matter where you are, you just go out to have fun.”* The Olympics were seen as an opportunity for Self Advocates to socialize

and be with their peers. Some also commented that it gave adults an opportunity to be with people other than family; one participant said, *"...the enjoyment of most of that is just the contact with someone else other than family."* As one parent described further, parents were not encouraged to stay.

Others commented that positive feelings about Special Olympics had to do with the fact that it was run strictly through family volunteers and did not cost participants anything. Family members also mentioned that in some communities, there was a shortage of programs and the Special Olympics were really the only activity available to these adults. The Special Olympics were also seen as providing travel opportunities to those who would not normally have such opportunities. For example, one participant described, *"[for] people that never get to go any where, they get to travel, stay in a hotel, eat in the restaurants."*

When discussing the Special Olympics, a few participants recognized that it was a segregated event, but they also seemed to argue that this fact made the event special. One participant said,

"I know a lot of people don't like segregated things but then they'll have to get rid of Para-Olympics, we'll have to get rid of wheel chair basketball, we'll have to get rid of all of these other things 'cause they're no different. But our people cannot seem to be in a group with their peers without it being classed as segregated."

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."

Finally, another participant added that *"there's nothing like being on a winning team in Special Olympics, you know, that really is perfect for him and don't ever take that away in the name of integration because he needs it."*

Despite the segregated nature of Special Olympics, both Self Advocates and family members explained that being part of a team and winning a medal was very important to many adults and as such, this organization should be able to remain.

Post-school Options

In terms of post-school options, one parent discussed how small communities were limited in the integrated settings they can create due to smaller populations. Thus, in some cases, segregated options that operate within the larger community enable these young people to participate in "typical" activities. This was an example of how a segregated support worked to make it possible for adults to live a life they desired.

Respite Important

When describing why respite was important, all family members basically said the same thing – it provided a much needed break for immediate caregivers as well as for the adult with a developmental disability. Some participants described how grateful they were to have respite. For instance, one participant said she would not have made it through the last few years if not for her friends and family providing informal respite.

Outcomes of Non-residential Support

Day Programs Offer Opportunities to Socialize

Day programs provided individuals with the opportunity to socialize and see their friends. One Self Advocate 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."

The social nature of day programs was a feature that most families and Self Advocates identified as extremely positive. 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."

Another parent discussed the importance of a social life and how mainstream schooling did not enable her daughter to have such a life. She explained that since exiting high school, her daughter's social life had vastly improved;

"...now she has a social life and that's just the biggest difference right there, it [the day program] has provided her with that. It's provided her with a stimulating environment. She's treated as an adult, she's party to decision making that affects her and that's just great."

Attending day programs was cited as an avenue for making friendships, particularly when an individual participated in a number of programs or

similar supports. Such opportunities enabled individuals to build friendships with multiple people in a variety of different contexts.

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

Family members were asked to think about the supports and services their family member has received both currently and in the past, in terms of what was ineffective. A summary of participant responses are provided below.

Features of Non-residential Support

Structure Limits Choice

Despite the fact that structure was described as a positive feature of day programs, some other family members explained how the structured routine of day programs means that their family members often had little choice in the activities that comprised their day. Similarly, some individuals saw day programs as a model that was built on the idea that "one size fits all". This was viewed as a poor fit for some.

One Size Fits All

Another example of poor fit provided by some family members related to the nature of their family members' disabilities. Some participants discussed how their family member could not handle large groups of people and would engage in disruptive and, at times, self-destructive behaviour. One family member stated,

"I always find it sad that, at the programs, the day programs I'm talking about, there's very low functioning people and that they're all in there together. And I know that when she

comes, particularly from her Friday program, 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 with. It's really tough, it's really tough."

Heterogeneity of Needs Among persons with Disabilities

When talking about programs and services and what works and does not work, many participants made reference to the vast individual differences that exist among persons with disabilities. Specifically, participants identified the inability to deal with these differences as a major problem and limitation with current services. In particular, participants described several core issues related to the heterogeneity of needs of Self Advocates; these included, lack of individualized programs, loss of important services, inadequate facilities and trained staff, and problems with diagnosing disabilities.

Consistently, participants stated, either directly or indirectly, 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 without forcing people."

In some cases, participants acknowledged 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 specific activities had been cut. In some cases, the changes were due to funding cuts, in others it was due to changes in the majority needs of the group as a whole. Furthermore, one participant argued that it was just easier for the program to treat its clients as a homogenous group. One parent stated, "*[the program] often defaults to what the staff would like to do and what is the easiest for everyone.*" In this particular example, life skills components were replaced with more recreational activities.

Other participants reported difficulties in finding adequately trained staff to deal with the unique aspects of their family members' disabilities. In most cases, this was the issue when discussing physical disabilities. These participants also reported difficulties with inadequately equipped facilities to meet the needs related to physical disabilities. Finally, family members noted that staff and programs were used to dealing with low functioning individuals and they did not know how to work with and meet the needs of higher functioning individuals. It is important to note that the continuum of functionality underlined the majority of the discussion regarding the diversity of needs.

The last core issue that was identified related to problems with labelling or diagnosing individuals. Participants reported their family members did not receive accurate diagnoses due to the unique nature of their disabilities. At times, this resulted in inabilities or difficulties in obtaining services. Some family members also noted that due to their high functioning, their family

members' appearance contradicted the perception of persons with disabilities, which ultimately affected how they were received in both communities.

Too Many Choices

Some family members discussed the array of associations and societies that existed within a region and the challenge this posed when making decisions about the best option for your child. 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

Access to programs was also a challenge for some people living in different parts 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 town³]."

Dissolution of Networks

In talking about networks, several family members indicated that they do not last forever. These participants pointed out that such networks were often established when Self Advocates were young, but as the Self Advocate and everyone around him/her gets older, the network began to dissolve. One participant said, *"...it might go five years and then that*

³ Quote revised to protect the anonymity of participants.

family network dissolves." Participants indicated that the problem with networks was that as people get older (e.g., siblings) they began living their own lives and moved on. It was not that they no longer wanted to include their family member, but they simply had too many other things going on (such as a family and children of their own).

Similarly, some participants talked about how neighbours were once part of their network, but with time, they all moved away, and it could 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."* Unfortunately, the consequences could be very negative for Self Advocates who are left behind. One participant stressed, *"...it's hard to keep putting your child in that situation and knowing that their heart is going to be broken because it just never works out."*

Most of the focus was on the problem of networks dissolving because family was moving away as they got older. For many Self Advocates, moving to a new community to remain connected to the individuals in their networks was not feasible because of attachments to environment and community. One participant also added that it was not fair to assume or require that siblings take over care of family members because elderly parents were no longer able to. This was a clear message shared by many parents.

Service Provider Training, Absence or Lack Thereof

Many participants discussed experiences and concerns about care worker training or lack thereof. As one participant clearly stated,

"...what about training? You got people who have absolutely no training to work with our most vulnerable 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."

This statement highlights a number of core issues family members identified in the discussion about training.

First, participants acknowledged there are courses available through various post-secondary institutions; however, not all agencies required their employees to have formal education or training. Several participants said they only wanted to hire trained or experienced workers to provide services such as respite, but it was extremely difficult to find such workers. As one participant argued, training and experience was a must; *"...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 disorder, has a neurological disorder. Just love won't do it."*

One caveat raised by participants in regards to training, was that simply taking courses did not automatically mean a person was qualified to support an adult with a developmental disability. For instance one participant said, *"...they take this course at the college right but that doesn't necessarily qualify them to work with all people and I think that could be a challenging."* Another participant described the false sense of knowledge that can come with completing courses:

"...they thought they knew it all because I mean I've heard them talk, 'well what does she know? She doesn't have any courses,' well, look at them, their courses were three months long, excuse me I have thirty-four years experience."

The lack of training was often attributed to shortages in staff and high turnover rates, while others thought it may have to do with a lack of funding to train staff. But whatever the reason may be for the lack of training there were serious consequences. Some participants alluded to receiving inconsistent care, while others reported Self Advocates being injured. 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.”*

Types of Support

Special Olympics

It is important to note that there were a couple of negative comments about Special Olympics. For instance, one participant described a letter she received from organizers asking her not to bring her daughter anymore. The reason for this request was because her daughter was no longer interested in participating in the activities, but rather just wanted to socialize. This was the case, even though her daughter attended the “fun meet” which is the non-competitive stream of Olympics. Finally, one participant argued that the Special Olympics were only plausible for the higher functioning minority as opposed to the “more disabled” majority. In addition, she felt the event required too much time from caretakers.

Concerns about Respite

When talking about respite⁴, participants voiced several concerns regarding the service. In particular, most participants raised concerns concerning the accessibility of respite. A few participants clearly stated that there simply was not enough respite services available, especially for families taking care of their family member at home. Some also stated that even when there were some respite services available, these were often unreliable services. As one participant 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 participants stated it was difficult to find respite workers for specific times, such as on weekends. Another participant explained that funding for respite was not the problem, but rather locating people to provide respite care was the challenging issue. In fact, many participants spoke of the difficulties and frustrations associated with having to arrange for respite themselves. They argued that established respite workers and facilities were needed.

Related to this point was also a concern mentioned about monitoring of respite care and ensuring that the workers and services are providing appropriate and specialized care. For instance, one participant recalled inquiring about services and was told,

"...we've got somebody ten miles down the road there. And my first question is, 'do they know anything about seizures?'"

⁴ Respite is included in the "Non-residential Supports" category because for many such a support is viewed as a short term and even day program supplement. However, in some cases, respite was understood and accessed as a complement to the current residential arrangement.

She had to ask [the respite provider if (s)he did in fact know about seizures] and that's not very reassuring."

Family members also stressed the notion that respite care was provided as a crises management tool. That is, in situations of crises, such as caretaker illness and other emergencies, respite was available. However, in terms of crises prevention, such as caretakers needing a break from their family member, the services were not available. One participant also argued that he was always required to justify why respite was needed, *"Well after forty-three years – why would we want it? We're getting old. It would be nice to have a weekend where you didn't have to worry about them being there. We'd like to go for dinner."*

Outcomes of Non-residential Support

Factors that Impede Inclusion/Integration

In terms of work settings, family members described challenging situations in which their child did not feel included in social activities or organizational features that got in the way of a positive integrated work experience. Feeling excluded in various settings was described as difficult for many people and some parents believed that the community needs to make the effort to welcome people. With regards to organizational features of work as a barrier to integration, one parent stated,

"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 Planning

As a result of ineffective supports, a subsequent theme was identified. Many participants articulated the experience that ineffective supports led to "panic planning" when wanting to secure, obtain appropriate supports and services for their loved one. Planning for activities and necessary support was a part of the lives of most families with a member with a developmental disability. Some planning was panic planning which could happen when families were desperate for services or when crisis situations arose. In such situations when a support is offered or made available, family members were able to enter a state of relief; however, over time, this state of initial relief could be replaced by wonderings - is there something out there that would be a better fit? Due to time constraints and other life issues, a thorough exploration at the outset, or at any point, was not always realistic which could translate into challenges and poor person-environment fit. To address these challenges, some family members requested a list of information on all available supports and services within the region and community.

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 non-residential

supports, barriers get in the way of accessing supports and services in the community that both meet the needs of the individual and foster connections within the community.

Beliefs about Ability

Some family members expressed frustration about the limitations to their family member's autonomy and choice because of their disability.

"...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, whatever, whatever, so you know. 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."

Trust was identified as a challenge for some family members. To elaborate, having an adult child out in the community, participating in activities, taking public transit, interacting with support people required parents to trust the workers and the environment; for some individuals, such trust was difficult. Trust is connected to beliefs about ability and can either limit or enhance independence. If parents are unable to trust that it will work out (whether "it" is taking the bus, having a bank card) then such beliefs can act as a barrier to independence.

Lack of Funding and Resources

This theme crossed topic areas and thus exists in many sections throughout this report. For a full description of this theme, please refer to page 47 of this report.

Lack of Continuity

This theme crossed topic areas and thus exists in many sections throughout this report. For a full description of this theme, please refer to page 47 of this report.

Fear Based Decision Making

Some families talked about decisions that were made based on fear. For example, some families made decisions to remain in a current situation or with a current support for fear that if they complained or asked for something different, the current services might be threatened. Another family explained that they didn't want to ask for help with their child because they feared he would be removed from the family home - this was something they had seen happen to another family.

Barriers to Inclusion

Other specific barriers to inclusion included: mobility challenges (wheelchair accessible), lack of effort on the part of the general community to include individuals, and beliefs about the opportunities that exist (or the lack of opportunities).

Another organizational barrier existed within the post-secondary education system. Classes at university and college were often lengthy which could be challenging for some people to sit through. Thus, for some families, inclusive post-secondary options were not viable opportunities for their young person.

Belonging

Family members spoke both directly and indirectly about issues of belonging. Specifically wondering, where is the place for my family member to participate and share his/her gifts? Where is the place where my family member can feel comfortable, hopeful for their future, listened to and accepted? Some family members discussed that relationships with other individuals with disabilities are comfortable and a good fit for their family member. In these friendships, individuals were better able to feel more free to be themselves and have a good time.

"They want to be together where they feel they belong. 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, so you know, these are their friends. They can talk to them. They can laugh. Nobody's looking at them weird."

Unrealistic Goals of Social Networks

Natural networks were mostly credited as being positive and peer groups were seen as a place where individuals could share their gifts and feel a sense of belonging. However, some family members felt the *mandate* of forming social networks was unrealistic. Some thought the requirement of networking was intrusive; *"...we don't know or feel comfortable with that,*

it's an intrusion. We don't know how to do it and it feels like an intrusion." Many of these individuals felt it was too much of a burden to ask other people to step in and help out with their family member. And this is not because they were thought of as not liking these adults, but rather because they had their own commitments to tend to (such as families or children of their own).

Some participants, however, did indicate that if people were not professionals working in the area of disabilities, they were unlikely to want to be involved. There was some consensus that networks cannot be used as a form of forced integration. For example, one participant said,

"...it's that common interest or that common goal. You might make it if you're in a club together but a lot of people just aren't in the same clubs. They're in Special Olympics or they have their own drama or they have things that are for them and so the community is often not involved."

D. Gaps

This category refers to those aspects of non-residential supports that were missing or those issues that were not addressed according to family members. Self Advocates were asked to discuss what they would like to do more of (e.g. travel, spend time with friends).

Lack of day programs was identified as a challenge and a worry for some family members. Another concern about day programs was that they were essentially "adult day care". Family members cited a lack of individualized options within day programs and a lack of activities in general.

The most commonly desired activities were different types of sports, different means of socializing (e.g. a dance, "guys' night"), travel, and opportunities to participate in meaningful activities, such as volunteering and work. Overall, individuals expressed a desire to do more activities, whatever they might be. The most commonly cited reasons for not participating in activities were not having enough money, the programs no longer existed, or a lack of support workers to engage the Self Advocate.

Respite care⁵ was important for many family members; however, the lack of appropriate and available respite workers/situations was prevalent. Participants clearly argued that respite was a difficult service to access. There were a number of participants who stated directly that there was inadequate funding for respite services. For instance, one family member described an at home program in which the respite worker comes to your home. The family had access to such a program when their daughter was younger, but the service was not available to adults. A number of other participants described the problems or difficulties they encountered when having to take their family away from the home to access respite services. For example, one parent discussed how her daughter's schedule and routine was disrupted when accessing respite outside of the family home which created a stressful situation for both her daughter and the rest of the family. Participants also described how respite was only available in emergency situations. For example, one participant discussed how respite was not available for general everyday situations, and was told *"respite is not an entitlement. You have to fill out a form and you have to*

⁵ Respite is included in the "Non-residential Supports" category because for many such a support is viewed as a short term and even day program supplement. However, in some cases, respite was understood and accessed as a complement to the current residential arrangement.

say what the emergency is and why you want it. What about just general living?"

Many family members felt they were not asking for a lot by requesting respite. What they were asking for was some relief here and there. As one participant said, *"the weekend respite again for families, that's where the burn out starts. You don't get a night off, you don't get a weekend off."* Another parent further stressed the desire for short term respite; she explained,

"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."

This quote also highlights how respite provided a much needed break for the Self Advocate as well as the family member. Similarly, one participant said, *"a) it's respite for me and b) social interaction for him"*, while another said, *"respite helps her social growth by spending time outside family especially with young people. [It also] gives her parents a break."* Other participants stressed how respite provided an opportunity for caregivers to have time to themselves and maintain a social life. For example, one participant said looking after a Self Advocate *"curtails your life so much that you lose your social life, you lose your independence,"* while another participant explained *"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 Self Advocates were invited to think about and discuss their hopes, desires, and plans for the future with regard to the way Self Advocates will live their lives.

Parents consistently recognized the importance for their adult child to have his/her own life. In some cases, parents compared the desire for their adult child to have an independent life to the natural processes by which siblings or other adults their age begin to lead independent lives. One parent stated,

"...[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."

Furthermore, parents recognized that their adult children need to have their own relationships without having parents "hovering" around.

According to parents, it was also 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."*

Similarly, parents discussed the normative change in relationship as a child becomes an adult and explained that it was important that these changes in relationships happened for their adult child with a disability. For example, having one's own place was seen both as a means to independence and a signifier of independence. One parent stated, *"...he's now in semi independent living situation. We're getting on in years and it was essential for us that the cord was broken and that he has to learn to survive himself in the community with assistance."*

Independence was also discussed in the context of highlighting opportunities for Self Advocates to engage in activities that were of interest to them, rather than those prescribed by an agency or organization. An aspect of this topic also conveyed flexibility which would allow Self Advocates to develop their own schedules rather than conforming to those already existing. A number of Self Advocates and family members also discussed their desire for more employment opportunities. These were seen as being established through the greater participation of local business and the availability of resources for Self Advocates to establish their own business. Through more opportunities it was believed that Self Advocates could gain access to employment that suited their own interests and would be more meaningful. Finally, family members expressed interest in Self Advocates being able to build and expand their social networks, whether it was through services, employment, or leisure opportunities. One family member clarified that this may be facilitated through a greater separation of services, which would allow the individual to interact with different people more often.

For some Self Advocates, independence meant not relying on your family all of the time. For many, references to transportation were key in enabling their independence; however, it was discussed as an issue that was challenging due to lack of transportation options. Some Self Advocates made it very clear that they were capable of doing the things they wanted to do ("I can do it on my own") and asking for help when they need it. When talking about her desired living arrangements with her boyfriend, one young woman stated,

"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."

Another Self Advocate discussed how she enjoyed being an advocate both for herself and for others. She stated,

"...all the different opinions and everybody's different views, you try to put it together to see how you can make something work, you know, and that makes me feel really good that I can make it work for me and for [my friend] and for everybody else."

In order to learn about being an advocate, this participant took books out of the library and asked a lot of questions. Eventually she would like to create a work opportunity for herself in which she would accompany people to meetings with government and workers to act as a support.

"I'm quite excited about doing it because I'm not doing it just for me but I'm doing it because I want to do it for somebody else too. It makes me feel good that I can do something for someone else."

One Self Advocate explained that if she had more to do, she would not feel as lonely, however, opportunities are limited. She stated,

"...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."

In terms of desirable features of day programs, one family member discussed consistent staffing, the opportunity to socialize and the existence of a place for her son to go should he need some down time when he was having trouble coping.

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. This point was illustrated by references to both activities of personal interest and travel. Finally, there also appeared to be a focus on employment in general and the ability to earn more money specifically. Ultimately, the focus on finances conveyed a particular link to independence.

Future Aspirations of Self Advocates

Self Advocates generally had several visions for the future. First, a few indicated a desire to start their own business or acquire other means of employment. Many Self Advocates described wanting to become more independent, which would allow them to have more control over their lives so they could do the things they wanted, such as having friends over and "retiring."

Recognizing Heterogeneity of Needs

During the discussion about programs and supports that did not work, family member participants also identified solutions which focused on assessing the individual needs of each client. For example, one participant said *"...you have to just find what that person likes or enjoys and it's a matter of trying and if it doesn't work, hey, okay, it didn't work but we tried that."* While another participant suggested, *"...you have to also look at what level of functioning they fit into. Not that they have to be categorized but there are some that get more out of some things than other things."* Finally, it should be noted that some participants indicated that the diversity of disabilities also leads to diversity in the degree to which services are received and needed; *"it's noteworthy to know that less than ten percent are creating 90 percent of the demands. The others are quite happy as to what they are getting."*

Seeking a Different Kind of Government Support

One parent stated she was interested in a different kind of government support - this kind of support did not revolve around money, instead she explained, *"I'm not really interested in their money, all I want is their*

support. Can you lend us a strategic planner? Can you provide some space for me?"

Services for Seniors

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

Janicki (1999) articulated that one of the challenges facing older adults with developmental disabilities is the problem "...inherent in growing older in a system that has not accommodated older people previously" (p. 291). Aging and disability service providers have reported that their services were inadequate to meet the needs of the population of aging adults with developmental disabilities (Sparks et al., 2000). In order to increase service capacity in this area, service providers identified key recommendations centring on training, identifying strategies to provide

counselling support to this aging population, and enhancing service provider collaboration.

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

A. What is working? What is effective?

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

Autonomy and Self-determination

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

Opportunities to Deal with Loss or Grief

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

Proactive Planning

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

should she be unable to communicate those wishes in the future. This Self Advocate also reported wanting some help to formally outline this list of preferences down on paper.

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

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

Death, Loss and Associated Changes

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

C. Barriers

Barriers are those things that get in the way of successful and effective support that enables an adult to live the life he or she desires to live. Barriers may be structural, such as lack of funding or waitlists, interpersonal, such as relationships with others or lack thereof, or attitudinal, such as beliefs about abilities or available supports. Specific to services for seniors,

barriers get in the way of continued support that maintains connections to the community and contributes to overall quality of life.

Nature of Networks - Dissolution

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

D. Gaps

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

Respite Needed as Health Conditions Change

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

Respite as a Transition Tool

The need for respite was identified in some focus groups with family members. Respite was discussed as a support that could assist in the healthy and necessary separation of parents and adult children. For example, one parent stated, *"He's now in a semi-independent living situation. We're getting on in years and it was essential for us that the cord was broken and that he has to learn to survive himself in the community with assistance."*

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

"...I think that by going to respite and breaking that tie to get her to realize that she can exist without mum, without dad, that she can continue to live a good life and I think respite would give her that confidence that gee, I can sleep in another bed besides my own and still be comfortable."

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

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

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

E. Desires/Aspirations

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

Concern and Worry about the Future - Lack of Peace

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

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

Another parent stated,

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

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

F. Services for Seniors Specific Themes

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

Later life planning

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

Proactive Planning

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

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

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

"I'm always buying ahead because I think I might not be here. Like I bought him a new ski suit at the January sales because I thought he'll need one within two or three years and I might not be here to buy it for him and I'm always thinking that way; I have to stock pile for him."

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

Resources Accessed

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

CLBC

This section of the report contains themes and information based on the experiences and opinions of participants about Community Living BC and the government in general. Participants were not asked questions about CLBC, however, discussions about what is working, what is not working, and hopes for the future were often connected to CLBC as the support system.

The organization of this section differs from the other sections in that it includes the following subheadings:

- A. What are people uncertain about?

- B. What is not working?
- C. Barriers
- D. What do people hope to see?

Much of the information shared by participants about this topic area was neutral or negative. It is important to be aware of the context in considering these findings; this research was conducted one year after CLBC assumed responsibility for adult Community Living services.

A. What are people uncertain about?

In some situations, participants discussed their uncertainty with regard to what CLBC was going to look like and how it would support individuals and families. This was different from those thoughts and experiences participants shared about aspects that are not working, as these dimensions centred on wonderings.

Confusion

Some families were wondering "what will services look like?" as CLBC assumed responsibility for adult Community Living services. One family received good and creative services through a service provider previously, and this family was uncertain about what the formation of CLBC would mean with regard to continuing to receive such supports in such a way.

Some family members asked - Where would the "centre" be? There was concern that the centre of CLBC services would be in Vancouver; it was expressed that such a location would not meet the needs of people living outside of this region. One family member requested more of a presence

on Vancouver Island. There were also some questions about the structure of CLBC – *"...I'm not sure, from what I understand, the structure of CLBC came from top down. I don't know how much the actual social workers were involved to create that structure but I suspect they had very little input."* Not only were some families confused, but some also believed that CLBC was confused about their role and vision.

Concern

Many family members reported that they were "concerned" about the plans for and the reality of CLBC. Specifically, there was some concern noted by many with regard to the trend toward accreditation. Family members made it clear that, in their opinion, accreditation did not take the place of monitoring. Many families held the belief that accountability and responsibility were key and felt that CLBC was not taking any responsibility in these dimensions; this was an area of concern for many family members. In addition, some family members were concerned that CLBC was not heading in the right direction. For example, one participant believed that the lack of a consistent social worker/facilitator working with a Self Advocate would act as a huge barrier to future planning.

For some family members concern existed in the form of fear. One family member stated, *"...I really fear for this new system because I think that people put way too much power in the hands of the service provider. There's no-one at all to even track what's happened."*

Disbelief and Negativity

Some family members did not believe that the "vision" of CLBC would become a reality; there were overall tones of disbelief and negativity in the discussion. For example, one family member stated, *"It's a nice dream but it isn't going to happen."* Similarly, another participant remarked, *"...nothing is going to change and I don't have confidence that it's going to change anyway."* Some reasons expressed by participants for this disbelief/negativity included:

- Creating an informal network of support was not feasible for all – some people did not have any close family and/or family dynamics changed over time with different priorities;
- The same people were in the same positions of financial power;
- Cut backs to workers and the increased geographical distances they must cover.

Similarly, some family members believe that CLBC's vision was "unrealistic" – one family member noted *"...some of it. we've been there, done that, and it didn't work the first time so why is it going to work now?"*

Some family members believed that change was not necessarily a good thing, particularly if the change was not going to demonstrate almost immediate results. One family member explained that the supports in place for Self Advocates needed to work right away, it could not be a future vision;

"...for these kids, it has to be there today, it has to work today. It can't be somewhere down the road and maybe it's going to be there, maybe it's going to work, because while there is indecision, well decisions can't be made. Nobody is going to be able to progress forward or advance."

A message from family member participants was that services that do not work today act as a barrier to planning for the present and future.

Follow Through

A theme present in many transcripts was the idea of follow-through. Family members and "consumers" had heard the words and the promises from CLBC and they wanted to see some follow-through and results.

B. What is not working?

Family members discussed those aspects of CLBC and government they believed were not working. A summary of participant responses are provided below.

Communication

Families were frustrated with the barriers to clear communication many had experienced in their interactions with CLBC and staff. For example, one family member noted that getting in touch with CLBC was a challenge from the initial point of calling in and having to choose from a complicated list of automated options to completing necessary forms. In addition, some family members identified poor communication across service providers, with family, and within CLBC as a problem. The issue of secrecy regarding available support options and the lack of truthfulness were also reported complaints. Finally, one family member was confused about who the government listens to – she said, "*...it was a matter of trying to get them to pay attention. They don't listen to parents and they don't listen to people with disabilities.*"

Accountability

Accountability, and the lack thereof, was cited by many family members as a complaint with CLBC. Similarly, family member participants asserted that self-evaluation by service providers does not create safe situations for their adult family members. Safety accompanied the issue of accountability for many family members; safety in terms of those providing direct care and safety in terms of the absence of a designated person to follow up with a Self Advocate and family (previously social workers). The unrealistic workloads for facilitators and the general absence or lack of social workers was also identified as "dangerous".

Follow Up

Some family members reported feeling disappointed with the reality of CLBC after the hearing the vision that was initially presented. Some family members wanted to see, and were waiting to see the follow-through on, the vision/plans/talk/promises. One family member wanted CLBC to come back and check in with families to get their feedback since the introduction of CLBC to ask families, 'Are things better? How are things going?'

Limited Knowledge of Disability

Some family members noted that support people and others involved in the system demonstrated a limited knowledge of disability and the range of disabilities that exist.

Back to Basics

One family member discussed, that in the midst of all this change, it was important to remember the reason why such a system was in place - to support those people who require assistance.

"...I know they're trying to make things better but sometimes you lose track of some basic things. And I think we really need, I generally believe that the world needs to get back to some very, very basics. We've gone way beyond including services. We're not looking at the basics anymore and that would be the clients, the people, the adults."

Systemic Factors Impede Advocacy

There was some discussion about how systemic factors got in the way of agencies advocating on behalf of the people they support.

"Community Living BC is funded by Government, [community agency] is funded by Government, it's really hard for them to stand up and say 'this is bullshit' and I understand that and the community, unless you are touched in some way you don't need to know and you don't care. You got your own stuff to look after. So isn't there some way we can have an independent living agency or something that says, 'we're just

here for the people that need us and our funding is not contingent upon anything.'?"

Similarly, one parent stated that, although she believed CLBC was heading in a positive direction, people and families without strong advocacy skills would get lost.

"I honestly see it as only a good thing if they have a strong advocate in their corner. If they don't, I see them getting lost in the shuffle. 'Cause like I'm here standing going - I'm not going away. I'm gonna help my daughter, right. But I can see how people who aren't strong enough to weather this storm, they're gonna get lost. They really are."

The complaint process continued to be frustrating for family members. One parent described her experience with the complaint process at CLBC; she said,

"I said, 'well what can I do, what are my like, what's my options here? You've turned me down flat. I'm at brick wall right now, what do I do?' And she said, 'well you can go to our website and get a complaint form and fill it out.' That's the answer? Fill out a complaint form? And I was just, I was disgusted."

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 CLBC, barriers are those things that get in the way of accessing clear and consistent information and support for the individual and his/her family.

Philosophy

During the course of the interviews a number of participants addressed several issues on a philosophical level. That is, they spoke to matters on a more global and belief based level. Many participants often presented philosophies as in contradiction with one another. Three main types of philosophies were discussed: administrative, developmental, and care related. Administrative philosophies related to the governance of disability services and resources. Developmental philosophies related to perspectives that saw age or another milestone as indicative of a change in ability (e.g. turning 19 signifies independence). Care related philosophies related to approaches to and perspectives on support and care based on training and/or experience and/or role in the adult's life (e.g. parent, social worker, etc).

One participant commented specifically on the potential for fairness and equity in the province when each city/region may contain care workers operating from different care philosophies. Another participant expressed concern about the current state of "limbo" that people have been placed in by recent policy changes. Rather than make necessary amendments to the previous system, the participant felt it had simply

been abolished, and people were left to function by themselves while the new rules and regulations were being created.

D. What do people hope to see?

Despite many negative experiences and general negative tone with regards to CLBC, some family members expressed hope for the system. The hope for CLBC was presented in direct contrast to some perspectives on the current experience with the new system. Generally speaking, the current experience at the time was described as a "mess".

General Hope for New System

Some participants' perspectives on CLBC included positive and hopeful tones. One family member expressed hope for the system in general and she recognized that it would take time for people to accept the new system. Another family member stated he was "excited" about CLBC and thus far, he reported positive interactions with the organization; this was in direct comparison to a negative experience with MCFD and previous approaches to supporting adults with developmental disabilities.

Accountability and Monitoring

There was hope that some aspects of CLBC would change, particularly in the area of service provider self-evaluation. Many family members believed such evaluation was not sufficient and does not make anyone accountable.

Improved Communication

The hope for improved communication both within CLBC and with family members and service providers was noted by many family members. Specifically, one family member discussed how she hoped CLBC would implement and listen to the Community Advisory Boards as planned. Another family member wanted CLBC to provide advance notice of changes to programs and supports.

Some participants also engaged in a conversation about their desire for CLBC to participate in outreach efforts. These family members wanted CLBC to make efforts to reach beyond the 10% of families that were well connected and participative to the 90% of families that were unaware of CLBC and associated jargon.

Finally, when CLBC conducted community meetings, there was the desire for accessible information sharing to take place on a practical level. To clarify, when presenting at meetings to the public, one parent wanted CLBC to make sure microphones were present so that the information being shared could be heard by all in attendance. One family member reported attending two meetings about CLBC and, at both, she was unable to hear a word that was being said.

Follow Through

Many family members hoped that CLBC would follow-through on their promises. *"I really would like to see CLBC going to the place or getting to the place that they were telling us about a year ago."* Some examples of these promises family members' identified included:

- They stay responsive to people;

- They "...support people according to their needs and goals and not the opposite - that the individuals have to do what the agency can only provide."

Individually Tailored Supports

Some family members hoped that CLBC would ensure that supports available to people would be individually tailored to meet the unique and distinct needs of these adults; this includes person-centred programming versus agency/service centred programming.

Another component of individually tailored supports had to do with eligibility criteria. One parent stated,

"...I would like the Government to understand that their criteria for what they consider CLBC to be able to cover is too narrow. My daughter's off by two percentage for IQ to be covered. That's not fair. Not fair at all."

Thus, recognizing individual differences as the system works to support individuals could help to provide individuals with access to the type of support they required.

Recognition of Gaps in Service

In speaking with families and individuals, the following specific service gaps were identified:

- The need for counsellors;
- The need for local options;
- The need for someone who was knowledgeable to "bounce" ideas off of.

General Points

This section of the report includes themes and information that are general in nature and do not specifically apply to one of the five topic areas (i.e. transitioning young adults, residential supports, non-residential supports, services for seniors, and CLBC). Although not specific to a particular topic area, the information summarized in this section has important implications for the overall community of adult Community Living and the way in which adults and their families are supported.

Advocacy

Generally, advocacy was described by families as fighting, lobbying, and being very vocal which could result in being perceived as an irritating individual; however, family members recognized that what was important was ensuring their family member was cared for and received the necessary support. At the same time, some family members identified the different ways to go about advocacy. One family member stated that sometimes people (i.e. support workers) need to *"suffer until you get what you need"*. Another parent explained that advocating in a diplomatic manner can lead to better results than being a complainer;

"...it really does make a huge difference how you do it. If you go in there with guns like I say, never use a canon when a peashooter will do. I mean, it's so true and if you're rude and nasty, then that's your reputation; they just roll their eyes at you and you go on and you're negative about stuff all the time, they'll sit there and listen to you and then they turn around and walk away. Diplomacy is huge. I mean you can still get what you want and at some point you might get angry but it really helps to work with people."

Another dimension of advocacy described by participants was that advocacy in community living occurs in a distinctive historical context resulting in an associated pattern. Many family members discussed how they had to fight for inclusion for many years for their child and how the need to advocate provided them with experiences that fostered the development of strong advocacy skills. Some family members believed that "new" or "young" families did not possess the necessary advocacy skills because they did not have to fight for inclusion. Some family member participants believed that when these new parents' children reached the time of transition, they would be confronted with difficulties in the system but would lack the advocacy skills to address the challenges. Many parents believed that these new families need to be taught some advocacy skills so they could successfully navigate the system and receive appropriate supports for their child. One parent discussed her experience receiving some advocacy training which she identified as one of the most valuable experiences she had. Another family member had been an advocate for a very long time and had many families and individuals come to her for support and guidance. She was worried about what would happen when she retired from this role. Other individuals believed that all people should have the same access to supports despite their ability, or inability, to advocate.

Advocacy Leads to Burn Out

Accompanying this theme of the history of advocacy is the theme of family member burn out. Many families discussed how they were tired and burnt out from years of advocating for their family member.

"...as older parents are getting burnt out, when you start from the time your baby is two weeks old and you start fighting to get what's necessary, fighting for life, fighting for education, fighting for some kind of program that will enhance his well-being and make him more agreeable to the family and then ultimately, when you're almost seventy you're still fighting for some kind of safety and cohesion in the community, by the time families are old, by the time they're overburdened, there's only so much care giving that they can squeeze out."

In addition, family members identified the time consuming nature of advocacy as a factor that both led to burn out and impeded active involvement from families. Some families were too busy to have the time to engage in advocacy which meant that there were a few families who were doing most of the work in this area.

There was consensus among family member participants that changes to the way individuals with developmental disabilities were supported have come about as a result of parents' initiative and efforts. Family members consistently stated that parents were the individuals behind the change; *"...it's always been the parents that have changed things that are bad, it hasn't been done by the government."* Another family member echoed this sentiment but believed that some politicians had good intentions and it was the structure that impeded change.

"I don't think the government listens anymore. He'll talk to you really nice and he'll make you feel really nice and pat you on the head and say, 'I'm so glad you shared your story with me and I'm gonna carry it on.' But again they, I think politicians, I think politics have changed. I think politicians now really believe that they can make a difference, really believe that

so they want to listen to you and they're very empathetic. But the structure has got so tight now that no matter how much they want change, I don't think change can happen to any great degree. The only change that happened, and has happened over the last ten years is how we can get it cheaper."

Some parents and siblings discussed how their family member was lucky to have someone in their family who was a strong and capable advocate. As a result of these strengths, some individuals had been able to access all of the necessary and beneficial supports. One sibling stated,

"...my sisters are blessed that I can speak on behalf of them but there's a lot of individuals that don't even have families that can speak for them and they're in worse shape than my sisters because, the family has been standing up for them and saying 'no, this is not working and that's not possible and that's not good.' There are many in the community right now that are just living not in very good condition and my heart goes out to them right now."

Independence is Important

Independence was discussed by family members and Self Advocates in terms of one's general life as well as specific to living arrangements, work, day activities, and relationships/social interactions. Within current life situations (day programs, living situation), family members stressed the importance of having support workers listen to the communication of the Self Advocates. Some parents also talked about the different ways their adult child communicated his/her preferences and the need to really

listen to these messages. Giving Self Advocates choice in their lives and the services they accessed was described as contributing to overall well-being.

"I'm trying to encourage her to do more for herself and she seems to really thrive and really enjoy being given tasks to do that are for herself which help me out. She likes the opportunities to be more independent."

A. What is working? What is effective?

Family members were asked to reflect on their experience of those supports and services their family and/or family member has received either currently or in the past in terms of what was helpful or what worked well. Similarly, Self Advocates were asked to talk about those aspects of their lives that they enjoyed, looked forward to or were important to them. A summary of participants responses are provided below.

Initiative

Initiative refers to instances in which family members, Self Advocates, or agencies and their staff took steps to change the current situation either on a personal level or to a broader group (i.e. all transitioning young adults in a community). Most instances of initiative come from parents taking action due to a recognition of gaps in support and service. One family member stated, *"...we're going to seek out our own programs. If they're not there, then we're gonna to develop our own programs. And if the work isn't there, we'll develop our own work."* This action was in the

form of research on various topics and creating opportunities in the following areas: employment (individualized), post-secondary education, and volunteering.

Many work opportunities family members strove to create were entrepreneurial in nature involving their family member and one support staff. Some examples of family member initiative involved a process beginning with an idea for a particular support from which parents worked out the details of the idea and then got other people involved in making the idea a reality. The "people" family members turned to included ministers, MLAs, support workers, and other family members.

Some parents discussed the challenge of unsustainable funding in creating supports for their family member. One parent explained that the group he was involved with had set themselves up as a non-profit organization so they could fundraise and be less reliant on the availability of government funding. Other family members described how the process of realizing an individualized support often involved pushing past "no"; this was often the response given when family members attempted to create something new for their family member. However, those attempts that were successful the individual or organization was always able to push past "no" (i.e. avoid giving up) and realize their vision.

Independence

In discussing the factors that influenced success, many participants made reference to the notion of independence; in particular, independence was discussed in four contexts. First, participants described independence as the ability for persons with disabilities to establish a

social life beyond their immediate family and care providers. In this respect, participants did not attribute independence to the ability to look after one's self and be self sufficient, but rather independence was viewed as an opportunity to develop social networks and friends. One participant spoke positively of their family member's establishment of a private life.

Independence was also discussed in terms of not having to rely on others for complete support. For instance, one participant discussed how access to public transportation increased her independence because she did not have to rely on family members to drive her to the theatre when she wanted to go see a movie.

Thirdly, independence was seen as the ability to have choices and make personal decisions. Both family members and self advocates described this as a fundamental goal and key aspect in the lives of persons with disabilities. This was also related to notions of maturity and adulthood. As one participant said, *"it's worked so much better than school because they treat him like an adult and they give him choices which is what he's needed all of his life."* Another family member said his son *"feels as if sometimes he is treated as a child and not allowed to make his own decisions."* In these contexts, family members argued that independence was critical in the establishment of self-esteem and confidence and empowered persons with disabilities to be part of the community.

Finally, a number of participants also described independence in terms of stability. When persons with disabilities were able to establish independence through their decision making, as well as being able to live in their apartments, family members felt they gained important stability in

their lives. For instance, when faced with changes in staff, already established independence would remain constant and thus, future transitions would have less of an impact. This aspect was certainly comforting to some parents who felt that when they died, their children would be better able to cope.

Advocating can get you what you need

This category explores the ways in which family members, Self Advocates and support workers engaged in advocacy or acted as advocates. Participants used the following language in describing approaches to advocacy:

- *"rattling cages"*
- *"begging and begging and begging"*
- *"yell"*
- *"stamp your feet"*
- *"be obnoxious"*
- *"cooperative"*
- *"let them suffer"*
- *"you have to be super together and super articulate to actually push off the bogey man"*
- *"threaten violence".*

One family member stated, *"...nothing ever happens, nobody ever offers it, you gotta yell and stamp your feet and be obnoxious um, till they just don't want to see you anymore."* Similarly, other family members

mentioned the need to make threats in order to see any action. Contrastingly, another perspective on ways to advocate came from another family member, she stated,

"...it really does make a huge difference how you can do it. If you go in there with guns like I say, never use a canon when a peashooter will do. I mean it's so true and if you're rude and nasty, then that's your reputation. Diplomacy is huge, I mean you can still get what you want."

Many family members recognized that the way one approaches speaking up about the needs of their child and family made a difference. There was discussion about a balanced approach that involved being both assertive but kind and polite at the same time.

Taking issues or concerns to the person at a higher level of influence/responsibility was another strategy identified. One family member stated that pulling together a small group (5-15 people) who shared a perspective on an issue could create a successful outcome. In addition, others discussed how outlining a clear plan of action with facts and figures could build your case for a particular issue and again facilitate a successful result.

Family members identified a negative approach to advocacy that we have termed "deficit marketing"⁶ which means to market using negative descriptors. Here is one family member's rationale for using this approach:

"I went to the Ministry to get her under Ministry care and I had to then go into all the worst part of who she was in order to do that. I had to, I used to joke and say I had to, you know,

⁶ The term "deficit marketing" comes from Erin Riehle, Director of Project SEARCH, Division of Disability Services. She introduced the term in the context of the business world and employment for people with disabilities.

talk about, I had to wipe her mouth three times a day and stuff, you know because any of that good stuff would have not made it."

Other families echoed this sentiment.

One family member discussed how she was exploring advocacy options for her family member for the future. She stated,

"I think a court appointed somebody will have to be his advocating power and I can see myself getting somebody like that because once I die he really needs somebody who will look out unconditionally for his benefit, work on his behalf."

Community Composition

Some features of communities or regions that were highlighted as offering great supports included: an open and accepting community, supportive staff and neighbours ("*...the personal interaction with the social workers, you really feel you could talk anything over with them.*"), and more creative planning.

Some family members discussed the benefits of living in a small community with regard to having a child with a developmental disability. The most commonly cited benefit was that a small community meant the individual was well known to others; this translated into more work opportunities and more general support.

"...a lot of people knew Sam so when the supportive work program wanted to find work for Sam it was a little easier to find. They were extremely creative. They were extremely creative and flexible. It's a little easier to sell somebody on the*

idea of someone that they know, so if they were talking they'd say well, 'you know, we have a client that would really like to work in the post office...how about if I bring him down?'"

Acceptance was another beneficial feature of a small community. Family members spoke of the general acceptance of their family member by the wider community.

Microboards Address Gaps and Offer Control

Many participants discussed microboards as a means for accessing funding and managing their family members' care. A large number of participants had been involved in creating microboards or indicated they planned to look into establishing one in the near future. Some participants stated they found out about microboards through participating in a pilot project, discussions with social workers, or through the internet.

Participants identified the need to establish microboards for four main reasons. First, participants found that there were no existing services that could meet their family members' needs. Second, participants saw microboards as a means of providing better service for their family member. For instance, participants cited constant staff turnovers in programs as a cause for concern, or that they simply were uncomfortable with not knowing program staff. Other participants felt existing programs could not offer the personalized care their family members required and deserved. Third, a few participants indicated that microboards were necessary because family members could not directly receive funding on

behalf of a Self Advocate. Finally, the establishment of microboards was seen as a way of planning for the future of these adults when family members would not be able to provide care or help make the necessary decisions in their lives.

The microboards that were established consisted of mostly family members, with a few participants identifying the presence of a non-relative from the community. Some participants stated they considered the long term stability of the board when making decisions as to who would be on the board. For instance, they included members of all ages, thus ensuring that, in the future, the current young members would have experience in making decisions on behalf of the Self Advocate.

Microboards were argued as having many positive features, but undoubtedly most participants saw microboards as a means of having control in the lives of Self Advocates, as evidenced by one participant, *"by us having the microboard we feel in control of what's happening."* Participants felt it enabled them to hire appropriate staff and purchase needed resources, such as transportation. By having control, family members were able to make their own decisions. For example, one participant said, *"We've had a microboard for about five years now and we have our funding through health and CLBC now and you know what? We have just always done our own thing the way we wanted to."* Another aspect commonly described about microboards was that of flexibility; for example, *"one of the things that I like about having that is that it's flexible, you don't have to be attached to a program."*

Participants also felt they could provide more consistent care by controlling hiring and maintaining staff, as well as meeting the individual's

needs as they arose. One participant said, *"the funding is ours and when we see that there's a gap somewhere, we can fill it."* Some family members argued that, through Microboards, Self Advocates were able to have more of a direct impact on the supports and services they received. It was explained that this was because decisions were being made by those who know the Self Advocates the best and were oriented toward meeting their needs and goals. Some participants also liked that the process involved multiple people in making decisions, rather than a single family member. Finally, participants also felt it was a more efficient manner of providing care for family members. For example, *"It is very cost effective too with the level of service that she needs. I don't think a group home could give her the same, anywhere near the same service for the same money."*

Circle of Support – Creative Options

The "circle of support" was a very specific process engaged in by a family which resulted in the creation of a document that described the adult with a developmental disability and acted as a useful resource for new care providers. Furthermore, this document worked to ensure all relevant individuals were on the same page with regard to supporting this adult. The circle and subsequent document was created in response to an absence of suitable options for an adult. The circle was comprised of past and current support workers, family, and friends.

Important People

Self Advocates and their families listed a number of people they considered to be important to them, including family, staff, and other

caring individuals. These people were important in that they provided companionship, assisted with daily activities, and acted as an advocate for the adult. Overall, important people were those who genuinely cared for the adult, were supportive, helpful, kind, and understanding.

Planning

Generally speaking, family members discussed the importance of planning. The reasons cited for the importance of planning included:

- It can provide some direction;
- It allows for the exploration of ideas/options;
- Wishes are clear in case of emergency or unforeseen circumstances;
- It lays a foundation for the future.

Individualized Support

One factor argued to influence success was that of individualized support. Overall, participants stated that individualized support worked because it could better meet and address the individual needs of Self Advocates compared to group based programming and funding. Participants indicated that such support provided Self Advocates with a choice about what they want to do; therefore, providing an opportunity to meet their interests. Specifically, individualized support was argued to be more flexible and planning could take place from week to week. It was also viewed as being more adaptable to changes in things such as weather or a client's mood. For instance, one parent explained,

“If he’s having trouble on a particular day, it’s not a major thing to change his program or to take him out in the playground for something physical which you can’t do in a huge school where everything is so rigid.”

Another participant liked individualized support because it enabled individuals to be trained to care specifically for her family member. One participant simply stated that he/she liked that the money/funding was “attached to the individual.” Finally, participants also talked about the benefits of individualized support in terms of their family members being much improved, better adjusted, and displaying less problematic behaviour.

Direct or Individualized Funding

When discussing funding, many participants raised the issue of direct or individualized funding. Most participants spoke positively of this type of funding. For instance, one family member argued that it was more flexible and made money more readily available. Another family member credited individualized funding with enabling him to hire staff that were specifically trained to care for his family member. Other participants attributed greater accountability to individualized funding. Specifically, individualized funding provided more freedom in deciding which services and supports to access and therefore, requiring services and supports to demonstrate they were providing quality care. As one participant said, *“...now they’re dependent on providing that good service or the quality service in order to retain the money.”* Another participant indicated that such a process could free up additional resources because families were capable of monitoring the services accessed, rather than officials.

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

Family members were asked to discuss those aspects of supports and services that were ineffective. A summary of participant responses are outlined below.

Features of Support

Administrative Requirements for Microboards

While many of the shared experiences about microboards were positive, there were also some negative issues raised. For the most part, negative discussion revolved around the administrative requirements of microboards. Many participants stated that microboards were difficult to operate because of the meetings and paperwork. This was made even more difficult because it required a particular type of experience and skill that many participants did not have. As one participant said,

"...[there's] not a lot of support from anybody to help you do it so, you know, somebody from the ministry saying, 'look, I'll sit down, I'll help you do this' [would be helpful]. Or it doesn't have to be anybody from the ministry, it just has to be somebody who's out there doing that kind of stuff."

Although one participant identified the option of hiring people to help with aspects such as bookkeeping, she felt that, across the province, this was a considerable expenditure of funds that would be better served going directly towards services and supports for adults with developmental disabilities.

Other comments included difficulties with getting people to commit to be on a microboard given the lengthy requirements of such a commitment. Some participants also felt that information about microboards was being withheld because local service providers did not want to lose control of funding. Finally, a number of participants voiced concern over the involvement of unions and the burdens collective bargaining would place on their family members' service plan (e.g. employees' work schedule).

Inequitable Distribution of Funding

Many parents spoke clearly about their beliefs about the inequitable distribution of funds and overall support across the province. Vancouver and the Lower Mainland were repeatedly cited as regions in which greater funding and more opportunities were made available. One family member explained that if there was a more equitable distribution of funds she would be better able to accept the current situation for her child.

"I guess what I find extremely upsetting is if everything was square and the same across regions, I could maybe swallow it a little better but when I know that if my daughter had the same proposal put forward to the Langley region, it would have been accepted like that, but because we live in the North and our regional manager doesn't believe in that. I mean, she's well liked because she stays under budget. I guess if it was fair across the board, I could be more accepting of things but the fact that I know in another region, it would be a totally different story, it's very hard to swallow."

In reference to the difference in weight large towns carry compared to small towns, one family member asserted, "...if you're big and you make a

lot of noise, it's the old squeaky wheel gets the grease. If you're small and you're jumping up and down and waving a small flag, it's easy to ignore."

Financial Limitations

When discussing issues around financing and funding, many participants discussed the manner in which they believed monthly disability benefits to be limited. With respect to family members, there was a consensus that the amount provided to individuals was drastically insufficient. As one family member said, *"Nobody can live on what the government gives them."* Family members also discussed the difficulty they had with justifying the government's position that "\$856" was sufficient for Self Advocates to live each month. As for Self Advocates, they stressed that in order to do the things they wanted, such as travel, they had to save up, which was difficult given their limited income. Another Self Advocate argued that he simply did not receive enough money to pay bills, get groceries, and pay the rent, without being in debt.

Limited Options, Lack of Innovation

Family members explained that some provincial regions that offered limited and stifled options did so because they had been supporting people for a longer period of time thus creating programs that were functional, "socially acceptable", and funded. One parent stated,

"...[interior community] has been serving people with handicaps like a long time. There were services in [interior community] before there were services in Vancouver so I think for me, unfortunately they've got on this route of - these are the programs that we offer and they are socially acceptable programs, they are easy to deliver programs and easy to get money for, funding for. So I think they get onto this

route and it's hard to get off that route to offer something different."

Lack of Clarity

The theme of "lack of clarity" was present throughout the transcripts in a variety of contexts. Some family members reported they were unable to see what the next step should be and such lack of vision impeded their ability to plan. Along those same lines, some family members discussed having too many choices with regard to agencies and not enough information about the agencies and what they offer to make informed choices.

Another family member noted that planning without the knowledge of how much money would be available was not a helpful process. Instead, this acted as a barrier because when you knew how much money you had to work with, then you were able to plan and make decisions within a certain framework. Also, many family members discussed how they were repeatedly told by support people and systems that there was "no new money". Wondering, on the part of the family member, about the availability of funding acted as a barrier to engaging in proper planning. One parent created and completed four or five plans and submitted each of these, she explained, *"...every step of the way they want me to take something that I know is going to fail for [my daughter] because it's so little money. They're not looking at a sustainable plan that's going to be effective."*

Planning Takes Too Much Time

Some family members discussed how time gets in the way of planning in that it is time consuming to research all of the support options available.

This means that planning often takes place without an awareness of all possible options. This theme of 'planning takes too much time' is also related to the theme of 'lack of clarity'; a lack of clarity about those available options in the community can mean that a family must invest the time to do the research. If such information was more readily and clearly available, such a barrier might be surmountable.

Accreditation

A few participants raised the topic of accountability during discussions of service standards. In terms of service standards, one family member indicated that accreditation was a means of assessing the standards and policies of different programs, as well as monitoring. From this process, people could then see which programs received accreditation and which did not. To his disappointment, the family member stated further, however, that CLBC was changing its criteria regarding which programs could be accredited. As a result, programs making over five hundred thousand would not be accredited.

Another participant, involved in a recent accreditation, indicated that the process provided an opportunity to raise issues concerning safety and quality. However, the participant raised doubt about the process because accreditation credentials were still given despite documented problems. Finally, another participant argued that the process of accreditation was not synonymous with accountability, *"I don't think accreditation is accountability. I think it's a bunch of paperwork."* The participant believed that accountability could only be obtained through routine follow-up and speaking with families.

Union-collective Agreement Issues

Family members appeared to suggest that unions did not work when supporting adults with disabilities. For instance, one family member spoke to the frustration she experienced when seeking funding, especially when there were labour disagreements holding up the process. Another family member discussed the difficulties in providing twenty-four hour care for her son when unions limit the number of hours support staff can work (e.g. unable to stay overnight). Lastly, two individuals expressed dissatisfaction with the labour restrictions because it limited the work options available to Self Advocates. Specifically, labour unions imposed labour codes that *“preclude the possibility of handicapped people ever having the protection of a supervised sheltered workshop. This has had a devastating effect on their lifestyle.”*

Types of Support

Funding and Microboards

In their discussion of issues related to funding, many family member participants seemed to argue that the two biggest issues were (1) accessing funding and then once the funding was accessed, (2) maintaining funding levels. While a number of participants also believed the funding they received was insufficient, there were also a number of participants who indicated they were happy with the degree of funding they were receiving. However, they maintained they had difficulty initially accessing the funds and feared that it could be lost at any time due to restructuring or budget cuts. These two issues were cited as a major source of stress for participants.

With respect to obtaining funding, a couple of participants indicated they were often subjected to a sort of strategic manoeuvring. For instance, one participant shared an experience, of how they (decision makers) were adamant about her daughter living specifically with another Self Advocate so as to ensure funding. Another participant was angry about how her daughter was being used by an agency to secure funding, *"...there's that neon sign overhead, blink, blink, dollar, dollar, you know. They used her all the time to get more staff and they let things happen instead of trying to protect her."* Other participants simply spoke generally about how there were situations or opportunities to *"get funds attached to your name."*

Family members also discussed the vulnerability of funding. In terms of maintaining funding, some participants indicated that once funding was obtained, it was not possible to change living situations, such as having a child move back home. Other participants questioned the sustainability of funding under the new transition. Specifically, one participant spoke of impending cutbacks she thought were to occur in 2010. Another participant stated, *"the only way you can get that [quality of life] is through sustainability. You can't go budget to budget."* Thus, according to family members, the instability of funding translated into challenges in planning and ultimately was an example of what is not working.

Another component of this theme was the voiced frustration on the part of family members about all of the agencies involved in funding and the difficulties that arose from such organization. One participant explained, *"...there's so many ministries involved. If there was just one, we could go there and work from that centre."* One family member believed this problem could be resolved by establishing more responsibility at a local

level. While others felt an organization, independent of the government, was needed in order to monitor the situation.

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. This category includes barriers that speak to general supports and services and are applicable at a broad level.

Philosophy

During the course of the interviews a number of participants addressed several issues on a philosophical level. That is, they spoke to matters on a more global and belief based level. Many participants often presented philosophies as in contradiction with one another. In terms of developmental philosophies, participants expressed their experiences interacting with people who blamed or held them responsible for their family members' disabilities. These views were demonstrated by teachers, support workers, and people with no experience in interacting with people with disabilities.

Another participant also reflected on how she was told when her daughter was completing high school that her daughter would now be independent. The parent disagreed with the philosophy that a certain age or milestone (such as graduating high school) signified automatic

independence. Finally, one participant expressed concern about people trying to impose their values and desires on persons with disabilities.

“Parents saying well, ‘my son is always alone’, or ‘my son goes off and wants to be on his own’. Well, yeah, he wants to be on his own, I mean if I want to be on my own I get to be so, you know, we have to watch that we’re not trying to, I’m not saying this for anybody here, but there’s a lot of people try push a social life on people that don’t necessarily want that.”

Geography as a Barrier to Accessing Needed Supports

Participants spoke of the differences in support in regions of the province and, in some cases, the differences across cities within a particular region (e.g. services in Burnaby were cited as stronger than services in Vancouver). Differences were cited in the following areas: living options, employment opportunities, qualified staff, the way staff treat families, day program options, and transportation.

Experiences of supports and services also differed within the same region. Some family members discussed their pleasure with the supports their family member was able to access in a community; another participant discussed her disappointment with the services available within this same community.

In discussing small communities, some family members identified several undesirable features; such features included: limited formalized support options, limitations to existing supports (i.e. maximum number of members), limited staff, limited residential options (what does an adult

child do when he/she is ready to move out of the family home and there are absolutely no housing options?), violence/drugs/vandalism.

Another issue related to geographical differences that was raised by a family member were the challenges associated with transferring funding from one region to another. This particular family moved from one part of the province to another and was experiencing difficulty in accessing the respite funding that was available to them in their previous community. Other families who had moved from one community to another experienced a difference in services. One family had travelled around the province over the years with their son and when they settled in a small northern community they felt as though they *"got hit with a brick wall"* in that there were absolutely no services available. Such a reality had not been their experience in other regions of the province.

Both family members and Self Advocates were scared at the possibility of having to move to another community in the province in order to have better access to services. Similarly, some parents spoke of how their adult child was afraid that someone was going to come and take them out of their community and move them elsewhere so they could receive services. One family member told a story in which such a situation occurred, she stated,

"...unfortunately for my in-laws they had to actually ship her out, out of the community many years ago just so she could get some help. And we don't want to see that here in this community. Why should individuals have to be torn away from their families to get the right support?"

When family members learned of a program in another region of the province doing useful and relevant work, it was always a challenge to access support from that program (e.g. Vela) because there was a lack of funding available to enable travel either on the part of the agency/organization or on the part of the family. This further prevented individuals and families in small towns and remote regions from accessing useful and relevant supports while remaining in their community.

Concerns about Advocacy

Some parents reported feeling afraid to speak up about the inadequacy of the services their family member is receiving. This fear existed because families had witnessed situations in which other families had spoken up only to have their child removed from the family home and out of the community. Similarly, families feared that if they spoke up then any service they were receiving would be removed. Thus, some families say nothing about the way their child is being supported even though current supports are inadequate.

Secondly, one family member was frustrated with *"the people who had the power to advocate"* (implied that these people with the power are support workers or agencies or government) but chose not to use this power. She speculated that this lack of action may have had to do with how the individual viewed his/her role and/or the lack of understanding about what it meant to care of an individual with a developmental disability. To clarify, family members overall made it clear that caring for

an adult with a developmental disability is hard work and challenging. In this case, this mother wondered if the people in power lacked the understanding of this challenging care role.

Lastly, one family member was concerned about "vocal advocates" who created change that was viewed as undesirable by some. A written response participant stated,

"...few vocal advocates with little foresight (or savvy) managed to convince the school board that their handicapped children should be a part of the regular school program. No teacher would honestly say that the results were beneficial to anyone concerned. Therefore a valuable asset was lost. So much for ill-informed vocal advocates! Lesson One to be learned - beware of vocal advocates with strictly selfish objectives."

Isolation

Isolation was discussed in the way that many Self Advocates were isolated from the community in which they lived because they did not participate in activities within that community. Family members explained that often to access programs and supports, individuals had to leave their community which meant they were not known to their local community and thus, were isolated. One parent stated, *"I don't see there's any access. They always have these programs way away and they're segregated, where, what is it, disability world where they have to go and never around their neighbourhood."*

Attitudes

"Old age thinking" was discussed by one Self Advocate who described her experience of participating in "typical" activities; she stated,

"I go down to the little bar on Friday night sometimes and they'll look at me as much to say, 'what are you doing here' and it's really odd how many people think that because you have a disability you shouldn't be able to do stuff. And I don't know where they get that in their head but maybe it's because of all the stuff years ago that you didn't do. I don't know and then they think well, you're a person, they don't think of it that way. It's just, you know, 'oh, you're here, what are you doing here?' 'well, I'm having dinner and a beer just like you are', you know, 'oh yeah, I guess you should be able to do that too' and it's sort of like a light just went on in their head, oh why not? You know, it's just how people were taught to think years ago and sometimes it's still there."

Similarly, a parent discussed how attitude played an important role in inclusion and that simply creating inclusive opportunities did not result in inclusion; she believed a welcoming and accepting attitude was also key.

Beliefs

In many cases, beliefs (held by family members, by "bureaucrats", by other families) dictated what decisions were made or influenced the decision-making process. For example, one family member believed that bureaucrats or the people in power viewed people with developmental disabilities as *"the lowest stake on society"* which they believed then dictated how decisions were made as to how to support adults with developmental disabilities in residential settings. This theme of beliefs also surfaced when parents talked to other "people" who shared their values

about what decisions should be made with regard to their child. Finally, the beliefs of the parent about the abilities and needs of their child influenced decision making. For example, one parent was concerned for the safety of her son and believed that he would not be safe on his own and thus, did not want her son out of the family home. Another parent, in consultation with the family doctor, decided to put her daughter on birth control to put "...*that part of her life off for awhile.*"

Communication

Participants argued that there was no single source they could access that contained information about all the services and supports available. Furthermore, they indicated that there were no steady streams of communication among family members, Self Advocates, and organizations providing supports, services, and/or funding. As a result, many participants cited frustration at no one being able to provide them with a sense of the "big picture." Additionally, many felt that the lack of communication kept them in the *dark* and resulted in missed opportunities due to bureaucratic rules.

Panic Planning

Panic planning is a phenomenon that was discussed throughout the project and within multiple contexts. Panic planning is a process of planning that is engaged in because of the fear of not receiving any supports and thus the family will accept anything because of last minute

situations created often by systems (e.g. school system, ministries). Some family members identified an absence of choice when thinking about barriers to planning. An absence of planning due to an absence of choice meant that decisions were being made in order to have some support irrespective of the suitability of that support. This was not a process of planning based on choice. One parent highlighted this perspective by stating, *"...we just decided because nothing is happening that I've just put in an application for Jennie* to go one more year because she turns nineteen and she can go until her twentieth."*

Lack of Consistency/Continuity

This theme was present across many dimensions of the project and refers to the lack of continuity of the support people in the lives of Self Advocates and their families. Many families remarked on the many changes in support people they have experienced over the years. This created particular problems in the area of planning because the support person who was responsible for organizing the plan may not have known the person for whom he/she was planning with which made it difficult to create a plan that was in line with the individual's interests, abilities, hopes, and desires.

Disconnection among Ministries

One family member discussed the many ministries through which her family member accessed supports and services. She explained that each ministry has its own mandate and policies and the separateness of this set-

up meant working with each was a challenge and might not result in the best interest of the individual with a disability.

"That's the way the system works. So we're dealing with the health, we're dealing with Income Assistance, Mental Health and Community Living. Those four ministries all involved in this. They all have a mandate to do something but it's not driven by the client, it's driven by the ministry. We need more of them working and talking to each other."

Separation between Person and System

Other barriers to support frequently identified by family members were that those people making the decisions did not have first hand experience living with or interacting with individuals with developmental disabilities. As a result, many family members believed the decisions being made about funding, services, and supports were misinformed and unrealistic. For instance, participants described their difficulties in having their family members' needs recognized in order to receive services. Much of the problems occurred as a result of not acknowledging the heterogeneity of needs among these individuals. Furthermore, participants believed the only way they could indulge the eligibility criteria set forth by decision makers was to engage in *deficit marketing*. As a result, the accomplishments and abilities of those adults are often ignored.

System Interaction

Overall, families expressed frustration with the system. They felt as though there was a lack of money and that it was a constant struggle to obtain services or supports. Family members spoke of a lack of continuity of services, a lack of planning for the future, and a need for communication between service providers and an amalgamation of the services. Some family members developed creative strategies to obtain services, such as being cooperative, not asking for too much, or developing plans and attending meetings, whereas others felt a sense of powerlessness and as though they were *“left in the dark”*. Overall, family members described working with the system as being a full-time job, as they were often plagued with a lack of funding, a lack of communication, and unfulfilled promises of change.

Direct or Individualized Funding

When discussing shortcomings or limitations of the process of obtaining direct or individualized funding, most participants indicated uncertainty or lack of knowledge about the process. Some believed this was due to a lack of communication with funding providers and stated that CLBC should ensure that the information was disseminated and that everyone was made aware of the process. Some participants also stated they were unclear as to how things were going to change under the new policies. Finally, participants identified frustration and uncertainty around the requirement of having to establish microboards or societies in order to access funding. Some argued that this process was simply another barrier to accessing funding.

Funding Availability

Participants raised four general issues related to the availability of funding. First, many simply stated there was not enough funding for people. *“There’s not enough money to support people with disabilities in the way that they should be supported.”* Another participant said, *“...there’s always that discrepancy between his needs and the rigidity of the system as it exists.”* One family member explained how his daughter could not attend a beneficial program because there was no funding available to hire additional staff, which was needed to maintain the staff : client ratio. Another participant added that *“the block funding gets so diluted because it’s a little bit for everybody but nothing that’s really effective for anybody.”*

Transportation

One final barrier that was discussed to a large extent was the lack of transportation. Many participants argued that public transportation was too limited in terms of availability and convenience. And while some recognized the potential of taxis and the Handy Dart, they described these services respectively as being too expensive and inflexible.

D. Gaps

This category refers to those aspects in general that were missing or those issues that were not addressed according to family members and Self Advocates. Findings related to gaps are summarized below.

On a broader scale, the need for advocacy from the larger community was identified.

Even families who were strong advocates and were well connected reported wanting and needing some support sometimes.

"...as I say, we're relatively astute parents, I've been plugged in relatively politically forever and I used to work with people with disabilities before I got married and so it's not like the whole thing is unfamiliar to me. And fortunately I can advocate, but even those of us who are strong families who can advocate, who know where we're going, we still need support and then someone who might check in along the way."

Regional Gaps – Small Towns

Many participants in smaller regions of the province, particularly the North, spoke about the limitations to and absence of supports. One parent stated, *"...anytime there's anything offered on the internet, it's never in the North. There's no funding to get families that live in the North to things, so, it just continues the old way."* The North was described as a *"totally neglected"* region. Similarly, another family member discussed how the lack of competition in terms of day program supports in smaller regions meant that options and opportunities remained the same.

Recognition of the Role of the Family

Many different levels of family involvement were discussed. Specific family members that were involved in the support of relatives with a developmental disability were: parents, siblings, in-laws, cousins, aunts, uncles, and grandchildren. Families were directly involved in providing

care from full-time, to part-time (e.g., weekends). Family members also provided care through a multitude of means, such as education and life skills training, taking courses on providing disability care, establishing non-profit organizations to provide better services, and advocating. Some participants argued that families were not recognized for the care provided and were not being helped through respite or resource development. A number of participants indicated this was going to become a major problem in terms of aging parents and their decreasing ability to provide full-time care for their family members.

When participants were asked about the importance of family involvement, they indicated it was too difficult to rely on others, especially volunteers. As one participant argued, taking care of an adult with a developmental disability required too much commitment from volunteers. Other participants discussed the problems they encountered when families could not be involved. For example, one Self Advocate chose to remain in her community following her parent's decision to move to a new community; however, once the family moved, the Self Advocate no longer had family support in the community and she experienced difficulties without this support. Her family member explained, *"...we brought her back, 'cause she wasn't managing without her family 'cause we moved my parents up and she wanted, she thought she wanted to stay. She didn't realize how much she relied on her family."*

Paying Family

Participants raised the issue concerning families not being paid to look after a family member with a disability. It was recognized that, on one hand these individuals are their children, but at the same time they are *adult* children. Typically, parental care significantly decreases when

children become adults. Often for families with a child with a developmental disability, this decrease in care does not take place.

Frustration was expressed at the cost of hiring someone to provide respite, while a family member who did the same service day-in and day-out received no money. Other participants discussed the inequality between families who put their family members into homes and those who kept their children at home to look after them. In all, participants wanted to be recognized for their commitment to their family member. As one participant said,

"Parents who "download" are often the most vocal in advocating what needs to be done, because they have more time. Parents who keep their handicapped children at home are seldom heard from, because they have not time to spare. Yet this tremendous saving of Government funds by keeping their handicapped children at home is not recognized by Government."

Sibling Roles/Responsibilities

There were many instances in which participants described the roles of siblings in taking care of family members. In many cases, the siblings' relationships were described as great and beneficial to all those involved. Some described the siblings as serving as great role models for family members with developmental disabilities. In some cases, participants described how sibling relationships got better as the "typical" sibling grew older and matured. However, in terms of providing full-time care, many parents indicated they were not comfortable asking their other children to assume complete responsibility for their brother or sister. Many described the commitment and burden that caring for an adult with a disability

places on a family. Other participants argued that as their other children grew older and began to have their own children, taking care of a disabled sibling would be too much. Finally, one sibling participant described the difficulties she was having with looking after her brother. In particular, her brother saw her as a “*nagging sister*” rather than an authoritative care provider.

Future Concerns of Family Members

On the topic of concerns for the future, family members overwhelmingly described concern about what would happen when they could no longer look after their loved one. There was a certain degree of doubt regarding who would take over and whether or not he/she/they would have the tacit knowledge to provide the necessary support. Concern was also discussed around funding and what degree of support would be provided in the future. In addition, family members highlighted concern around the monitoring of supports and services to ensure they continue to meet their overall objectives. Overall, family members worried about the stability of their family members' lives.

Future Concerns of Self Advocates

Similar to family member concerns, Self Advocates also expressed concerns regarding their parents' age and what would happen if their parents could not take care for them. As one participant said “*if my dad dies what the future will be for me?*” indicating there was definite uncertainty as to what the future has in store.

E. Desires/Aspirations

Geographical Considerations

In terms of funding and recognizing the different needs of various regions within the province, one family stated that the North deserved larger budgets due to the winter season which has implications for heating bills and transportation. She compared this rationale to the rationale that Vancouver needs larger budgets because living costs are higher.

Access to Counselling Support

In response to isolation and feelings of depression, family members wanted their family member to have access to a mental health professional so they would have someone to talk to about the challenges they were facing.

Ideal Society

Quotes of many family members illustrated an ideal, not just for immediate family members with disabilities, but for all of society. As such, the focus was not only on Self Advocates or their family members, but rather society as whole. References ranged from the general acceptance of disabilities and their heterogeneity of needs, to the acceptance and building of friendships, to a more global distribution of resources.

Conclusion

This report organized and summarized the thoughts and experiences of Self Advocates and family members throughout B.C. who participated in

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

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