Abstract

The purpose of this study is to gain an understanding of the experiences of families/caregivers who provide support for intellectually disabled family members as they navigate government systems in order to find and secure a home for their disabled family members. The study focuses on families in northwestern British Columbia. Policy analysis, complemented by feminist and critical disability theory, serves as the framework for the study that used ethnographic and autoethnographic methods to explore the experiences of caregivers in this distinct subculture. Data collection involved semi-structured interviews with eight family members/caregivers. Thematic analysis of the data was used to determine significant issues that these families/caregivers face.

Twelve subthemes emerged from the data analysis and as a result of the findings specific areas were explored: the experiences of the family caregivers; the experiences of the researcher who is part of the subcultural group; lessons from Canadian history; the present and the future in British Columbia; and recommendations.

This research provides a snapshot of the lived experiences of families/caregivers supporting an intellectually disabled family member and the impact of current policies on these families. Future research should focus on the voices of the intellectually disabled individuals - citizens within our society.
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Chapter One: Introduction

"As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do" (Ratzka, 2005).

The Issues

Current provincial economic conditions in British Columbia (BC) have resulted in diminishing resources and funding for the most vulnerable and marginalized individuals within society—the disabled. Provincially, one of the areas in which supports have declined is appropriate homes for adults with intellectual disabilities. The Community Living British Columbia (CLBC) funding crisis is a prime example of how service delivery supports were removed from individuals with developmental disabilities and their families. In 2010, the BC government attempted to recover $22 million of their budget deficit by initiating a "service redesign" process. This resulted in drastic cuts to supports for people with developmental disabilities and their families.

Part of the service redesign was the rapid closure of group homes (Inclusion BC, 2012-14). Community Living British Columbia (2011) Requests for Service Report identified a budget of $710 million for the fiscal 2011/12. This budget provided funding for a range of supports such as community inclusion, residential support, respite, and support for individuals and families. In this report Community Living British Columbia identified 13,696 individuals registered with developmental disabilities and stated that “all requests for funding are assessed on an individual basis and those with immediate health and safety needs are provided with supports” (Community Living British Columbia, 2011, p.1). Compare this with the Community Living British Columbia (2014a) Annual Report 2013-14, where 15,942
adults with developmental disabilities were registered for services with a budget of $788.7 million (p.4). One anticipates this is not enough to meet the increased needs as it equates to a per capita decline.

This research focuses on the stories of parents and siblings of individuals with intellectual disabilities trying to secure a home for their future in the current financial and sociopolitical climate. Themes emerging from stories of those caring for an intellectually disabled family member provide a means of interpreting what is currently experienced by these families. This research can enhance the knowledge of our province's policies and social structures by examining themes emerging from the experiences of families trying to navigate the system. I will argue that future disability policy development needs to take into account whether current disability policies and funding are meeting the needs of individuals with intellectual disabilities. In addition, my study includes a feminist orientation regarding the role of women and caregiving. I conclude that the need for a secure place to call home for disabled individuals requires prioritization by the BC government, and an increase in funding for supports and services. The BC government needs to build policies based on the needs identified by families caring for an intellectually disabled individual. It needs to ensure that families feel secure that mechanisms of quality assurance are in place to safeguard the rights of their son/daughter when they no longer can advocate for them.

It is important to define the term intellectual disability. Throughout this thesis I will use terminology utilized during the particular historical period such as mental retardation, intellectually disabled, etc. as this terminology provides a perspective on the social beliefs during the time.
The Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000) is the guide used by registered psychologists to assess developmental disabilities. The DSM-IV-TR refers to developmental disorders as learning disorders, mental retardation and pervasive developmental disorders. The DSM-IV-TR defines mental retardation as:

Significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. The onset must occur before age 18. Mental retardation has many different etiologies and may be seen as a final common pathway of various pathological processes that affect the functioning of the central nervous system. Significantly subaverage intellectual functioning is defined as an IQ of about 70 or below (approximately 2 standard deviations below the mean). (p. 41)

For the purpose of this study hereon in, I will utilize the term “intellectual disability” rather than “mental retardation” as the latter conveys the idea that the entire person is disabled because of a specific impairment (Devlin & Pothier, 2006).

As a parent of a son with an intellectual disability, my role is to protect and provide for my child’s future. In my vision of his future he has a safe living environment, his uniqueness is celebrated, he is allowed to age with dignity, and his human rights are safeguarded. My research has provided me with a means to critically analyze the ability of the government of British Columbia to support and protect individuals with intellectual disabilities and their families living in northern British Columbia. Before conducting my
research, I thought that my child's future was safeguarded by our country; what I discovered in hearing the stories of families caring for relatives with intellectual disabilities is that lifelong advocacy is required to ensure basic human rights. The safeguard, I realized, is the family that advocates for safe living conditions, financial security, physical well-being, and independence.

Rationale

Our current Canadian narrative of progress is one that sets the stage for government down-sizing, budget-cutting, and retrenchment, of all which impact the social system supporting individuals with disabilities (Devlin & Pothier, 2006). Specifically, this research identifies the impact of social programming for individuals with intellectual disabilities living in northwest British Columbia. Human rights advocacy to ensure the safeguarding of social programming for individuals with disabilities is best expressed through the voices of their strongest advocates, their families. Families express their views to policy makers who decide which programs to cut and which programs to retain. This research provides a better understanding of the lived experiences of individuals with disabilities, as expressed by the voices of their family members, and therefore can lead to policy and practice that is more responsive to, and reflective of the needs of individuals with disabilities and their families.

Canadian families, in general, are working more for less as “wages have not kept pace with inflation, with new hires are making 40 per cent less than the average worker” (Yalnizyan, 2012). According to the 2009 Canadian Centre for Policy Alternatives (CCPA) Ivanova report, BC’s Growing Gap:

Families in the lower tiers of the income spectrum saw the worst declines in their real (inflation-adjusted) earnings. [Monthly] Earnings fell by 74 per cent for the bottom
10 per cent of families, from $5,140 in the late 1970s to only $1,336 today. The second, third and fourth deciles saw their earnings drop by a staggering 57, 42 and 29 per cent respectively, despite working more hours than their counterparts a generation ago. Even the seventh decile did not see an increase over the 30-year period, with earnings staying flat at $78,000. (p. 6)

These figures help explain why so many families have been feeling that they cannot get ahead.

MacDonald (2012) states that:

*Stagnant wages for most of us has meant that household debt has mushroomed, standing in for the raises that mainstream Canadians used to get....Many Canadians don’t know when they’ll be able to retire. At the same time, their federal government is threatening to change the rules of the public pension system....But there’s little indication their federal government is listening. In fact, the federal government has been dodging these issues. The government has warned $4 to $8 billion in public spending cuts are on the way but our own Finance Minister has said publicly that he may not include the details of pending cuts in this upcoming budget. We’re calling on this government to deliver a transparent budget—not a hide and seek budget—one that protects the services Canadians rely on but, also expands them in key ways.* (pp. 3–4)

So if families in general cannot get ahead, where does this leave families with the extra financial challenges of caring for individuals with intellectual disabilities?
The World Health Organization (2000) defines the term *intellectual disability* as the following:

Any set of conditions, resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, that affect intellectual development. These conditions result in a lifetime of lower than average overall capability for self-determination and general independent functioning and performance in vocational, social, and personal functions. (p. 5)

Canadian families, supporting individuals with intellectual disabilities while coping with the current economic climate and strategizing to ensure their family member is cared for now and in the future, are looking for solutions. More specifically, this study looks at families in British Columbia supporting intellectually disabled family members and the provincial government structure called Community Living BC (CLBC), mandated to provide social supports. The question is whether the CLBC supports are sufficient.

Due to the drastic cuts in provincial budgets many volunteer organizations have emerged to provide services for children and youth with special needs. One such organization is the “Moms on the Move: BC families supporting people with special needs,” a volunteer network formed in 2001 “to fight Premier Gordon Campbell’s [premier of BC Liberals from 2001 to 2011] drastic plan to cut services to vulnerable children and families by over 20%” (Moms on the Move, 2014). This group organized formal protests in 2001 and again in 2009 in response to “new cuts and to Premier Campbell’s failure to honour his commitment to improve supports for children and youth with special needs” (Moms on the Move, 2014). This organization’s mandate is to support families in crisis and to connect families with other
community groups to aid them in acquiring supports that have diminished with the current system of provincial supports and services (Moms on the Move, 2014). This group believes that “the Province seeks to balance its budget on the backs of BC's most vulnerable children, adults and families” and stands committed to educating and informing the BC government and public on the importance of investing in future of individuals with special needs (Moms on the Move, 2014, p.1).

In a letter to the Honourable Rich Coleman this group requested explanations from the BC government regarding promises made:

Some months ago, you told British Columbians that budget cuts to other programs were being made in order to protect services to people with disabilities. Yet media reports recently revealed that your government has cut the budget for Community Living BC by more than $20 million, forcing community-based agencies to close group homes for adults with developmental disabilities, with disturbing reports of residents being forcibly moved from their professionally-staffed homes to cheaper home-sharing models that may be unsafe or unsuited to their needs. These moves are being made against the wishes of residents and their families, in direct contradiction of promises made by your government. (Moms on the Move, 2010, p.1)

Moms on the Move further identified that:

Families also report that new applicants are being denied group home placements and forced into informal residential care models that may not be right for their needs and/or that may expose them to a high risk for potential abuse. Further disturbing reports indicate budget pressures are also eroding service quality, standards and staffing in residential care settings, jeopardizing the safety and wellbeing of residents.
In addition, CLBC is also promoting cluster care, despite overwhelming community opposition to cluster care as a regressive step backwards to institutionalization when this was first proposed in 2002, and subsequent assurances from your government rejecting this as part of the CLBC service delivery model. (Mom’s on the Move, 2010, p. 1)

‘Moms on the Move’ is an organization focused on bringing together self-advocates and families wanting to ensure that the BC Government honors its promises to the most vulnerable children, youth and adults. This organization believes that “It is a very grave step to force individuals with profound intellectual challenges from their homes and to forcibly relocate them to a different care model. It is highly irresponsible to take such actions without demonstrating the utmost care and transparency to assure the public that such actions are in the public interest as well as in the best interest of the individuals concerned” (Moms on the Move, 2010, p.1).

Similarly, other organizations are speaking out about transparency, including the BC Coalition of People with Disabilities (BCCPD), stating their concern about the assessment and reallocation program of group home residents initiated by CLBC. In a BCCPD (2010, August 13) letter to the Honorable Rich Coleman, the group stated that “Group home residents are evidently being assessed for their suitability for alternative residential arrangements without their knowledge or permission, or that of their families. They are then being informed that as a result of these arrangements they must relocate to a home sharing arrangement against their wishes” (p. 1).

On the issue of forced re-location, Moms on the Move (2010) identify that there is a need to:
Halt the current ranking and relocation program pending an independent and transparent review that includes advice from families and self-advocates on an appropriate framework to ensure that all placements are consistent with the welfare and safety of residents as the paramount consideration. (p. 2)

In an interview on the Voice of BC (VBC, 2011) Michael Prince, a professor at the University of Victoria, expressed concerns regarding government transparency as an issue to families caring for children with developmental disabilities in British Columbia. In a Voice of BC (2011) interview, Prince noted that families had advocated for a structure such as CLBC to give them more say in the provision of social services but Community Living British Columbia (CLBC) “went off the rails” from its original vision. Prince stated that CLBC’s initial intent was to have 11 Board members of which six would be family representatives and/or self-advocates [person with a development disability]. In 2010, the Liberal government amended the Board representation to replace parents with people with good business experience to run the Board. As Prince points out, 2010 is when the shift occurred, creating “today’s mess into viewing it [CLBC] as a contract management agency” (VBC, 2011).


Budget 2014 affirms government’s ability to balance its budget on an ongoing basis. Modest economic growth, weakness in taxation revenue and reduced federal transfers, are offset by improvement in natural resource revenues, the impact of government’s debt management strategy and ongoing expenditure management, enabling
government to provide additional funding for health care, social programs, and economic development. (p. 1)

The BC provincial government cuts and the lack of transparency regarding group home closures are the results of a top down approach to providing supports to families with intellectually disabled family members. How do British Columbians access the validity of the provincial government claims and, if a balanced budget is the focus, then who decides which programs get cut and which programs get funded? In my research, I found a few non-profit organizations (e.g., Fraser Institute of Vancouver [with right-wing perspectives], and the Canadian Centre for Policy Alternatives [with left-wing perspectives] focused on generating public discussion among citizens interested in improving the lives of people through better public policy.

The Fraser Institute was founded in 1974 as an independent Canadian research and educational organization with the explicit intent to “measure, study, and communicate the impact of competitive markets and government interventions on the welfare of individuals” (Wen, 2014, p. 41). The Fraser Institute reports information regarding the “economic and social effects of current public policies, and offers evidence-based research and education about policy options that can improve the quality of life” (Wen, 2014, p. 41). A recent study by the Fraser Institute, Capital Budgeting and Fiscal Sustainability in British Columbia report (Wen, 2014), identified that “although the BC government expects a surplus of $384 million in its operating budget in 2014/15 ($184 million after accounting for the forecast allowance), provincial debt will grow by $1.9 billion. Pronouncements about balanced budgets by the government must therefore be interpreted with caution” (p.i). What does this mean for social programming for individuals with intellectual disabilities? More waitlists? How are families
coping with the waitlists? Is the well-being of individuals with intellectual disabilities and/or their families compromised by the lack of program services and information? My research begins to answer these questions, by speaking directly to the parents and siblings of those affected by cuts to social programming.

British Columbia conducted a Disability White Paper Consultation process from December 3, 2013, to March 11, 2014. British Columbians were asked to share their thoughts on how government can better support people with disabilities to fully participate in our communities. The end product was the “Disability Consultation Report: Moving Together Toward an Accessible B.C.” providing government with opinions, ideas, comments and suggestions of British Columbians regarding disability issues (BC Ministry of Social Development and Social Innovation, 2014). The consultation process provided the British Columbia government with the means of complying with the UN Convention on the Rights for Persons with Disabilities to ensure persons with disabilities have a voice on issues that impact them.

However, what does this report mean for our current structure of CLBC service redesign? How is future funding going to be secured with an ever-growing population of transitioning youth at age 19 and aging parents no longer capable of caring for their intellectually disabled child? There is a growing issue of aging adults requiring supports as parents who have been providing care age and are no longer able to provide at home support. This report will only have an impact on services if the recommendations address issues such as these, and if they are implemented.

Stainton and Hole (2014) state that “While recent efforts to improve transition such as the automatic respite funding, common assessment platform and the pilot navigators project
should have positive benefits, none of these will significantly address the most common concern raised in the research which was the lack of timely and sufficient access to needed supports" (p. 5). According to Stainton and Hole, "Too often, the response is crisis driven rather than planned thoughtful transitions" (p. 4). Prince (2004), states that Canada has a déjà vu discourse record on disability policy: “[there is the] official declaration of plans and promises by governments and other public authorities, followed by external reviews of the record, and then official responses with a reiteration of previously stated plans and promises” (p. 66). I question whether the 2014 consultation process described above is a beginning point for prioritizing funding to support services or whether it is just a means of complying with the consultation requirements in the UN Convention on the Rights for Persons with Disabilities, and perpetuating the déjà vu discourse record.

In 2011 the British Columbia government agency that oversees services to people with developmental disabilities, Community Living British Columbia (CLBC), began to close group homes and move residents into less expensive housing. Families and stakeholders spoke out against these closures and service cuts, and the government responded with a formal apology given by Doug Woollard, the interim chief executive officer of CLBC: “we acknowledge that we caused significant stress and difficulty for some families who felt that they were pressured and that they didn’t really have any options” (Kines, 2013, p.1). It is interesting to note that this apology was directed to families, not the individuals with intellectual disabilities. Imagine the risk to disabled individuals if family members were not there to protect their rights.

Families living in British Columbia are trying to deal with the pressure of caring for their family members with disabilities, but it is obvious that our current system is not
responding appropriately. For example, recently in Prince Rupert, Angie Robinson murdered her 16-year-old autistic son Robert and then killed herself (Baziuk, 2014). The family commented on CKNW radio, and said to reporter Laura Baziuk, “when Angie asked the Ministry for a residential placement, she was told nothing was available” (2014). In a press release from Inclusion BC (2014), the executive director, Faith Bodnar, commented that “[f]amilies are in the position of fighting for supports year after year, with many receiving too little and some never getting what they need. Parents become exhausted and hopeless. Clearly for some families like the Robinsons it is life and death” (p. 1). Bodnar also stated that “Inclusion BC continually brings to the attention of government that endless waitlists and lack of access to what are life sustaining supports must be a priority. Yet too often we hear stories of families who get little or nothing at all, leaving them alone or isolated. Early information indicates a repeated and catastrophic systemic failure contributed to these horrific events” (Inclusion BC, 2014, p.1).

The accounts in the media of families driven to desperate actions due to lack of resources speak to the inadequacy of our current social policies and support networks, and also reflect on challenges I will have to grapple with in my own family situation. What prompted this research was learning of the 2002 murder-suicide of a Kelowna family that had a disabled child. Maurice and Belva Baulne, facing health and financial problems, were turned down by the Ministry and were not granted funding to care for their 34-year-old disabled son, Reece. In a note to family and friends, the Baulnes said they could not face putting their mentally challenged son in a home (Moore, 2002, p. 2). According to neighbours, they [Maurice and Belva Baulne] had asked the government to provide remuneration to them for attending to the care of their son but instead the government offered
the services of a respite worker a few hours a day (Life Site News, 2002, p.1). My question was why were the social supports not available to this family that they needed to resort to such drastic measures? Why was the government unwilling to provide sufficient supports for his mother to enable Reece to live with his family?

Families need assurance that appropriate government services will be provided and funding secured for the lifetime of their dependent family members. According to the article on the Baulnes murder-suicide in the Trail Daily Times, Gordon Hogg, the Minister of Children and Families, stated that approximately 26,000 British Columbia families were caring for family members with developmental disabilities at home. Hogg is quoted as saying, “You’re in the care of the state and that costs the state $70,000 a person on average, or you’re being cared for by your family” (Moore, 2002, p. 1). Hogg also said that “he hopes for a change this year,” but said the 26,000 families currently caring for loved ones at home should not expect a windfall. “The moment you say we’re going to provide some funding to parents, they’re entitled to that” (Moore, 2002, p. 2).

To understand what current Canadian policy says regarding the protection of the rights of individuals with intellectual disabilities in safeguarding funding for program services, we need to understand the Canadian political framework. Canadian citizens are part of the state, and the state has a network of explicit and hidden power relations whose primary objective is to manage the “economic life, health, civil order, and social mores of society” (Prince, 2004, p. 63). Prince points out that power is exercised by political and bureaucratic rationality as a top down approach, categorizing people for the purpose of determining policy and program eligibility or exclusion. He states that:
Governmental practices of déjà vu discourse have included the following strategies or tactics when it comes to disability policy such as: stressing gains made on the surface while overlooking the structural gaps; consciously not taking action on further measures, an example of non-decision making; downplaying disability as a human rights issue and, at times, discrediting the use of litigation and the Charter of Rights and Freedoms to advance equality and equity claims; and promising additional actions, often in unspecified tomorrows, to be taken up, in accordance with the principles of limited government and shared social responsibility, by various institutions and groups. (Prince, 2004, pp. 68-69)

According to Prince (2011), Canada has inherited a policy mindset of institutionalization, charitable and medical interventions, and rehabilitation followed by a gradual and uneven policy shift toward human rights and a social model of disability. The last 25 years of Canadian reform has been shaped by:

- Public attitudes and the lack of information; the relative powerlessness of the disability community; the constraints of economic thinking and public finances; federal-provincial jurisdictional issues; and the absence of robust accountability mechanisms for disability policy within Canada’s welfare state. (Prince, 2004, p. 59)

Prince (2004) states that the primary obstacles keeping people with disabilities from participating within society are attitudes, the economic market, and legal and political barriers.

The Canadian socioeconomic environment does not fully provide an adequate framework to protect the rights of individuals with intellectual disabilities. Devlin and Pothier (2006) identify liberalism as a dominant ideology and principle of social organization
within Canada. Societal organization is based on able-bodied norms with the idea that an individual’s ability to produce is essential in ensuring their rights of citizenship, equality, and liberty. This notion has its roots within capitalist theories. People are valued insofar as they contribute money or labour to the economics of a society. They further state that individuals with disabilities are people who are constantly faced with reoccurring coercion, marginalization, and social exclusion, as disability is viewed as a misfortune or bad luck (Devlin & Pothier, 2006, pp. 1–2). Canadian liberalism has resulted in a type of welfare state that creates dependency for individuals with intellectual disabilities, leaving them vulnerable to the political dictates of the day. In some countries there is less of a social safety net, and people with intellectual disabilities are even more vulnerable.

At the BC provincial level, lack of support for individuals with disabilities remains an ongoing issue according to the Submission to the Disability White Paper Consultation report (Stainton & Hole, 2014). The report states that the lack of “access to services remains a serious barrier to ensuring all British Columbians have the support they need to be full and active citizens” (p. 2). The report further identifies that residential support issues for aging adults becomes more acute as their caregivers age and become unable to provide care, or pass away.

The core consideration in how we, as a society, perceive disability and allocate resources to individuals with disabilities rests in our social values. Devlin and Pothier (2006) state that “issues of disability are not just questions of impairment, functional limitations, or enfeeblement; they are issues of social values, institutional priorities, and political will. They are questions of power: of who and what gets valued, and who and what gets marginalized” (p. 9). On March 11, 2010, Canada ratified the UN Convention on the Rights of Persons with
Disabilities and it came into effect on April 12, 2010 (Minister of Canadian Heritage & Official Languages, 2014). The Convention provides a safeguard for the rights of persons with disabilities and it upholds their full participation in society. All jurisdictions are responsible for implementing the Convention through policies, programs, and initiatives targeted at providing services that support individuals with disabilities and their families. The Convention provides individuals with disabilities an avenue to bring a claim before federal, provincial, and territorial independent administrative tribunals, human rights commissions, and tribunals or courts to enforce their rights. Yet one can ask whether the federal/provincial jurisdic­tional policies adequately safeguard and uphold the rights of persons with disabilities in British Columbia. My interest in particular, is to examine whether British Columbian policies provide housing options and a means of securing a permanent place that individuals with intellectual disabilities can call home.

A number of sources of evidence suggest that policies have not been implemented effectively to protect the rights of individuals with disabilities. For example, the Submission to the Disability White Paper Consultation report (Stainton & Hole, 2014) states that in British Columbia “the vast majority of people with developmental disabilities live below the low income cut off” (p. 7). As I found that information from government publications did not initially speak of the group home closures, I then follow up on newspaper articles relating to the CLBC crisis. Lindsay Kines, Times columnist, received a national media award from Inclusion BC [formally BCACL] for his relentless efforts in fighting to have the stories of families and individuals heard in the media in 2011-12 (BCACL, 2012). In a recent news article on Community Living BC, Kines (2013) writes that CLBC is still “chronically under-funded,” and claims that “clients still can’t get what they need; but if you’ve got a good
advocacy network around you, you can push CLBC into doing something. But if you don’t have that, you get nothing” (p.1). In a previous news article by Kines (2011) he highlights CLBC actions, identifying an example of the infringement of the rights of people with disabilities: “the move to close group homes was part of an effort by CLBC to deal with a limited budget. Its plan was to shift people into less-expensive living arrangements such as home-shares and use the savings to help 2,800 people on its waiting lists” (p. 1). British Columbia policy must protect the rights of individuals with intellectual disabilities because this group comprises individuals who are substantially limited in their ability to function within a social context.

The Centre for Inclusion and Citizenship (CIC) is a university-based research centre in British Columbia focused on intellectual disability policy and practice. CIC’s submission to the Disability White Paper Consultation report (Stainton & Hole, 2014) concluded that the lack of access to services for individuals with disabilities kept them from being full and active citizens. In addition, the 2014 Robinson murder-suicide (Baziuk, 2014) suggests that a sufficient remedy to protect families is not in place. I question whether we are doing enough in Canada to ensure that the rights of individuals with intellectual disabilities are protected. One route to follow would be to present information in an international forum in order to hold Canada and the provinces accountable.

Information is limited because our federal and provincial governments cut funding to many organizations that offer independent research information. One such federally-appointed body was the National Council on Welfare, a council that advised the Minister of Human Resources on poverty in Canada for 43 years. Monsebraaten (2012) states that “since the Harper government was elected in 2006, it has ignored the Council’s research and advice
on how to address growing disparity across the country” (p. 1). In her article, Monsebraaten (2012) identified that the Council’s role was to report on welfare incomes in Canada but Ottawa has now ended the Council’s funding. As New Democratic Party (NDP) MP Olivia Chow said, “without the information, no one will be able to report on how many people this Conservative government is leaving behind...It’s called out of sight and out of mind. And don’t get in the way” (Monsebraaten, 2012, p. 1). A recent Globe and Mail article (McKenna, 2014) carried the headline, “Why Canada has a serious data deficit” identifying that:

Ottawa has cut funds from important labour market research, slashed Statscan’s budget more savagely than many other departments, and scrapped a mandatory national census in favour of a less-accurate voluntary survey. The Canadian government has demonstrated “a lack of commitment” to evidence-based decision-making and producing high-quality data, according to a global report on governance released last week by the Bertelsmann Foundation, a leading German think tank. (p.1)

Data collection is costly but lack of data might be even more costly as it leaves Canadians blind to the country’s policies and decision making processes.

Governments currently hold all the power and government must be held accountable. This study will show that the participants’ experiences provide evidence of the British Columbia government’s budget cuts, waitlists and limited access to program information, resulting in a lack of transparency and infringement on the rights of individuals with intellectual disabilities.

Parents are aware that waitlists exist for all government service programs (e.g., respite, housing, safety programs, etc.) as they are users of the system. What is not
transparent is how many individuals are waitlisted and based on what criteria, how many individuals are known (e.g., how many individuals with disabilities are living with aging parents), and who gets program funding and who gets housing. Do families need to be in crisis to get funding? Government ministries are constantly looking into stakeholder concerns but the end result is that decisions are made in backrooms without parental or self-advocate consultation.

Families must have a voice, access to information, and a vote when it comes to securing a home for their intellectually disabled family member. My intention in conducting this research is to empower the families and aid them in securing supports for their disabled family member. This research explores family advocacy now and in the future. It identifies the means that families are using to ensure that their intellectually disabled family members’ rights and freedoms are protected within Canadian society, and more specifically in northern British Columbia. In addition, this research provides an avenue for families with an intellectually disabled member the ability to voice their perspectives on housing options in British Columbia, now and in the future.

**Research Topic and Research Significance**

The label “handicapped” automatically brands individuals with intellectual disabilities and the brand brings with it social exclusion, and dependence on the social system. This study focuses primarily on adults with intellectual disabilities and their families living in British Columbia and the social supports to which they have access through government programming. Services include funding for a range of supports such as respite, community inclusion, residential support, and financial support for individuals and families. The BC Ministry of Social Development and Social Innovation funds Community Living BC
to provide supports for adults with developmental disabilities and some services for children and youth with special needs and their families (Inclusion BC, 2012-14).

Transitioning youth with intellectual disabilities at age 19 are shifted from child and youth programs to adult services. Transition planning of youth begins between the age of 14 to 16 and it includes “accessing informal community supports and developing support networks” (CLBC, 2011 May, p.1). Child services for developmental disabled individuals are provided by the Ministry of Children and Family Development (MCFD) and the Ministry of Education. Adult services are provided by CLBC and other ministries (CLBC, 2011). CLBC [a crown corporation] provides a service model “built on identifying disability-related needs that affect specific life goals, then working with clients to secure supports and services to help address those needs” (Queenswood Consulting Group, 2011, pp. 3—4). Families deal with significant challenges as they transition into adulthood and begin to contend with multiple organizations and “more stringent eligibility criteria and differences in service levels and availability” (BC Ministry of Finance, 2011, p.1).

In the Improving Services to Peoples with Development Disabilities report (BC Ministry of Finance, 2011), CLBC acknowledged that some families are finding the youth transition process very stressful as there are differences in the levels of support provided after the youth transitions to adulthood. In a study conducted by Stainton and others (2008) on the experiences of individuals with disabilities and those of family members, participants used words such as the following to describe their experiences of transition: “very scary,” feelings of “powerlessness,” “Bumpy transition,” “Everything stops,” “It’s too much all at once,” and “Floundered” at time of transition” (p.20). The BC Ministry of Finance (2011) report states that as families transition there family member into adulthood “there is no consistent
replacement for a school system that has, for many, been an important daily part of their regime” and that “financial and other supports are no longer provided through a single focal point and have varying degrees of transparency to the individual” (p. 8). The transition from youth to adulthood creates stress on families caring for an intellectually disabled individual as they experience loss of services or a gap in services as the transition to the adult oriented systems.

Intellectually disabled individuals, for the most part, cannot advocate for themselves and therefore families take on the role of advocating for the needs of their child/sibling. In the survey of family members of people with disability who are receiving services from CLBC, Stainton et al. (2010) found that 77% of the participants reported information on supports was not easily accessed, and of those who obtained information, only 48% found the information that they received was straightforward and easily understood. Building on research of this nature, my study examines the experiences of families living in northwestern British Columbia as they explore present, past and future transitioning of supports and services to accommodate for their intellectually disabled individual. I am interested in discovering if families think social services provides adequate supports and, if not, what solutions could address the gaps.

**Theoretical Framework**

My theoretical approach in this study is based primarily on policy analysis, complemented with critical disability theory, a theory that emerges from the lived experiences of family members supporting disabled individuals who experience a regime of dis-citizenship. What is required is a bottom up approach to our current Canadian system in order “to develop an anti-necessitarian understanding of disability that focuses on genuine
inclusiveness, not just abstract rights” (Devlin & Pothier, 2006, p.2). This study employs a qualitative ethnographic approach, through the collection and interpretation of case studies. Through the experiences of eight family members living in northwestern British Columbia, I examine issues regarding housing options for individuals with intellectual disabilities in this area of the province with reference to past and current policy frameworks. This study emphasizes families’ firsthand accounts and everyday realities of caring for a disabled individual and coping with the disability. I used a case study approach in order to complement the critical disability principles and policy analysis framework of this study; this included in-depth interviews with caregivers. This study is conceptualized in relation to a number of political, policy, and theoretical contexts. For the purpose of this research, I have focused specifically on two areas: disability studies and ethnography.

Our current Canadian liberalism mindset approaches disability as misfortune and favors individuals that are “normal” over the abnormal. Able-bodied, productive individuals form the majority of our society and can enjoy the fruits of their labor. What fruits can individuals with disabilities enjoy? Critical disability theory provides a means of emancipation for individuals with intellectual disabilities through a focus on human rights as identified in the United Nation Convention on Rights of Persons with Disabilities (2006).

Critical disability theory identifies disability as being about “politics and power (lessness), power over, and power to” (Devlin & Pothier, 2006, p. 9). These authors say that liberalism does not sit easily with critical disability theorists because it supports “a framework of charity and pity rather than equality and inclusion.” They also argue that liberalism “has been unwilling and unable to pursue substantive equality” and that a new
post-liberal voice has created a new critical realism. Issues of disability are questions of “power: of who and what gets valued, and who and what gets marginalized”.

Prince (2012a) identifies that Canada’s perspective on disability issues and disability studies is directly related to Canada’s dominant discourse on “neoliberalism, Quebec nationalism, the self-determination agenda of indigenous peoples, feminism, and multiculturalism” (p. 3). Mudge (2008) describes neoliberalism as having three interconnected “faces”—intellectual, bureaucratic and political:

(i) Its intellectual face is distinguished by (a) its Anglo-American anchored transnationality; (b) its historical gestation within the institutions of welfare capitalism and the Cold War divide and (c) an unadulterated emphasis on the (disembedded) market as the source and arbiter of human freedoms.

(ii) Its bureaucratic face is expressed in state policy: liberalization, deregulation, privatization, depoliticization and monetarism. This family of reforms is targeted at promoting unfettered competition by getting the state out of the businesses of ownership and getting politicians out of the business of dirigiste-style [i.e., government directed] economic management. Neoliberal policies also aim to “desacralize” [i.e., secularize] institutions that had formerly been protected from the forces of private market competition, such as education and health care.

(iii) Its political face is a new market-centric “politics”—struggles over political authority that share a particular ideological centre or, in other words, are underpinned by an unquestioned “common sense.” On the elite level, neoliberal politics is bounded by certain notions about the state’s responsibilities (to unleash market forces
wherever possible) and the locus of state authority (to limit the reach of political decision-making). (pp. 704-705)

Mudge (2008) argues that neoliberalism’s three faces share a common ideological core and that is “the elevation of the market - understood as a non-political, non-cultural, machine-like entity--over all other modes of organization” (p. 705). As parents trying to secure a future for our children, we must understand our provincial, federal and municipal systems in order to begin to advocate. Even if we accept that the market is prime, the challenge becomes how to secure a portion of the funding governments collect from us as taxpayers for our children’s wellbeing. Families ought not to be left vulnerable to the political party of the day.

The British Columbia government has had constant pressure to fund program services for individuals with intellectual disabilities through the decades but they have failed to improve program funding and social policy. Families have carried the burden of caring for their disabled children with limited support from government. I believe that information is power, and the lack of information creates powerlessness.

McChesney (1999) defines neoliberalism as the “political economic paradigm of our time” (p. 7). It consists of:

The policies and processes whereby a relative handful of private interests are permitted to control as much as possible of social life in order to maximize their personal profit. Associated initially with Reagan and Thatcher, for the past two decades neoliberalism has been the dominant global political economic trend adopted by political parties of the center and much of the traditional left as well as the right. These parties and the policies they enact represent the immediate interests of extremely wealthy investors and less than one thousand large corporations. (p. 7)
McChesney (1999) further states that “neoliberalism works best when there is formal electoral democracy, but when the population is diverted from the information, access, and public forums necessary for meaningful participation in decision making” (p. 9). McChesney (1999) describes the American system but I believe our Canadian context is similar as Canadians are being cut off from the information we need to participate in the decision making process. Essentially, citizens have experienced a loss of access to a democratic process. I believe we need to get back to the table so we can have a voice. Canadians with disabilities and their families need to insist that the lack of support for individuals with intellectual disabilities is a human rights violation and that our government needs to be accountable.

Statement of the Problem

Crawford (2008) estimates prevalence of intellectual disability in Canada at “0.7 to 3 percent” (p. 3). According to Statistics Canada (2006) there are 27,130 individuals with developmental disabilities living in British Columbia. The Queenswood Consulting Group (2011) CLBC Review reports that presently there is limited support provided to families who want to transition their adult child or sibling from their family home into an alternative housing option. This problem is compounded in the case of individuals with developmental disabilities living in northern British Columbia because residence options are limited. CLBC’s growing caseload of transitioning adults with disabilities has caused concern within CLBC and with stakeholders (Queenswood Consulting Group, 2011). Limited government funding has created waitlists in all areas of CLBC program services. Transition plans exist for families but actual implementation of the plans often lags for years. Waitlists for housing the young adult at 19 years of age continues to be an issue. Families are left to house their
disabled adult child year after year, at their own expense with limited funding supports from the provincial government.

MCFD funding ends at a person’s 19th birthday, and families are encouraged to begin the CLBC planning process of transitioning their child prior to their 16th birthday. Families must apply to CLBC for funding to access one of the following residential housing options: group homes/staffed residential living, supported living/semi-independent living, cluster living/intentional communities, and home sharing. Crawford (2008) states that:

*Group home* models provide both housing and support to people with disabilities. Typically the place is a regular home in the community, although some have specialized modifications specific to disability (e.g., ramps, widened doorways and halls to meet fire codes and other regulations). Usually, support services are provided full-time to residents when they are physically present, e.g., after returning in the evening from a day program, employment centre or regular job in the community. Such homes can range in size up to 15 people and can be publicly or privately owned and operated. (p. 21);

*Semi-independent living* services provide support to people with intellectual disabilities to live quite independently with a few hours of supportive services each week from paid staff. Support may be in the form of help with grocery shopping, paying bills or budgeting. Individuals receiving these services may live alone or with roommates in their own home or apartment. (p. 23)

*Supported living* is a residential service model that is based on the provision of only those supports required by the individual who lives in their own home, with supports tailored to meet individual needs. (p. 23)
Cluster living has many variations: Campus type living or Village Communities (Crawford, 2008, p. 22). Emerson (2004) describes cluster housing as being associated with “village” or “intentional” communities of intellectually disabled individuals. Arrangements are typically a campus-style in that: operated by charitable foundations; relatively independent of public services; support more able individuals with intellectual disabilities. Emerson’s study on cluster housing identified that individuals were: “more likely to live in larger settings, be supported by fewer staff, be exposed to greater changes/inconsistencies in living arrangements, be exposed to more restrictive management practices (seclusion, sedation, physical restraint)” and so forth. (p. 187)

Home sharing model involves a home owned or rented and occupied by an individual or family, in which they provide paid care and support for one or more unrelated persons with an intellectual disability. (Crawford, 2008, p. 24)

The CLBC eligibility process for accessing housing uses a priority ranking tool. A person with an intellectual disability and/or the person’s caregiver are scored according to or the following criteria:

- The caregiver is struggling to cope with the client in the current home setting;
- The client has lost or will imminently lose his/her current home setting;
- The client needs more complex supports;
- The client has high priority behavioural/mental health and medical needs; and/or
Scores assigned range from 0 to 110. If a score is lower than 70 then the family support and shelter is deemed stable, and the individual’s needs are not considered to be acute and the individual is waitlisted. Essentially, what this means is that only those individuals who are imminently in crisis receive housing, and the families of the rest of the applicants are expected to continue to provide a home for their adult family member with an intellectual disability on an ongoing basis. Parents are expected to house the adult family member until housing becomes available.

Grant and Whittell (2000) see a need for research on “how families manage as they go through life-cycle transitions where the course of disability, changes in support networks, family life-stages and service transitions may all bear upon coping resources and coping strategies” (p. 258). They argue that families require a professional assessment to evaluate if the families are coping over the life course or at least at important transition points of their intellectual disabled family member.

According to Stainton and Hole (2014), transition planning remains a concern in that there is a “lack of timely and sufficient access to needed supports” (p. 5). If youth are not transitioning into suitable residential options, where are they going? Stainton and Hole (2014), estimate that 41% of individuals with intellectual disabilities are living with their families (p. 3). Families are urged to contact MCFD when their child is 14 to 16 years of age to begin the transition planning process. A transition planning workbook such as the Inclusion BC (2013) “On My Way” provides families with direction on how to plan for their intellectually disabled family member’s future. Crawford (2008) reported that “relatively few people with intellectual disabilities are living within the formal system of ‘residential care facilities’” (p. 1); rather they are more likely to be living one or both parents or alone or with
others who are not related by ties of kinship. Families are the primary caregivers but they too are waitlisted for supports and services. The issue is that parents are aging and the lack of supports and services for parent caregivers providing housing options within their own homes beyond the age of 19 has created a crisis situation. Who will take care of these individuals when parents can no longer provide the support? Is it feasible to think that siblings might take on this role? According to Bigby (2000) aging parents become more reliant on formal services for their intellectually disabled child when siblings do not take on the parental role of advocacy. Emotional costs to parents providing a lifetime of care are enormous especially when the needs of the intellectually disabled family members are high. In addition, an economic cost to society exists in that parents are diverted from paid work to one-on-one home care.

The BC Law Institute and Canadian Centre for Elder Law (2010) elevated the need for care work law reform to support family caregivers to balance paid work and unpaid caregiving. Their report noted that taking care of vulnerable adult family members covers managing:

Medical care, assist with intensely intimate elements of personal care, and provide a range of services including emotional support, meals, housework and mobility assistance – all tailored to the needs of the particular loved one and organizing around the other demands paid work, family and community pose on a caregiver’s time and energy. (p.1)

The report further identifies that there is a cost in terms of energy and time. The possible ramifications on caregivers are “emotional stress, health deterioration, exhaustion, social isolation … as well as work-related consequences such as a reduction in employment
income, pensionable earnings and opportunities for career development" (BC Law Institute and Canadian Centre for Elder Law, 2010, p.1). How does government alleviate the wear and tear that family caregivers experience? Planning, collaboration and funding are essential. Unfortunately, waitlists and the constant need for advocacy to get services have put a strain on families. The Robinson murder-suicide (Baziuk, 2014) is one example of the ineffectiveness of our current system, and the stress that this puts on families due to the lack of supports provided to parents caring for an individual with an intellectual disability.

Using guiding principles from critical disability theory, the past and the current policy framework, and input from family members advocating for the users (their children or siblings) of the system, I examine possible ways that the British Columbia system can change. CLBC was established in 2005 to provide disabled-related services and supports for adults with developmental disabilities. A few years later the Board was restructured, input from families was removed and a top down approach dictated by funding allocations was created. Families became numbers based on scores, and the contextual situation of the families was no longer taken into account. It is unclear how a baseline of options for developmentally disabled individuals can be established without input from families. A number of recent family consultations have occurred in British Columbia but so far they are only the beginning of a dialogue between families and government.

Studies show that families with a disabled child experience social isolation due to financial, time and respite limitations creating a stressful environment that can affect family members’ mental health (Gardner & Harmon, 2002; Patterson, 2002). Close up, parents with a disabled child are more likely to experience stress, lower levels of marital satisfaction, poorer mental health and lower levels of well-being (Gardner & Harmon, 2002). Patterson
suggests that “families living with chronic health conditions require public policies
and programs, and adequate funding of these, to enable a high quality of life through full
community integration and access to the resources that all citizens enjoy” (p. 359). Hearing
the experiences of caregivers supporting an individual with an intellectual disability is a key
issue explored in this study.

**Research Questions**

The primary question in this study is: “What are the experiences and perspectives of
parents and adult siblings of individuals with intellectual disabilities regarding locating a
home for their disabled family members once they reach adulthood?” The secondary
question is: “How do families supporting individuals with intellectual disabilities perceive
policies of the Government of British Columbia regarding housing options for individuals
with disabilities?”

I approached this study within the theoretical, political, and policy contexts as
described above, and also from my own situated position. As such, I have identified myself
as a researcher and parent of a child with an intellectual disability and explored my own
story. I fleshed out the dominant discourses embedded in the stories of the families I
interviewed and with the information I gathered from my own reflexive journaling. An
ethnographic approach to my qualitative research provided me with the tools needed to
answer the fundamental question: In our current economic situation in British Columbia, how
are families coping while trying to locate and secure homes now and in the future for their
intellectually disabled family member?
Chapter Two: Literature Review

"Knowing what happened earlier is critical for grasping the meaning of what currently is going on. By gaining a historical understanding, we avoid the arrogance of presentism, whereby we focus on what is current as if there never had been another time that is the basis for the state of the present" (Peshkin, 2001, p. 243).

Historical Overview of the Notion of Disability

Over the centuries, perceptions about individuals with intellectual disabilities have shifted from a religious belief that disability was a sign of deviance, to disability being a human rights issue in that all citizens have the right to be accepted for what they can contribute to society. Specifically, Canadian policy on disability was first developed using a "law-and-order approach" (Jongbloed, 2003, p. 204); prior to 1840, disabled people were kept at home or jailed (Jongbloed, 2003). Canadian policy then moved towards a protection model (Jongbloed, 2003). Ultimately, a socio-political model has provided the current framework for Canadian policy in that "disability stems from the failure of the social environment to adjust to the needs of people with disabilities rather than from the inability of disabled individuals to adapt to societal demands" (Jongbloed & Crichton, 1990, p. 25).

Since the publication of the Obstacles Report in 1982, the Canadian government and provinces have made efforts to improve the lives of individuals with disabilities by focusing their goals on inclusion and equity. Bond and McColl (2003) report that "there is considerable evidence that despite all this effort, disabled Canadians are not much better off than they were 30 years ago" (p. 4).

Canadian disability policy evolved as part of collectivist social policies influenced by colonial links to Britain and Europe fostering the belief in respect for authority and in the acceptance for the need for state intervention (Jongbloed, 2003). In the 1840s and 50s, the
Canadian government assumed the responsibility for mentally retarded people by feeding, clothing and housing them. Once government had assumed this responsibility, public pressure ensured it maintained its role (Simmons, 1982). Initially, both criminals and individuals with mental illnesses (no differentiation was made between intellectual disability and mental illness) were housed together in jails. Gradually policies shifted from caring for persons with intellectual disabilities to protecting them, which was the main justification for an asylum model of care (Jongbloed, 2003).

Fakhoury and Priebe (2007) state that the emergence of modern psychiatry in the mid-1800s “was closely linked to the establishment of large asylums” (p. 313). Several factors came into play in the development of asylums: the social welfare movement, urbanization, location, and morality. The social welfare movement was a means for the state to provide care for the ‘feeble’ in asylums “built with a degree of architectural splendor and with good living conditions” (Fakhoury & Priebe, 2007, p. 313). During mid-1800s families were moving from rural settings to industrial urban centers. Asylums provided families with accommodation and basic care for their mentally ill family members.

Asylums were normally located outside industrialized towns in remote locations. Remote locations were ideal for hiding mentally ill individuals who exhibited bizarre and odd behavior that did not fit into the strict moral codes, elegant appearance and morally correct behavior of the Victorian era (Fakhoury & Priebe, 2007).

By the end of the 19th century in Canada, large provincial institutions provided the means of housing “senile older persons, those with intellectual impairments, mental illness, or syphilis” (Jongbloed, 2003, p. 205). Institutions also provided a social support system for those without means of support, including children, adolescents, and adults such as
unemployed young women, and served as a mechanism of social control (e.g., keeping a watch on unmarried mothers who had violated the moral standards of the time). The institutionalized were cared for at public expense but at the cost of their individual freedom (Jongbloed, 2003).

At the beginning of the 20th century, when industrialized societies were economically depressed, asylum intake increased but funding to asylums decreased. Asylums became overcrowded, and particularly during World War I, many patients starved to death. As Fakhoury and Priebe (2007) state, "over time, asylums became notorious for poor living conditions, lack of hygiene, overcrowding and repeated cases of ill-treatment of patients" (p. 313). The increasing numbers in asylums and unacceptable standard of care prompted professionals and the public to find other means of housing the mentally ill and intellectually challenged. This led to "reforms in the widespread closure or downsizing of asylums and the development of some form of community mental health service" (Fakhoury & Priebe, 2007, p. 313) as well as alternative housing options.

In 1998, Salvatori, Tremblay, Sandys, and Marcaccio suggested that until not long ago, the longevity of individuals with intellectual disabilities was significantly less than it is now, but now their life expectancy has increased and they are living to old age. For instance, a child with Down syndrome born in the 1930s was not expected to live beyond 11 years. So why the increase in longevity? Salvatori et al. (1998) state that increased life expectancy is the result of "improvements in health care, living conditions, and overall quality of life" (p. 253). According to Janicki and Ansello (2000), individuals with intellectual disabilities are living longer because of improved health care and because their parents are living longer and able to provide them care within the home. The increased longevity of parents is significant.
because the majority of all people with developmental disabilities live in the community with their families.

An evaluation of the needs of this population in our communities needs to be undertaken. The current government supports provided to parents caring for a family member with an intellectual disability must be evaluated to ensure they are adequate. Government staff have identified and estimated numbers of intellectually disabled individuals entering the system within the upcoming years. The BC provincial government needs to show how they are going to accommodate the upcoming pressures of aging parents and the need for residential services for their intellectual disabled family members. Funding measures must be in place to ensure that this population is provided for to assure quality of life.

Salvatori et al. (1998) state that “despite the increasing number of [intellectually disabled] individuals, relatively little is known about them, their life experiences, or their needs. They remain a largely invisible, undervalued, and often overlooked population, seldom being the focus of new policy or program initiatives” (p. 250).

In Canada, the trend is a move away from institutions to a community model of support. According to Fakhoury and Priebe (2007) closure of institutions began to occur in the 1950s. In British Columbia, the last residential institution for people with intellectual challenges was closed by the provincial legislature in 1982. In 2003, the Provincial government apologized to former residents of Woodlands Institution for incidents of mental, physical and sexual abuse it deems likely to have occurred over many years (de Courcy, 2004). Kennedy Shriver and Kennedy (2000) states that all citizens have similar basic needs: “a safe home, a secure financial situation, physical well-being, and independence” (p. xxiii).
Now that individuals with intellectual disabilities are free from the confines of institutions in British Columbia, where are the supports needed to ensure that their basic needs are met?

Community Living British Columbia (CLBC) is a crown agency established in 2005 under the Community Living Authority Act, to provide services to adults with intellectual disabilities and their family through a progressive delivery model that helps meet the individual needs of each client and provides a vehicle for them to participate in the community. Its mandate is to deliver supports and services in British Columbia. CLBC services include supports to families such as homemaker support, respite and support coordination. CLBC also provides professional supports and community inclusion programming such as employment, skill development, community based and home based activities. In addition, CLBC provides residential support such as staffed-residential, shared living and supported living residential services (CLBC, 2011, October).

According to the 2013-14 Community Living British Columbia (CLBC, 2014a) Annual report, CLBC delivers a wide range of services to 15,942 adults with developmental disabilities. CLBC reported that “5,829 were receiving residential and community inclusion services; 928 were receiving supported living resources and community inclusion services but that the majority of the other adults and families were receiving community inclusion services and respite, or other services such as assistance to develop a support plan” (p. 4). CLBC has experienced an increase of seven percent in requests for services for adults with developmental disabilities, autism, and fetal alcohol spectrum disorder (FASD) within this past fiscal year and they expect that in the next five years, an increase of 13 percent will occur in the number of individuals between the ages of 45 to 64 requiring residential services and supports (CLBC, 2014a). In addition, CLBC states that each year, hundreds of youth
turning 19 become eligible for support and services. In 2013-14 CLBC reported 739 youth turning 19 and 292 new adults over 19 registering with them (CLBC, 2014a, p. 18).

Individuals with intellectual disabilities and their families are struggling to enhance or at least maintain their current level and future access to supports and services. Parents caring for their intellectually disabled family member at home past the age of 19 are constantly struggling to receive supports such as respite. CLBC (2011 October) defines respite as providing families with “Respite provides families with a break from the challenges of caregiving. Families can use this service in the manner that best suits their unique circumstances. The service may be delivered in the family home, the home of a respite provider, or within the community” (p. 5). Respite funds are limited and families must apply to access funding. Families are normally placed on a waitlist until funding becomes available or if situation with family is at crisis levels. Information is crucial for these families as they battle the current system in order to acquire resources to support their family member. According to Battle and Torjman (2013) “information is the life blood of sound public policy and good government. Without comprehensive and reliable statistics, policy making will be done in the dark” (p. 1).

One organization that provided such information was The National Council on Welfare (NCW), an independent, federally appointed watchdog body, created by an Act of Parliament in 1969. The Council provided the federal government with research and advice on poverty and equity issues in Canada. The NCW was abolished by the Harper government in March 2013. With respect to the abolishment of the NCW, Chase and Grant (2013) comment that “At 30,000-foot level it will be difficult to spot the difference, but as users drill down to smaller communities or small geographical areas they will likely discover the
findings are fuzzier, or even missing” (p.1). In Chase and Grant’s (2013) article, Ian McKinnon, chair of the National Statistics Council, states: “For small groups and small areas, it will be harder to get a clear view of Canada” (p. 1).

So how will this small subculture group of individuals with disabilities advocate with this gap in knowledge? During my research, I noticed a number of organizations that provided information to Canadians slowly become eliminated by governmental budget cuts. If our government continues to cut information access by cutting funding it will become extremely difficult to obtain reliable information. The Caledon Institute for Social Policy is a nonprofit organization with charitable status that provides an independent and critical voice on policy. It is independent as it does not rely on government funding and it is not affiliated with any political party. In the absence of federally appointed bodies, the Caledon Institute could be a source of reliable public policy information needed for families to advocate for supports and services.

As mentioned previously, Canada ratified the UN Convention on the Rights for Persons with Disabilities on March 11, 2010, thus providing Canadians with disabilities a tool in removing the barriers that prevent full and effective participation in society (Collin, 2012). The UN Convention provides a good base, but I believe that ultimately Canadians need to move beyond theorizing about social responsibility and move towards viewing all people as being part of a community. The Canadian government must see the current reality faced by individuals with intellectual disabilities and their families and act upon it.

One strategy for advocates of Canadians with disabilities is to appeal to a higher international organization like the World Health Organization (WHO). The WHO’s report, Better Health, Better Lives (2010a), states that the current reality of children with intellectual
disabilities is that they remain one of the most vulnerable population groups. The report recommends that barriers that prevent them from “participating as equal members of society and full enjoyment of their human rights, including the right to health” must be tackled (p. 1). The report further states that additional action is needed to ensure that their right to health and high quality health care needs to be safeguarded. Sections of the WHO report emphasize the need for concerted action to promote the health of children and adolescents, and that individuals with intellectual disabilities must have measures in place to prevent inequality in health. They need protection from neglect, abuse, and discrimination in order for “them to live stimulating and fulfilling lives in the community with their families, with a view to a successful transition to adulthood” (p. 1). The WHO report also comments that the right to health includes enjoyment of “family life, education and participation in cultural life, recreation, leisure, and sport” (p. 1). The report identifies that all children need to grow up in family environments that are safe and in which they have the ability to participate in community. The WHO report emphasizes that institutionalization, past systems of classification, treatment and so forth, resulted in lower life expectancy as access to health care, healthy lifestyles and healthy living was not attainable.

The WHO document lists ten priority areas that need to be addressed in order for persons with intellectual disabilities to achieve fulfilling lives. These are listed in Table 1.
Table 1: WHO – Ten Priorities to Address Needs of Intellectually Disabled Individuals

| 1 | Protect children and young people with intellectual disabilities from harm and abuse; |
| 2 | Enable children and young people with intellectual disabilities to grow up in a family environment; |
| 3 | Transfer care from institutions to the community; |
| 4 | Identify the needs of each child and young person to ensure planned support; is available to make seamless transitions at each life stage; |
| 5 | Ensure that good quality mental and physical health care is coordinated and sustained; |
| 6 | Safeguard the health and well-being of family carers; |
| 7 | Empower children and young people with intellectual disabilities to contribute to decision making about their lives; |
| 8 | Build workforce capacity and commitment; |
| 9 | Collect essential information about needs and services and assure service quality; and |
| 10 | Invest to provide equal opportunities and achieve the best outcomes. |

Note: Adapted from WHO, Better Health, Better Lives, 2010b, pp. 4-5.

My study uses this framework to address changes needed in British Columbian policy that affect individuals with intellectual disabilities and their families.

In Canada, families caring for members who are intellectually disabled are “under increasing stress, along with many Canadian families, working hard to stay afloat economically, and juggling work and family life” (Hanvey, 2002, p. 3). We live in an era where government holds financial power – who gets funding for supports and services and who does not. In this neoliberal economic climate, the current BC government supports are deteriorating as spending is prioritized and does not adequately support this subcultural group as seen by the current waitlists for housing and supports. Family supports, work/family policies, family economic security, child care, recreation, and so forth are matters that need to be addressed specifically as they impact people caring for family members who have intellectual disabilities. In British Columbia, parent-driven movements for social justice and equality have striven to advance the rights of individuals with intellectual disabilities and their families. Groups like Moms on the Move have demanded that governments be
accountable for their actions affecting the most vulnerable population -- the intellectually disabled.

Policy Analysis

Policy guides the development and delivery of BC’s disability programs now and into the future. My study critiques the BC policy framework that has situated disability in various ways and I look at how these policies have impacted resource decisions and the lives of people with disabilities and their families.

Policy analysis “explores the relationships between goals and objectives, and seeks out objectives that are at once truly representative of the fundamental values inherent in the goals and consistent with well-grounded objectives in other areas of social policy” (Bickenbach, 1993, p. 5). A policy framework guides the direction of programs and funding supports needed by people with intellectual disabilities and their families. In order to allow intellectually disabled members to participate fully in the economic and social aspects of society, appropriate policies must be in place.

This study looks at the goals and objectives of parents caring for intellectually disabled family members and whether government policies are adequate to maintain their quality of life. If current policy is not meeting the needs of intellectually disabled individuals and their families, policy solutions must take into account the voices of families navigating the system. Policy solutions are “defined courses of government action (including, if appropriate, inaction) that manifest concretely what is instrumentally valuable in the chosen objective. Policy solutions are moulded to existing conditions and subject to continuous review” (Bickenbach, 1993, p. 5).
Prince (2012a) points to a social liberalism model of activism to contend with the current neoliberal political discourse and policy making. He says that the Canadian disability movement “expresses a style of activism distinguished by values and beliefs which are a form of social liberalism” (p. 1). Whereas his primary objective is to examine interest groups and social movements and situate them within the realm of neoliberalism, my aim is more pragmatic.

My study shows that participants see a need for change to current policies that dictate who gets funding for supports and who does not. In order to change policy, social movements like Moms on the Move have facilitated a means of providing a voice to this subculture. Ideally, individuals with intellectual disabilities and their families need to have a voice in policy development such as they did when CLBC was initially founded.

Critical Disability Theory

In order to explore societal views of disabled individuals in BC, I reviewed the introduction to *Critical disability theory: Essays in philosophy, politics, policy and law* (Devlin & Pothier, 2006) along with *Canadian disability activism and political ideas: In and between neoliberalism and social liberalism* (Prince, 2012a).

Devlin and Pothier’s (2006) perspective aided me in exploring the questions of politics, power, and powerlessness. Their perspective also provided a theoretical foundation for understanding the rights of individuals with intellectual disabilities and using a bottom up approach. Prince’s (2012a) work pointed towards a social liberalism model of activism as a strategy to contend with the current neoliberal political discourse and approach to policy making in order to protect the rights of all BC citizens.
Devlin and Pothier (2006), in the introductory chapter of their edited collection of essays on critical disability theory, inquire into the limitations and potential of disability theory. They assume that disability is “a matter of politics and power(lessness), power over, and power to” (p. 9). In my study, I see the current BC system driven by policy initiated by CLBC; I do not see a mechanism that allows for dialogue between CLBC and the users of the social supports and services, whether individuals with intellectual disabilities or their families. The initial premise of CLBC was to include the voices of parents of individuals with intellectual disabilities, in legislation and policy regarding housing options for individuals with intellectual disabilities in British Columbia.

Devlin and Pothier (2006) identify four facets of critical disability theory. The first of these relates to language, definitions and voice. The primary concern of critical disability theory is the use of language; a person with a disability should not be referred to as a “disabled person” as the term implies that the entire person is disabled because of a specific impairment (p. 3). Second, relates to contextual politics and the politics of responsibility and accountability. Contextual politics is also of importance to critical disability theory because it is a theory that emerges from the lived experiences of persons with disabilities, rather than from the political agenda of the party in power (p. 9). The third relates to philosophical challenges. Disability theory is concerned with the philosophical challenges within our social construct as identified by Justice Gerald La Forest:

This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the ‘equal concern, respect and consideration’ that section 15(1) of the Charter demands. Instead, they have
been subjected to paternalistic attitudes of pity and charity. (Eldridge, 1997, p. 668)

The fourth relates to citizenship/dis-citizenship. Devlin and Pothier (2006) contend that individuals with disabilities experience a "regime of dis-citizenship" and associate this with "deep structural economic, social, political, legal and cultural inequality" (p. 1). Their point is that people with disabilities are viewed as being less than citizens, and thereby are disenfranchised from the fundamental rights and social benefits that other members of the society can take for granted.

Devlin and Pothier (2006) state that "critical disability theory demands a reconceptualization of the nature of, and the lived relationships among, the citizen, the self, and the community, reconceptualization that transforms the basic assumptions of contemporary philosophy, politics, policy, and law" (p. 20). My research contributes to a description of the lived experiences of families of individuals with disabilities and may provide direction towards rethinking the nature and impact of our politics, policies, and law.

Self-organization of the disability community is one means of political activism displayed within Canada. The 1970s independent living movement was an example of this type of activism. Identity politics was another means of activism in that self- and societal-conceptions of people with disabilities focused on positive self-created conceptions.

Prince’s (2012a) main concept is that individuals with disabilities should not be defined by their disability. He noted that the main driver of disability activism in Canada is a politics of socio-economic redistribution. He believes that the democratic politics of representation promotes more accessible, empowering, and accountable policy-making structures and processes. A key idea here is that all individuals with disabilities should have
rights and the ability to work and contribute to society based on their own abilities. As contributing members of society, individuals with disabilities are entitled to gainful employment that provides them with a means of caring for themselves and purchasing the services they require. These perspectives are in alignment with the principles that underlie my research.

In his book, *No pity: People with disabilities forging a new civil rights movement* Shapiro (1994) states that pity oppresses and that “people with disabilities are demanding rights, not cures” (p. 14). The disability movement has been a means through which, historically, individuals with intellectual disabilities have gained human rights standing. The disability movement in Canada has political roots and engages many aspects of government from cabinet ministers to political parties and elections. Ultimately we need a belief that each person is a moral whole with equal ethical worth and that there is value in community as individuals within communities are part of a larger social whole, a common humanity (Prince, 2012b). Values such as these have been articulated in critical disability theory, and form the foundation of core UN and WHO documents, and inform and provide a foundation for federal, provincial, and municipal policies and practices.

**Feminist Theory**

All of the caregivers interviewed in this study are women. Esquivel (2014) states that: “care has long been considered to be the ‘natural’ responsibility of women: around the world it is still the case that women provide most of the unpaid care in households and communities” (p. 424). This cost is not accounted for when the BC government cites the costs of providing supports to individuals with intellectual disabilities. The cost to mothers of caring is not costless. Esquivel (2014) states that: “costs of providing care, which fall
disproportionately on women, include foregone opportunities of education, employment and
earnings, political participation, and leisure time” (p. 424). This study provides a glimpse of
the cost to mothers caring for their disabled family member and the future costs to female
siblings, who often are expected to take over care where the parents no longer can provide
care and a home. Beyond the cost to individuals, there is a social cost that is gendered. These
individual and social costs are not accounted for in funding analysis.

**Canadian Disability Rights Movement**

Perspectives on the rights of people with disabilities has changed over the past 100
years, from a time when no rights existed with the law and order approach to a human-rights
model in which government empowers people with developmental disabilities under the
1982 *Canadian Charter of Rights and Freedoms*. This is the basis for the current model of
governmental residential options.

Rioux (1994) states that in the “first 80 years of this century, the policy and research
agenda in disability was driven [first] by biomedical concerns and second by service delivery
models” (p.1). Initially, disability was described as an individual problem rather than as a
social relationship.

A more contemporary viewpoint is that “a mentally or physically disabled child
should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance
and facilitate the individual’s active participation in the community” (United Nation

Brown, MacAdam-Crisp, Wang and Iarocci (2006) state that within the last 50 years
a movement away from institutionalization has occurred and individuals with intellectual
disabilities have been placed into supported communities with their parents or within
residential housing units. They comment that the added responsibility on parents, predominately mothers, creates considerable challenges for family. Brown, MacAdam-Crisp, Wang and Iarocci (2006) further question the family’s ability to function with the added responsibility of caring for a member with an intellectual disability. This study looks at the impacts on families carrying the load of responsibility and the dangers of overtaxing them if there are not adequate governmental supports in place.

Disability discrimination laws, such as section 15.1 of the Canadian Charter of Rights and Freedoms passed in 1982, promote human rights, dignity, and equality of people with disabilities. Section 15.1 specifically addresses the protection of the rights of individuals with disabilities. It states:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (Canadian Charter of Rights and Freedoms, 1982)

Article 19 of the United Nation Convention on the Rights of Persons with Disabilities provides the foundation for protecting the right of individuals with intellectual disabilities to live within community. In addition, the WHO’s movement from advocating for an institutional model of housing individuals with intellectual disabilities to a community-based approach provides a socially grounded approach to maintaining rights and freedoms. The WHO report, Better Health, Better Lives (2010c) recognizes that historically, vulnerable and marginalized members of society were placed in large residential institutions. Individuals were assessed as either needing medical care in long-stay hospitals, or needing special
education in centralized residential special schools often away from family homes. The intent of these institutions was to provide centralized care and services but the effect was isolation from families and communities. The institutional model of housing individuals with intellectual disabilities was wrought with numerous problems from overcrowding, physical abuse, and so forth.

In Canada a few larger institutions housing individuals with intellectual disabilities still exist, but efforts are being made to close these institutions to ensure that the residents have the right to live and participate in their communities. For example, in March, 2013, the Alberta government announced the closure of the North and South facilities of Michener Centre in Red Deer. Frank Oberle, Associate Minister of Services for Persons with Disabilities, stated that closing the institution would allow “125 individuals to take their rightful place within community” (Canadian Association for Community Living, 2013).

It is notable that the provincially-run Michener Centre had seven reported cases of residents abusing other residents, several which involved physical attacks. Given this, it is particularly notable that the institution remained open. The Canadian Press – Red Deer Advocate (2012) obtained records from Alberta Health indicating that they had “39 incidents of abuse of people with intellectual disabilities for the period between July 1, 2010 and May 1, 2012” (p. 1). The article further identified an incident reported involving a person dying after being scalded by hot water. In the same article, Cheryl Chichak of Alberta Human Services stated that “Michener was a large environment so you’re going to see more incidents there than a home with just a couple of people living in it” (Canadian Press - Red Deer Advocate, 2012, p. 2). Malacrida (2006) states that the practices of institutionalization and segregation that occurred at the Michener Centre reflect broader discourses and practices
prevalent in North America during most of the 20th century, in relation to science, eugenics, and fitness. She emphasizes that we need to learn from the experiences of individuals interned at Michener Centre so we do not repeat mistakes from the past.

The WHO report also states, in relation to the transfer of care from institutions to community, that:

Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high-quality community support. New admissions to such institutions should be stopped through the development of community services. *(Better Health, Better Lives, 2010c, p. 1)*

Yet, as I have argued here, it is clear that these community systems are not fully in place in communities across Canada. Nor are they funded adequately to ensure that all individuals with intellectual disabilities have this option.

**Canadian Social Policy Framework**

Canadian disability policy evolved from collectivist social policies fostering a belief in respect for authority and the need for state intervention *(Jongbloed, 2003)*. Since the publication of the *Obstacles* report in 1982, the Canadian government has made efforts to improve the lives of developmentally disabled individuals. *Obstacles* described the aspirations of disabled individuals: that they be treated with respect and dignity; that they have the same opportunities as other Canadians to participate fully in society; and that society accommodates their disabilities *(Bickenbach, 1993)*. It transformed disability issues “from an ill-defined collection of social problems to the object of social policy analysis” *(Bickenbach, 1993, p. 4)*.
In March 2010, Canada ratified the United Nation *Convention on the Rights of Persons with Disabilities*. This provided a new direction for public policy and social development that was attempted to close the gap between Canadians with disabilities and those without. Marie White, National Chairperson of the Council of Canadians with Disabilities, announced that:

[the Convention] signals the end of an era where people with disabilities were seen as objects of charity. Ratification of the Convention makes real our goal of recognition as full and equal citizens of Canada. Ratification of the Convention puts an end to the medical model and opens exciting new opportunities for building a more inclusive and accessible Canada. Canadians with disabilities applaud the Government of Canada for this historic action. (Government of Canada, 2010, p. 1)

Although Canada has ratified the agreement, a lot more work needs to be done.

Even in today's society, persons with disabilities are contending with human rights issues as budgets are being scaled back, limiting access to supports and services that would ensure quality of life. This is then leading disabled individuals to live with their families, fend for themselves with many living on the streets or being incarcerated, and so forth.

Jongbloed and Crichton (1990) assert that:

There is growing recognition that, in order to improve the status of disabled people, the emphasis must be placed on the external environment rather than on individual physical and economic skills, but this recognition has not yet led to changes in those areas which are central to the social and political status of disabled people. (pp. 27–28)
Devlin and Pothier (2006) identify critical disability theory as “emerge[ing] from the bottom up approach, focusing on the meaning of the lived experiences of individuals with disabilities rather than narrative of progress of liberalism” (p. 9). Individuals with disabilities and their families’ voices need to be added when discussions on resource allocations begin.

History of Housing Options for Individuals with Developmental Disabilities in British Columbia

In Canada prior to the mid-1800s, institutional segregation was the norm as a means of housing individuals with intellectual disabilities. A more well-rounded community-based living and social inclusion model was adopted in the 1970s. However, the success of deinstitutionalization in Canada has been limited because of “the lack of a broad conceptual framework of inclusion that, based on a disability paradigm, neither alienates nor requires mentally ill patients to succeed in being fully integrated in the community” (Fakhoury & Priebe, 2002, p. 190). According to the WHO report, Better Health, Better Lives (2010a), the institutionalization model fosters “inhumane, dehumanizing, coercive and abusive forms of experience that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death” (p. 2). As discussed previously, the term mentally ill is being used broadly to include people with intellectual disabilities in this context. The report further states that what is necessary is a shift in how people who have disabilities are viewed. There needs to be a change:

From viewing them as objects of charity, health and social protection towards viewing them as subjects with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent and on being active members of society. (WHO, Better Health, Better Lives, 2010a, p. 3)
British Columbia was the first province in Canada to close all its large institutions—the last institution was closed in 1996—allowing people with intellectual disabilities to participate in their communities and become full citizens (Inclusion BC, 2012-14). The provincial government initiated an administrative review of Woodlands as a result of allegations of physical abuse at the school (Woodlands). The institutional environment enabled perpetrators to victimize an extremely vulnerable population (McCallum, 2001). Although there had been an abuse policy in place since the 1970s, abuse did occur at Woodlands because there was a lack of internal safeguards to prevent abuse. A review of deaths and critical incidents produced many examples of unexpected deaths occurring in questionable circumstances, and the potential for abuse was still a problem at the time of the review.

The last finding is notable. Abuse continues today although disabled people in BC no longer live in large institutions like Woodlands. The report acknowledged three realities:

1) A large part of the vulnerability of people with a disability is that they live a life dominated by professional service providers who may be in a position to take advantage of their clients. This situation continues today although it may take place in community residences of all kinds but often cluster housing…

2) Notwithstanding BC’s new guardianship legislation that is based on a presumption of competence for everyone, that presumption can easily be set aside for people who are visibly mentally handicapped; and

3) There is always the threat of a return to an institutional response to the care needs of people with disabilities hovering over the social service system. Understanding what life was like in Woodlands will presumably act as a deterrent to any
retrograde change in policy to return to an institutional model. Some community living options, however, remain mini-institutional in fact and therefore how to prevent abuse occurring again remains critical. (McCallum, 2001, p. 23)

Institution closure was the beginning of providing human rights to intellectually disabled individuals, enabling them to live independently, and make their own choices on living arrangements and how they will spend their time. In order to ensure that deinstitutionalization is a success, appropriate resources must be provided.

In the No Place Like Home report, Crawford (2008) identifies that “adults with intellectual disabilities are more apt in recent years to be living with their parents than was the case in the early 1990s…The system of community living supports has been under considerable stress and waitlists have been commonplace in recent years” (p. 10). This subculture group’s demand for housing will only rise in the future as demographic factors contributing include: “increased prevalence of people with developmental disabilities from the baby boom generation who are currently cared for by elderly parents; increased life expectancy and lower mortality rates; and increased survival rates of young people with severe and complex disabilities” (Crawford, 2008, p. 11).

In the Review of Community Living BC report, CLBC acknowledges that:

Families may experience challenges contending with this transition due to the different eligibility criteria, service levels, service availability and client methods… Some of the services offered by CLBC are waitlisted due to funding limitations and, in some communities, a lack of service provider availability. (BC Ministry of Finance, 2011, p. 5)
Originally the CLBC Board of Directors consisted of stakeholders, which included individuals with developmental disabilities and their families, as well as individuals from the general public. In 2010, the composition of the board changed to comply with recommendations resulting from a review by the Crown Agency Secretariat in 2009. The change required the new board to include members with a broad range of experience and knowledge suitable to effectively govern CLBC. Now 11 members appointed by the Minister of Social Development and Social Innovation comprise the board. The Board of Directors has committees which analyze issues and provide recommendations for consideration (BC Ministry of Finance, 2011, p. 6). Effectively, this means that persons with disabilities and their families have reduced influence in shaping CLBC policies and governance.

In British Columbia, youth become adults when they reach 19 years. The Review of Community Living BC notes that “the delivery of services to individuals with intellectual disabilities requires Ministry of Child and Family Development (MCFD) and CLBC and other governmental agencies to collaborate effectively to facilitate a smooth transition for youth entering adulthood. This calls for all relevant government organizations to share information, and for the preparation of a transition plan before youth become 19” (BC Ministry of Finance, 2011, p. 15).

Empowerment is derived by “enhancing, securing and/or legitimating the power of oneself, another, or a collective” (Stainton, 2005, p. 289). Stainton (2005) believes that current policies and practices have moved away from the paternalistic model of caring for individuals with disabilities to a system of choice. Emphasis was initially placed on removing barriers to participation and providing legal protection from discrimination as seen in the Canadian Charter of Rights and Freedoms. The legal protection was effective in preventing
"involuntary sterilization, unfair discrimination at work and the denial of the right to vote, medical treatment or educational opportunities" (p. 290). Stainton (2005) is concerned with "how policy structures and instruments need to change to support the empowerment of individuals to exercise their rights and citizenship" (p. 290). He posits that capacity (how choices are made) and the ability to act on that choice are crucial. He further explains that if you provide someone with the freedom to decide on an action you must also provide funding to support the choice otherwise there is no choice at all.
Chapter Three: Method

"Ethnographers are not outsiders looking in. They have to be reflective insiders, negotiating roles and subjectivities, looking out." (Coffey, 1999, p. 57)

Government Supports in British Columbia for the Intellectually Disadvantaged - the Questions

The research for this study is designed primarily as an ethnographic study with a reflexive component from this researcher. However, in addition because of my participation in this subculture an autoethnographic component was added. This chapter provides information regarding the purpose and the main research questions explored in this study. In addition, characteristics of participants recruited for this study are described. The primary data collected was through the use of semi-structured interviews with family members, and this researcher's own journaling.

Richards and Morse (2013) describe ethnography as a way of exploring cultural groups. A thick description of the culture is explored in ethnography. Culture encompasses "the beliefs, values, and behaviors of cohesive groups of people" (Richards & Morse, 2007, p. 53). Mayan (2009) states that the focus of language that the group utilizes can be used to understand and learn about what is going on in the culture. Researchers are now using ethnographic methods to explore smaller subcultural units such as individuals with a particular shared illness or condition (Richards & Morse, 2007).

Turning to the autoethnographic component of this study, I felt that my experiences caring for a child with an intellectual disability enabled me to better understand my participants’ experiences. Ellis (2004) identifies that an autoethnography, in reflexive ethnography, involves researchers studying a group or culture and using “their own experiences in the culture reflexively to bend back on themselves and look more deeply at
interactions between self and other” (p. 37). It is a means of writing about the researcher’s personal experiences and their own relationship to their culture. Ellis describes the autoethnographer as initially looking through: “an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experiences; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations” (p. 37). I was able to explore my own feelings in greater depth and breadth as I looked at myself and my participants in this study focused on a better understanding of what was happening to families caring for an intellectually disabled individual as they tried to secure a place to call home.

Individuals with intellectual disabilities and their families are the subcultural group explored in this study. This research utilizes a focused ethnography as it “is a more targeted form of ethnography and is led by a specific research question, conducted within a particular context or organization among a small group of people to inform decision making regarding a distinct problem” (Mayan, 2009, p. 39). The question is: “What is happening to families supporting an individual with an intellectual disability as they located and secure a home now and in the future?” To this end I used qualitative, open-ended interviews. The specific questions I explored are: What are the experiences of my research participants with government supports? What are my experiences of government supports? What is the history of government supports? Finally, I asked: What is the current situation of government supports?

**What are the Experiences of Research Participants with Government Supports?**

**Participants.**

The study involved eight people from six families who are providing support for their
family member with an intellectual disability. All participants read a Participant Information Letter (see Appendix A) and signed a letter of informed consent (see Appendix B). Participants included parents who have children under the age of 19 (minors) and those who have adult children over the age of 19. I also interviewed some siblings. As per my initial ethics approval, any sibling that I interviewed had to be 19 years of age or older. However, I requested and obtained special permission from the UNBC Ethics Board to interview one sibling under the age of 19, and parental consent also was obtained. By including both parents and siblings among the interviewees, I gained insight into the perspectives of various family members who were responsible for securing housing for their family members with an intellectual disability.

My primary method for recruiting participants for the study was using posters which I put up around the communities where the study took place (see Appendix C). The text of my poster requested voluntary participation in a UNBC Research Study on family perspectives on housing options for individuals with intellectual disabilities. The poster identified the rationale for the research as to better understand family members’ lived experiences in locating a home for their family member with a disability to help rethink the nature and impact of our politics, policies and law. My initial projection of the number of participants I was seeking was three to five family members.

One of the challenges for a study of this nature is that access to family members is difficult because this specific population is not regularly seen in public places and family members cannot easily be approached. The only way I could identify a parent that had a child with an intellectual disability was by seeing them with a child that had noticeable physical characteristics.
The second method of recruiting participants was by word of mouth. Initially I tried approaching individuals within the community but found that this was an ineffective method of recruiting as I needed to infer that individuals I saw had an intellectual disability. The following is an example of trying to approach a parent to become part of my research study. I was visiting the public pool and in the change room I encountered a parent and a child that exhibited limited intellectual functioning and adaptive behavior. The child also had some physical characteristics of a Down syndrome child such as my own. I imagined saying to the parent caring for this child, "Does your child have an intellectual disability?" Yet intellectual disability is so stigmatized in our society, this question to me translated to "Is your child less than the normal child?" I felt uneasy pointing this out to the mother, not wanting to identify her child's diminished capacity, even though no one else was in the change room. Upon further reflection of my initial thoughts regarding the mother and child, I felt shame that I should think that the child with the disability was limited in their ability to do things as opposed to just exhibiting different characteristics of a human being. As a result of this experience, I realized I could not approach unknown community members to invite participation in the study. Ultimately, all participants in this study were referred by word of mouth by a member of the community who had seen the poster or who had otherwise heard I was conducting research on families caring for an individual with an intellectual disability.

The third method of recruiting participants that I considered was by requesting access to government databases of families with an intellectually disabled member living in the community and utilizing services. I approached Community Living British Columbia and asked if they could forward an email with my research request to parents caring for an individual with an intellectual disability but was told that due to freedom of information
concerns they would not be able to accommodate my request. For this reason the only alternative was to rely on word of mouth and talking to friends within the community that might know someone caring for an individual with an intellectual disability. As I was not seeking a representative sample, but rather individual accounts of lived experience, this means of gaining participation was not problematic in terms of the study design.

The criteria to participate in this study were: you are currently a parent or sibling of an intellectually disabled family member; you are 19 years of age or older; you will be involved in locating a home for a family member with an intellectual disability or already have in the past located a home for a family member with an intellectual disability; and you are willing to participate in this study’s research process voluntarily. The research began with an initial phone call to participants to determine whether they met the criteria. Participants were told that they had been referred to me by friends or acquaintances and that I was conducting a study to gather information on caregivers securing a home for their intellectually disabled family member. Eight family members participated in the study.

Each participant was asked to choose their own pseudonym for themselves and their disabled family member; otherwise, I created one myself. Pseudonyms also were used in describing the communities, such as for towns, streets, and so forth, as an additional means of protecting anonymity. The participants were informed during the first interview that I was a parent caring for a son with an intellectual disability and I wanted to hear about their lived experiences regarding planning for a home for their own intellectually disabled family member.

Demographic information identified in Table 2 identified a range of parent age groups sampled. All of the participants were female. They ranged in age from 15-19 to 65-69. Of the
family member with an intellectual disability, two are female and four male. They ranged in age from 5-9 to 35-39.

Table 2: Participant Characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Education</th>
<th>Gender</th>
<th>Relation</th>
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<td>Foster</td>
<td>Male</td>
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<td>Female</td>
<td>Parent</td>
<td>Lilly</td>
<td>Biological</td>
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<td>Female</td>
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<td>Jasmine</td>
<td>Adopt</td>
<td>Female</td>
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<td>Sibling</td>
<td>Alex</td>
<td>Adopt</td>
<td>Male</td>
<td>30-34</td>
</tr>
<tr>
<td>Tashan²</td>
<td>40-44</td>
<td>High School</td>
<td>Female</td>
<td>Parent</td>
<td>Walton</td>
<td>Biological</td>
<td>Male</td>
<td>15-19</td>
</tr>
<tr>
<td>Poggy²</td>
<td>15-19</td>
<td>In High School</td>
<td>Female</td>
<td>Sibling</td>
<td>Walton</td>
<td>Biological</td>
<td>Male</td>
<td>15-19</td>
</tr>
</tbody>
</table>

Note. From Interview demographic data collected.
¹ Parent/Sibling participants (family 1) and interviews conducted separately
² Parent/Sibling participants (family 2) and interviews conducted separately

The majority of participants in this study were married with the exception of one who was a single parent. I was fortunate to interview two mother-daughter pairs – Mary and Anne, and Tashan and Poggy. Mary had adopted a boy named Alex and her daughter Anne presented her view of what she saw for her adopted brother’s future. Tashan, speaking about her blood son, Walton, and his sister Poggy presented their experiences and plans for Walton’s future. Interviews were held separately and at different times. This study tried to recruit both male and female participants but only female participants volunteered. This was not surprising as mothers in most cases are the primary caregivers of their intellectually
disabled family member.

Data Collection.

This study utilized a semi-structured life-world interview, focusing on obtaining descriptions of the life world of the participants with respect to interpreting the meaning of their experiences and perspectives of locating a home for their intellectually disabled family member once he or she reaches adulthood and for those still living with the family, at some time in the future. I developed an open-ended interview protocol based on the Kvale and Brinkmann (2009) model. (See Appendix D for the interview questions.) I followed Kvale and Brinkmann's (2009) seven stages of interview investigation: 1) thematizing or constructing the study's purpose; 2) designing the protocol for the interviews; 3) interviewing; 4) transcribing the data; 5) analyzing the data, which involves coding and discovering themes; 6) verifying; and 7) reporting findings.

Data collection for this focused ethnographic study utilized one-on-one interviews. All family participants lived in northwestern communities in British Columbia. As described above, I employed purposeful sampling techniques to deliberately select participants immersed in the subculture of families caring for an individual with an intellectual disability. Through the use of purposeful sampling and posing specific research questions, I believe that I gained a valid representation of this specific subcultural group's shared experiences.

Initially only three to five families were anticipated for this study but I extended the number of participants as additional participants came forward and represented different age groups, both in terms of the interviewees, and also family members with a disability. The different age groups provided an opportunity to explore how the families received information on various service transition points. An attempt was also made to include
families that rely on different models of supportive housing within Northwestern British Columbia. Three groups not represented in this study as no one came forward: fathers, First Nation participants [although one participant cared for an intellectually disabled First Nation individual] and low income families.

I made use of audio-recorded primary participant interviews, supplemented by notes and my own journaling. Semi-structured interviews were face-to-face and scheduled in advance at a time convenient to the participant. My research interviews began on December 17, 2011, and ended February 19, 2012. Eight participants came forward to provide information for this study. Interviews were held at the UNBC Terrace campus in an interview room, with the exception of one interview; this participant wanted to meet in her home. I chose to hold interviews at the University of Northern British Columbia as it provided an interview room allowing for confidentiality and a place without distractions where the participant could focus on the questions asked.

Two audio recording devices (Olympus digital voice recorder (Model WS-321M); Apple MacBook Pro 2008 – audio recording only) were used to record the oral interview data. Initially I placed the Olympus digital voice recorder in front of the participant and the MacBook Pro in front of myself. I decided to alter the place of the digital voice recorder as I noticed that the participant was always focusing on the recorder and not the conversation. I decided to place the recorders on books in front of the participant and this seemed to take the emphasis away from the recorder and back to the topic being discussed. Each interview was subsequently transcribed.

Six broad topics were explored during the interview. These included a description of their family; the participant’s comments on the future quality of life that she anticipated for
her child or sibling with an intellectual disability; and her family's preparations for the future. As well, I asked about participants' experience with provincial policies and programs relating to housing options within British Columbia for their intellectually disabled family member; their expected future quality of life for themselves and their other family members; and what might aid their family in securing a home for their child with an intellectual disability.

My strategy for collecting data was to first introduce myself as both a researcher and as parent of an individual with an intellectual disability. I provided the participant with a research participant information letter (see Appendix A). I informed the participants that the reason for the study was to better understand a family's experience and perspectives of locating a home for their intellectually disabled family member once he or she reaches adulthood. I identified that they were invited to participate in this voluntary study because they were current caregivers of an individual with an intellectual disability.

I explained that initial participant interviews lasted approximately 60 to 90 minutes and that I would forward a transcript to them once I had transcribed the interview audio recordings. In addition, I advised participants that I would schedule a follow-up interview to allow for feedback on transcriptions relating to accuracy, clarity and to allow participants to ask for material to be omitted if they felt their anonymity was compromised or to add material if they felt they had missed articulating on a particular topic. I reviewed the benefits and risks involved in participating in this study, such as the contribution to research, and providing knowledge to the community. I stated that they could refuse to answer any questions and stop the interview at any time. I informed them that pseudonyms would be used in the final research document. I asked participants if they wanted to choose their own
pseudonym, otherwise, I created one myself. As a way of showing my appreciation for their
time and effort, I provided each participant with a $10 gift certificate to Tim Horton's.
Before the interview began, I re-emphasized that the participation in this study was voluntary
and that they could withdraw at any time. If they chose to withdraw all interview data would
be destroyed immediately.

Interviews began with a review of the consent form (Appendix B). I outlined items
such as: purpose of the research study, the ability of the participant to withdraw at any time
during the study, confidentiality, benefits/risks of participating in the study, and so forth. A
signature was collected from the participant providing consent to participate in the study. I
collected demographic information at the end of the interview such as: participant education,
age, and so forth (see Table 2).

Each parent was either provided a hardcopy of the transcribed interview data or
emailed the transcribed document for review and feedback or comment. All participants with
the exception of one accepted the interview transcription as correct. The exception was the
oldest participant who chose to edit minor identifying items in the transcript herself as she
felt that the pseudonyms were not enough. If someone in her community read this study, she
was concerned that they might be able to identify small details identifying her daughter,
thereby removing anonymity. Once the first and second interview transcriptions were
approved by each participant as correct, I proceeded to the data analysis stage of my
research.

Data Analysis.

I transcribed all of the interview data with the exception of one recording, which was
transcribed by a professional transcriber due to time constraints. Ethics approval was
requested and granted from UNBC to authorize the transcription of this final audio interview. The recording not transcribed by me was reviewed to ensure accuracy and to gain familiarity with the data.

Transcribed interview data allowed me to convey participants’ reflections as quotations to illustrate themes emerging from the raw data. I used an inductive thematic approach to analyze the interviews, and supplemented it with my own subjective reflexive journaling data to understand the meaning or worldview of participants’ experiences in the interview data. In addition, I utilized computer assisted qualitative data analysis software (CAQDAS) to aid in the coding of the raw data I collected. I incorporated demographic data and my research notes into my data analysis.

The initial step of handling the raw data was to transcribe the interviews verbatim. The transcription process was intense and I decided to let the transcriptions sit for a two-month period before I began the thematic analysis. Once I had temporal distance between myself and the data I was able to get a better sense of the overall social and personal matters that each participant brought to the topic area. I continued to carefully read and re-read the transcript data I collected. My next step was selecting the CAQDAS. I decided to use NVivo10 because the University of Northern BC provided this software free and I had prior course work experience using it. My hand-written reflections were used to enrich the interpretation of the data, as they recorded my own feelings regarding the emerging participant interviews.

Thematic Analysis.

This study used a qualitative method of thematic analysis (Boyatzis, 1998; Lapadat, 2010). Utilizing this data-driven approach allowed the themes to emerge from the data via
inductive coding. I read through the data and identified any patterns or themes that emerged from the participant interviews. The themes that emerged from the data were coded by identifying the similarities of common themes identified by participants in the study. By working out the conceptual links between codes and categories in the data, I developed a theoretical model to explain my findings. NVivo facilitated the process of recording, coding and connecting interview data. NVivo also provided a means of organizing and analyzing the massive amount of data text. I found NVivo to be an excellent tool in breaking down the massive amount of interview data. Data reduction was accomplished by rigorous and systematic reading of interview text required to develop a summary of themes or categories of the raw data. Similarities of themes across participants were also explored.

Themes emerging from the data provided a means of identifying issues that caregivers of individuals with intellectual disabilities were experiencing while utilizing the programs available to them in the provincial system in British Columbia. In addition, I looked for other prevalent themes or patterns within the data and throughout the entire data set.

My first layer of coding identified segments of interview data that I categorized (see Figure 1). I refined the initial categories into subcategories providing a better picture of the participants’ most important categories. My next layer was to group themes into subthemes to view. NVivo enabled me to code, identify themes, and come up with a preliminary interpretation. This software was used to draw tree models and display data in tables and lists. In addition, the software helped in the compilation of the data.

Overall, these analysis processes, along with the use of research memos and writing, aided me during the interpretive process. I found that a key theme emerging from the
interview data was Northwest issues that participants were experiencing. Therefore I added an additional theme: Northwest Issues. Figure 1 shows the tree structure of themes identified through inductive coding.

My Experiences of Government Supports

Researcher

In this section, I describe how I am positioned in the research, as a parent of a child with a disability, as a community member, and as a researcher. My story is that I am a fifty year-old parent with an eleven year-old son with an intellectual disability. As a parent of an intellectually disabled child, I draw upon my own experiences to broaden and deepen the scope of the study. I know that my child will not be capable of protecting himself or
becoming self-sufficient by adulthood. My question is: Who will protect and care for my child when I am gone?

This personal perspective and question has led me to want to better understand the perspectives and experiences of other parents and family members who care for a person with a disability. How do they provide a home and plan for the future? I see provincial monies designated for social programs dwindling, and I see the housing options for individuals with intellectual disabilities becoming more limited. The participants’ and my own personal experiences of the current situation families are facing is a concern for future quality of life for children like my son. The information gathered here provided insight into how these families cope and how I can cope. I have reflected on these matters as a member of the community committed to advocacy for vulnerable members of society, as a researcher, and also as a parent.

Data Collection.

Through the use of a reflexive journal, I situated myself within this research and the subculture represented by my participants. In addition, I documented my interpretive insights in a notebook as I journeyed through the research process. I created mind maps utilizing the iMindMap7 software to provide a visual image of my own understanding of the government system of supports as I researched topics.

Data Analysis.

The reflexive data was analyzed separately as it involved self-observation and reflexive investigation in the context of my focused ethnographic notes. My hand-written reflections were used to interpret the data of my own feelings regarding the emerging themes from the interviews. I wrote a reflexive account by journaling throughout the study to
document my decision making process through the study. In my journal, I recorded my thoughts, impressions, and feeling relating to each interview, and linked these impressions to my own situation as a parent. In addition, I created mind maps to provide a visual representation of data collected that helped me situate myself within the overall social framework and participant experiences. The mind maps and interpretive insights were used as strategies to synthesize the key themes and interpretations that emerged during the analysis.

**What is the History and Current Status of Government Supports?**

This research is nested within a description and analysis of the policy framework in BC that governs how resources are allocated to support individuals with intellectual disabilities and their families. The families providing information for this study provided a means of contextualizing their lived experiences and situate the issues they are encountering in trying to secure a home for their intellectually disabled family member into the overall BC policy framework. The stories provide a strong impetus for change as family members caring for an intellectually disabled family member are struggling and trying to find solutions to the inadequate funding of government supports.

**Resources.**

Research by L. Jongbloed (2003) provided the primary source of historical information in this study. Important additional historical material included website information as follows: Community Living British Columbia (2010a) website; World Health Organization; Human Rights legislation; Government of BC policy; newspaper articles; historical websites; and CBC radio interview information. The current government support information on community living was retrieved from websites as follows: Community Living
Data Collection.

Historical data was collected utilizing the UNBC library search engine using key words such as developmental disabilities, history, British Columbia and Canada. In addition, newspaper articles were sourced to provide information on the lived experiences of families caring for an individual with an intellectual disability. In particular, information on families in crisis was explored. In addition, I compiled information from websites such as Community Living British Columbia and Inclusion British Columbia (formally called British Columbia Association for Community Living – name change in 2014).

Current data collected stemmed primarily from government reports and parent advocacy group information. For information on housing options statistics I emailed Kristie Kristofferson (Government Communication and Public Engagement office of the BC Ministry of Social Development and Social Innovation). I requested statistical information (province-wide and/or the northwest) on current number of individuals in group homes, independent living, nursing homes, family homes, and estimates of adults not currently accounted for in the system.

Data Analysis.

Data was analyzed utilizing mind map to create two tables providing chronologies of dates relating to disability policy within Canada and British Columbia (see Tables 3 and 4). I was able to situate each participant’s experiences within the time period of social framework changes. The summary of policy development in BC provided the policy analysis framework.
discussed above in the literature review. It also helped to illuminate how participants’
experiences were impacted in different ways over time, depending on the age of the disabled
family member, thus aiding in my interpretation of the participants’ stories.

**Validation of this Study**

This research provided documentation from the literature, the voices of
parents/siblings supporting an individual with a disability and my own voice as a
parent/researcher advocating for the well-being of my child’s future. I utilized all three
sources: literature, parent interview data and self-reflexive notes enabling me to triangulate
research material. The three sources of data provided me with a means of deriving
conclusions, inferences, and propositions of how we as a society in British Columbia can
support families and individuals with intellectual disabilities. As an additional means of
validating this research one participant was asked to review the final thesis manuscript.

As a researcher and parent of a child with an intellectual disability, I contributed an
emic view of this research topic. By identifying my own worldview and providing reflexive
journaling I was able to provide an additional angle to this study. Through the use of several
data collection techniques (interviews, reflexive journal writing, and a literature review), the
data collected can be cross-checked with other data for accuracy of conclusions through a
process of triangulation. Goetz and LeCompte (1984) define triangulation as a means of
preventing the researcher from validating initial impressions quickly, allowing for a greater
depth of reflection and interpretation (p. 11).

My final means of validating my data was through having one of the participants read
the final thesis manuscript. The comments received from the participant are presented in the
results section.
Ethics Procedures

I adhered to the Tri-Council Policy Statement on the Ethical Conduct for Research Involving Human Subjects which governs all human-subject research in Canadian universities. I obtained ethics approval from the Research Ethics Board of the University of Northern British Columbia prior to conducting research. The objective of the interviews was to provide participants with an opportunity to tell their stories, and to gain information that may be used to positively influence provincial housing policy development to support individuals with intellectual disabilities and their families. There were potential benefits in participating, as outlined in the letter to participants, and potential harms were unlikely as anonymity strategies were strictly adhered to.

This research was conducted under the approval of the University of Northern British Columbia Research Ethics Board under certificate numbers E2011.1019.116.00 and E2011.1019.116.01 [amendment to include participant under 19 years of age]. University research ethics boards require that research participants are protected by anonymity. In my thesis, therefore, I use pseudonyms and only general descriptors of demographics to protect anonymity.

I realize that ethics must be carefully considered when researching the private lives of individuals who live under difficult circumstances. Therefore, I provided the voluntary participants in my study full information about the design and purpose of my study so that they were able to give informed consent. The data I collected is safeguarded in a locked and secure location at the University of Northern British Columbia, Terrace campus. Information and digital recordings are stored in a locked filing cabinet in my office. I made every effort to maintain sensitivity and moral integrity while conducting my research.
I had parents and siblings review their transcripts to ensure they were comfortable with the material I presented in my thesis. I gave participants the opportunity to withdraw the information I had collected about them at any time if they no longer wanted to participate, and assured them that all data collected pertaining to them would be destroyed five years after the successful thesis defence.

I documented my own experiences with the system in my reflexive writing. As I encountered new information from library searches, statements in the newspaper, interactions with professionals in the MCFD and CLBC system I reflected on these pieces and how it affected my own perceptions and feelings. I recorded notes along with creating diagrams to allow myself to visualize the interactions of participants and myself within the system.

**Summary**

The interviews were semi-structured and provided insight into the worldviews of people who had intellectually disabled individuals in their family, as well as into their experiences, hopes, and feelings. The data that participants shared provided me with a new vantage point into the social lives of family members. The interview data also provided additional information on how to assess options of housing and community life for individuals with disabilities living in northern British Columbia.

I found myself reflecting on every piece of information I read. As I heard the voices of parents and siblings I reflected on my own family situation and how my family was coping with preparing for our son’s future. The interview data provided me with my first encounter in the world of my subcultural group – caregivers providing support to family members with an intellectual disability -- which helped me to understand, accept, and re-imagine my role as an advocate. Questions arising from the interview data provided information on the
experiences of my research participants with government-assisted housing supports and
government non-housing supports. Furthermore, I gained an understanding of the current
government supports pertaining to housing and other supports [e.g., respite] through the
historical, participant data and my own experiences.
Chapter Four: Results

In this chapter, I begin by introducing the eight participants: Grace, Candice, Alexis, Sasheen, Mary, Anne, Tashan, and Poggy. I provide a summary of the key elements of each one’s story with selected verbatim accounts. I describe the themes that emerged from the interview data and explore the impacts of the BC policy framework on families caring for an intellectually disabled family member. As a result of the findings specific areas were explored: the experiences of the family caregivers; researcher’s experiences as part of subcultural group; lessons from Canadian history; the present and the future in British Columbia; and recommendations. Finally, I provide a participant evaluation of the thesis results to substantiate the validity of the findings.

The Experiences of the Research Participants with Government Supports.

The Family Caregivers’ Stories.

Grace.

Grace (65–69 years old) is the foster-care provider for George (35–39 years old). Grace has a high school education and owns her own house. She has provided care for George for at least 20 years and considers George to be her son: “Yeah. I want him to be buried with us. I’ve got a daughter that died, my husband is cremated and buried on top of her so will I [Grace] be and I want George to be too.” Grace initially fostered George when he was between the ages of 8 to 12 and then transitioned to providing George with a home sharing service that Community Living British Columbia has funded since the age of 19. Grace is the primary caregiver as she provides “24 hours a day, 365 days a year.” George normally accompanies Grace on holidays as she finds it easier for him to travel with her rather than finding someone to take care of him as she states it costs her “about $200 bucks a
day to take care of him, you know, and I think and I get about $2 dollars an hour [from CLBC].”

Grace’s primary concern, as expressed in her interview, is to provide care and support for her family. Grace was focused on the future care of her foster son and worried that government funding would not be available to enable George to have a good quality of life. She stated:

Well, I’m not getting younger. This is home to him and I when I go away and leave him at home, it almost kind of turns into uhm a disaster. Like where’s mom, when is she coming home? Got to go home, got to go home. This is his spot. So what’s going to become of him?

Grace was confident her biological daughter would care for George if Community Living British Columbia would allow a transfer of services to her daughter if she, Grace, were ever unable to care for George. As Grace states:

My son-in-law and daughter said if anything happened to me where I couldn’t take him [George] they would probably move in here. They’ve got a much bigger house than I do so uhm but they would probably at first move in here to stabilize him [George] and then slowly get him to stay at their house.

Grace was unsure if the Ministry [CLBC] would allow the automatic transfer. She stated: “They said they will and it’s in their records but to say something and do that. I’ve worked with the Ministry a long time so do I put lot of water behind that? No.” Grace’s primary thoughts are about the care of George after she dies, and the burial of George when he dies. Grace would like to see something in writing to ensure that George is taken care of while he is alive and after he dies. She said that it would be good “to have something in writing. To
know he [George] won’t be buried there [biological parents’ home town]” but rather with her [Grace and family].

*Candice.*

Candice (60–64 years old) cares for her biological daughter Lilly (30–34 years old). Lilly resides with her parents and receives support services from Community Living British Columbia. Candice and her husband are aging and are concerned about Lilly’s future care. They are content with the current supports Lilly receives in her community but are concerned with future advocacy to ensure supports are maintained. Candice expressed that she is fine with Lilly living with her at the moment but knows that with her [Candice] aging soon she will need her own supports. She wants to ensure Lilly is cared for in the future. Candice mentions future advocacy in that “Lilly really needs to probably go live with her brother” as her biological brother could advocate for his sister’s needs.

Candice’s primary concern is maintaining her daughter’s quality of life which, up to now, she has done through advocacy. Candice is a strong advocate for her daughter as shown in her description of her fight to obtain an equal right to education and inclusion in the regular school system. She stated:

When Lilly was very young she went to a Child Development Centre. We started her off there which was a really good thing, they really helped me and her a lot. At that time a ‘handicapped’ school was still going. It was a special needs school. It was the dark ages back then, the school was separate, and we said at the time she’s not going to a ‘handicapped’ school….It was never done. We just said she’s going to her neighborhood school where her brothers will go and that wasn’t received that
well....But you really don’t want to be pioneering these things because we had a lot of meetings and a lot of discussions and a lot of broad shouldering, you know.

Candice is a natural planner thinking about her daughter’s future care, while at the same time not expecting the government to protect her daughter’s rights and well-being. Candice had attended a workshop regarding housing options and she commented on the presentation stating:

They presented the different options and people commented on them and what they thought their use was and whatever. You get a lot of these workshop things and a lot of government groups come and they do their little chats but nothing really happens up here [Northwestern BC].

Candice was considering moving from her current location in the Northwest to be nearer to one of her other children as she thought that her son would have to take on the advocacy for Lilly and Lilly’s support.

Candice was concerned with future supports and services that Lilly received. She said:

I don’t know who advocates for the disabled adults who are in this town, actually. Some have no family here. They’re on their own. I think the Alternative Community Services [pseudonym] helps where they can. I don’t know because social workers seem to be fewer and far between. I presume they would have been the advocates before but there isn’t any around it seems like. We don’t have one. We used to. I haven’t really looked into getting one because they keep changing the name of the social system and it’s ministry of children, family and then it’s ministry of housing and then it’s ministry of this and that. And people come and go. I don’t know who
looks after things. It's sad really but I think we're into the situation now that if she stays here there is a lot of things she is connected with but there is no one to really oversee anything so that's a problem.

Candice thought that she would need to move, because Lilly had to be near her sibling. She stated: “He [brother] will ensure that she is looked after properly.” Candice had already scoped out the services in the new location [where her son lives] to ensure that her daughter’s quality of life could be maintained through family advocacy. I understood Candice’s primary concerns as being advocacy and safety. She believed that Lilly could not live independently. “She [Lilly] would need some caregiver there all the time” to ensure a safety framework was in place.

My impression of Candice was that she seemed fragile and tired. But I also saw her as a warrior, constantly strategizing and fighting for her daughter so that Lilly can enjoy, contribute to, and be included in the community to enhance her quality of life.

Alexis.
Alexis (50–54 years old) cares for Jasmine (5–9 years old) with her husband in their own home. Jasmine is adopted and lives with her adoptive parents, receiving Ministry of Children and Family Development respite and medical funding. Alexis is advocating for the current needs of her daughter and does not have the energy to look at the housing options for the future as “that’s a worry down the road.” Alexis’ focus is on building friendships for Jasmine and locating information to allow her the ability to advocate for services.

Alexis’ primary concern was to ensure quality of life for Jasmine through community and friendships. She valued relationships; she was constantly pursuing avenues that would result in friendships for her daughter. She stated:
It isn’t going to, I hope, I hope, isn’t gonna disappear once it becomes socially
unacceptable to hang around with someone who is so obviously not the same level as
you. Which is gonna happen eventually? I mean, she got a couple of friends she plays
with at school....I don’t hear parents saying, ‘Oh, they’re so good with my kid.’ What
they’re saying is, ‘Julie and Anne are really good friends.’....Well, I can’t say that.
What I have is a couple of girls at school who play really nicely with Jasmine. And
where, where, when I think of my own growing up, my network of friends, without
them where would I have been? So what is her network?
Alexis’ concern was how she, as a middle-aged parent, should advocate for her
daughter, particularly in the future: “That’s, that’s probably what we do all this for
[cultivating friendships] is our whole lives centered around what’s going to be like for her.”

Alexis did not think she could rely on other family members to care for her daughter
and ensure her rights when, in the future, she would no longer be able to advocate for
Jasmine. She was also extremely worried that the current government funding that provided
necessary income to support her daughter’s and her family’s basic needs would not be
available in the future. Alexis mentioned that she had approached the Ministry for support to
address Jasmine’s current needs but was told, “Oh, there’s no money for that, and there’s no
money for that, and there’s no money for that. And there’s no money for that either.”

Alexis is an advocate but she worries that:
If she needs help, dealing with the community when I’m gone which is my next fear
what will happen? I can, right now, I can get her to a point I hope that she can have
friends, and she can have activities, that she can do as best that I can do. Uhm but
then when I’m gone what does she do? Who’s gonna to take care of my child? Who I
don’t know will be able to take of herself. Who’s, who’s gonna ensure that she has a life after we’re gone. Because she doesn’t have siblings, and she doesn’t have uhm, uhm, extended family you know when, when my husband and I are gone… There is nothing.

Alexis is an older parent who questions: “Is she (Jasmine) going to stay at home? Am I going to be able to handle her?” She was concerned about her ability to access respite services in the future as she knew this support would end at 19. She asked: “Where does she go from there? The only thing I know are the group homes.” Ultimately, Alexis is focused on the present challenges in Jasmine’s life and didn’t seem too hopeful about the necessary supports and services being available in the future. She indicated that she struggles with the lack of information and funding available to support Jasmine.

Sasheen.

Sasheen (45–48 years old) is a single mother who cares for her biological son, Cliff (20–24 years old) in her home. Sasheen has postsecondary education and is employed in a professional capacity. Sasheen has a debilitating neurological disease. Their household consists of Sasheen and her son Cliff. Cliff currently pays rent with “disability so that’s a little bit nice but he [Cliff] costs me more than I make up, there is no doubt about that.” Sasheen has located a potential housing placement for Cliff, and he is currently on a waitlist for housing. Sasheen believes Cliff can live on his own as long as he has access to supports and services. Sasheen’s primary concern, given that her health is declining, was who will look after her son’s well-being once she was no longer able to advocate for him.

My impression of Sasheen is that she is a planner. She has accessed many of the current government services available to Cliff. Her employment has given her insight into
different avenues of funding, but her concern is to secure services that will ensure her son’s safety and well-being in the future. Despite her professional insights, Sasheen is another parent struggling with access to information on government supports and services. As Sasheen stated:

My concern is my kid. Right. I don’t need, I don’t care about all those other, I mean, I do, but you know I mean in a global, we-all-love-each-other kind of way. But the reality is I want what my kid should be getting [funding] for what he’s got [his intellectual disability]. Anyway, but yeah lots and lots of advocating for a long time. And even this if I hadn’t phoned up and said ok so ‘what’s up with the housing and when?

Independent living is one of the avenues she is pursuing, and her son is waitlisted for such accommodation. Sasheen has researched the housing units available for Cliff but noted that some of the units available had specific criteria. “There was one place where they have a one room for somebody with autism but not intellectually disabled and that’s I guess been empty for the longest time but unless you fit that criteria you can’t get into it.”

Sasheen spoke of waitlists and the need to be strategic in selecting the correct location for Cliff. She stated: “If you turn it down then something bad happens. You can only turn it down once or then you’re out of luck or something.” Sasheen was advocating for a unit that was in a safe community and close to amenities (e.g., groceries). She believed that once Cliff was placed in the unit he would stay: “Cause I figure once you’re in there, they’re not going to move you somewhere else.”

Sasheen’s worry focuses on support services and funding for independent living. She is concerned about government accountability, advocacy and funding. She recognizes that
families care about disabled family members in a way that government agencies may not match. She stated:

But uhmm you know a lot of us are thinking man, I hope, I hope, I outlive my kid [Cliff] because what’s going to become of them [intellectually disabled] when, when we’re gone? Because who’s going to take care of them? Where, what kind of state are they going to be left in as far as, you know, who’s watching the watchers [government], as far as, you know, the educational levels of people that are hired to take care of them and, you know, they are very busy and stressed and may not have time to notice the things the kids don’t necessarily self-report in. You know, will they be on the street or you know, they don’t have much money to take care of themselves or eat healthy or anything. So there’s a lot of supplementing that we do and we just are scared for them, how much suffering their life is going to be when we’re not around.

Sasheen is an independent woman who has excellent skills in locating resources and setting up a planning framework to ensure her son has a home in the future. Her failing health and fears of a failing system are variables that have added to the weight of the load she carries while caring for Cliff.

Parent/Sibling.

I had the opportunity to interview two parent/sibling pairs: Mary and Anne; and Tashan and Poggy. This added insight into the role mothers play in advocating for their intellectually disabled child while exposing their other children to issues and possible advocacy and guardianship roles.
Mary (Parent)/Anne (Sibling).

Mary (60–64 years old) cares for Alex (30–34 years old). Alex is adopted and lives in a group home in the same community as his mother. Mary has a high school education and is employed. Anne is the biological daughter of Mary and also participated in this study. Anne (35–39 years old) also provides support to her adopted brother. Anne has postsecondary education and is employed in a professional capacity. Anne has children of her own and considers her primary family her responsibility but thinks Alex is the government’s responsibility.

Mary.

Mary adopted Alex at the age of 2 years and knew he had special needs. As Alex grew into adulthood he began to “put himself in danger and others in danger by running away.” She said that Alex has the mentality of a 6 year old child. He currently lives in a group home with three other intellectually disabled adults and Mary believes “he is quite happy there.” Mary said that Alex requires a high turnover of caregiving staff at the home as he is extremely high maintenance and requires their constant attention. Mary wants Alex “to be happy and I want him to be involved in the activities that he likes and at this point he’s bowling, and curling, and swimming and playing basketball.”

Mary enrolled Alex for residential housing prior to his 19th birthday and Alex was placed on a waitlist for housing. As Mary recalls:

When Alex was 17 we actually put him on a list for a group home because we didn’t know at what point he would have to move [due to behavior issues]. And, yeah. And he was about 27 when we finally had to do something, so he was on their group home list for about 10 or 11 years.
When Alex was in his mid-twenties, a neighbor exposed himself to Alex and more serious behavior issues began. Mary noted: “And that’s when all of his acting out and behavior started and the running away and stuff. And it was really difficult to keep him at home because the neighbor is right across the street.”

Mary contacted CLBC regarding the behavior issues. After assessments were completed, CLBC said that they would find Alex a placement but only if Mary would “take somebody else [another special needs adult] in your [their] home.” Mary presented another option to CLBC, she asked for a family support worker to take Alex on outings or "you know to give us some relief and stuff" but CLBC refused. Mary was “running up against stone walls” in having options about Alex’s living situation through CLBC. She believes that if the appropriate supports had been provided during that time period, Alex would still be living with them.

Mary said that she received respite services for Alex until he was 19 but when he reached 19 years of age “then all services stopped.” Mary did receive some services from Alternative Community Services [pseudonym] unofficially. She recalls that organization as having been “our life line; they went out of their way and helped us to deal with him when we were going through all that stuff [behavior issues].”

Mary continued to wait for a housing placement but at a certain point Mary’s family felt that “they could not keep him safe and he wasn’t willing to listen to us about the things that he needed to listen to us about.” One night when he ran away again they told the police that they could not take him back. Mary recalls that event:

When, when we had to tell the police not to bring Alex home because we couldn’t take care of him, it was really difficult and the social worker was phoning from the
hospital and telling us to come and pick him up because he wasn’t sick. He [Alex] was phoning us as well and asking when he could come home but we couldn’t let him come home because we couldn’t take care of him and the frustration and the knowledge that you’re actually rejecting your child was really hard. It uhm was a difficult time in our lives and the guilt that you feel because of it lasts a lot longer than the, the week that he was in the hospital.

Alex was placed in a group home in a city [Rainville] a few hours away from the community of his parents. Visiting the group home during the winter months was difficult for the family in part due to road conditions. Mary said it was hard to leave Alex alone in a new community. Over two years later, Alex was moved back to his home town [Hub City] where he still lives in a group home.

In the interview, Mary expressed a strong work ethic and wanted her son to be a productive member of society. She did not have confidence that government funding for the group home in which her son resides will continue in the future. Mary stated:

Oh you never know what the government is going to do so. I mean, as far as I’m concerned they never should have closed group homes anyway, because the people that live in them those are their homes. What right do they have to close a person’s home? You know, it’s like them coming up to me and saying: “OK we’re closing your house you have to move out, you have to go somewhere else” And that is what they are doing to these people. And the reason they are getting away with it, is because the people aren’t, are disadvantaged intellectually and a lot of them don’t have parents or family to stand up for them. So they just get kicked out of their own
base. I mean they've gone from institutions to group home to home care, where's it going to go now.

Mary spoke about how services could be improved:

I think what's needed now is changes to that group home, to Community Living British Columbia, a lot of changes, and a lot of the way they are funding and the way they [provide residential options]. And they need, what they need is for some of those people that are in the executive positions, they need to take some of these people into their home and see, and live with them for a while, and see what goes on.

I found Mary to be a strong advocate for Alex. Mary believes he has a part to play in society and that her son has the right to a good home. She knows that CLBC "is changing the way they want special needs adults to live, there into the home care." Mary is referring to the "home sharing" model that CLBC defines as "a residential option in which an adult with a developmental disability shares a home with someone who is contracted to provide ongoing support" (CLBC, 2010b). Mary does not believe this model of care will work for Alex. She said:

We have the fear that ok these, this couple wants to take him into home care and what's going to happen if they decide a year, 2 years down the road, that they do not want to do it anymore. What's going to happen to him? Is he going to have to go into another home care situation? At this point he's in a stable home [group home].

Mary wants Alex to stay in his group home. Mary knows she cannot care for Alex the rest of her life and she does not want her children to have to care for him. Mary stated that: "Anne is going to be the one who will be a guardian to him" in the future when she and her husband can no longer take care of themselves and will need someone to look after Alex.
Anne described her family as a close family that is very supportive of each other. She spoke of siblings but more specifically of her adopted brother Alex who had an intellectual disability and cerebral palsy. Anne identified safety as a main concern, saying that Alex “doesn’t pay attention to some of those safety rules.” Safety issues included Alex running out into the road with oncoming traffic, and talking to strangers. Anne stated: “I find that I’m always reminding him like you’ve got to watch where you are going.”

Anne recalled a period when Alex kept running away [from home], but thought that it was related to siblings growing up and moving out of the house. “He saw all of us older siblings moving out. We have our families, we have our own places that we live, and he kept running away from home every time he didn’t get his way.” Note, Mary [adoptive mother] provided an alternative explanation for her son running away [neighbor exposing himself to Alex].

Anne knew the actions her parents were forced to take in order to get Alex into a residential home funded by CLBC. Anne mentions that “my parents basically had to abandon him in order for him to be able to get into a home where he would be safer.” She stated that she knew her parents had Alex on the waitlist for residential housing at age 17 but CLBC was not willing to accommodate him. She said: “Other people [were] getting into group homes and he’s not you know making it, because somebody else’s need may be more. He’s got a safe place to live so they continue, he [Alex] continues to stay with my parents.”

Anne spoke of Alex’s transition to Rainville after her parents abandoned him. She knew that he was unhappy living in Rainville as his “roommate yelled all the time and made loud noises but didn’t talk.” She remembered that Alex called his dad, asking him to
advocate for him. She believes Alex is happy now that he is living in Hub City as he can participate in things with his friends such as “men’s group, there’s like the Tuesday lunch, there’s the Thursday supper and things like that, that he, I think he really missed that while he was in Rainville.” Anne believes her future role will be to advocate for Alex. She describes this as “being the one that’s responsible to ensure that things continue for him. Like just the one. I guess, uhm, you know the one who speaks for him. In case they need somebody to do that...advocate.”

Anne’s primary concerns are her own children and family. Anne believes that the place that Alex resides in currently is a good choice:

Where my brother’s living now, he’s given some choices to make you know he can make his own choices but I mean he’s supported to uhm to try and make the right decisions for himself, so that he’s safe, because he doesn’t always make safe choices. He doesn’t understand all the safety rules. Uhm. He just forgets them, so it’s good that he has that support to help him uhm just to maintain his safety, more than anything. It helps.

Anne expressed a general concern for her brother and wants to ensure that his living arrangements at the group home will continue. She said:

But I see that, like, you know, in the future if it came down to it that, uhm, they may have me being, because I’m the only one of the family members that actually lives in town here, being the one that’s responsible to ensure that things continue for him. Like the one, I guess, uhm, you know, the one who speaks for him. In case they need somebody to do that. Yeah.

Anne’s believes Alex’s needs are met now. She stated:
I think, his most important thing to him is that he has his room, he has his game system and his music, and he has, you know, he can call his friend anytime he wants because it’s not long distance. Right. So they can talk on the phone.

Anne did not have experience with the provincial policies and programs for housing within BC but had a lot of questions as to “Why is this happening?” She expressed:

Having a difficult time understanding that you know this kid he kept running away from home, he’s putting himself in danger why can they not find a slot, why isn’t there a lot more houses in this town. There’s more people than just him that needs a house to live in. Why is there not more than that? So, uhm, I always find myself questioning why, why, right but it’s all, it’s all about the dollars. Right. And there is only so much they can have to spend on this and so much they can have to spend on that and then they have to cut back on things you know it’s all the government dollars that you see going into it.

Anne hopes that group homes:

Don’t end up being completely non-existent. Because I’ve worked with those clients and that’s their home, they love their home. And that’s the thing. It’s their space. They have their room, it’s like their little apartment. But somebody helps them, if they need help you know with things. Right.

My impression of Anne was that her primary concern was her immediate family. Alex was provided with governmental housing and she felt he was content with his group home. She thought that the government would take care of Alex in the future. Anne thought that she might have to advocate for services but believed that Alex had a right to stay in the place he called home.
Tashan (Parent)/Poggy (Sibling).

I also interviewed a second mother/sibling pair, Tashan, and Poggy. Tashan and Poggy both advocated for Walton. Poggy felt that Walton deserved his own housing and Tashan did not believe in residential housing options as she thought it would impact Walton’s freedoms.

Tashan (40–44 years old) cares for Walton (15–19 years old). Walton is her biological son and lives with his family. Tashan has a high school education and, together with her husband and daughter, cares for Walton at home. Poggy is the biological daughter of Tashan. Poggy (15–19 years old) also provides support for her brother Walton. Poggy is in high school and plans to work in the social services field after she graduates.

Tashan.

Tashan appeared to be tired, worn out and worried about her son’s future when I met her. She has remarried and also provides palliative care for her mother in her home. Her husband is twenty years older than Tashan and his health is poor. Tashan is concerned with Walton’s financial security and concerned about who will advocate for Walton in the future.

Tashan’s biological son Walton suffered a brain injury at the age of 18 months and received supports from the Child Development Centre as an infant. In elementary school Walton received supports from a teaching assistant and maintained a steady routine. As Walton transitioned to grade 8, Tashan said that he experienced a radical change in that he shifted from one teacher to “6 teachers, 8 courses, different rooms,” and no teaching assistant. Tashan said: “With his brain injury he could not comprehend where he was supposed to be, what teacher because everything has to be in routine setting with him.”
In addition, Tashan identified that:

When he got up into grade 8 there was not enough funding in our school budget for him to have a full time ASA [teaching assistant]. So if he had math in the morning well they don’t have math books for grade 2. They’re doing grade 8 math, well without an ASA teacher Walton could not do the math so he would sit there.

Tashan was told by a teacher that “We don’t have time to sit, to go over every little question for him.” In addition, the school could not monitor where Walton was going and teachers would continually call Tashan stating “We don’t know where he is!” Tashan said that Walton was pulled out of junior high school after attending only three months. She stated: “So he just got lost in the system” and he has been sitting at home since he was 13 years of age.

Tashan said she was exhausted. This was made clear as she described the weight she bears when contemplating teaching Walton at home:

But to sit there for 6 hours out of the day, in my life style, I have another child at home, I had my dad home in palliative care [dad had passed away since Walton was home schooled], my mom was not well, my husband took 4 heart attacks, all within this matter of the last 3 years of him being pulled from school. I didn’t have 6 hours to sit there every day to try to do grade 2 work with him.

Tashan worries that: “What if something happens to my husband and myself? That’s the scary part, like who is going to take care of him [Walton]?” She was confident that Poggy would continue to advocate for Walton, as her daughter began advocating for her brother at an early age in grade school. Tashan’s concerns centered on the future care of Walton:

How is he going to support himself making $9 to $10 dollars an hour? You see normal, everyday children at 18 and 19 trying to struggle to go to school and make
ends meet on minimum wage. What kind of family life is he ever going to have if he does get into a relationship and say he does meet somebody and have children themselves? How’s he supposed to support them? That is a big concern of mine....God forbid if something happened to myself and husband. Who is going to take care of this child?

Tashan had a good understanding of where Walton could live in the immediate future, on their property. She explained what Walton’s income would be when he turned 18:

Social assistance disability which is out at $898 dollars a month. He’s allowed up to $400 dollars a month rent and that’s if he’s paying $400 a month rent so if he gets some place like in the low, they do have the low income places. But the hydro and the natural gas in place are $200-300 a month. So he’s supposed to live on $70 a month for groceries.

Tashan said that Walton operated at a grade 2 level in reading and writing. She said that she knew that Walton could never go into a home setting that is regimented. She commented on the fact that he has insomnia and said that “I don’t want him to live that type of life that he’s got to be told when to get up, when to go to sleep, well breakfast is at 8, lunch is a 12, supper is at 5. Well he’s not that type of a child.”

Tashan believes Walton will live with her for the rest of her life. She says “You never look too far ahead” but she has tried to educate Walton on living skills such as cooking, baking, grocery shopping, and so forth. She said: “I always wonder in the back of my mind is it enough. Like it is a big world out there and when they get out there on their own, it’s scary. Yeah.”

Tashan is also concerned about the responsibility Poggy would have:
That’s a lot of responsibility for my daughter to take on her shoulders....Is she going to live the rest of her life, you know, the next 40 to 50 years worrying about him [Walton]? That’s what I think it, just breaks my heart, is, because I’m so scared that’s the situation where we’re going to be left at. But only time will tell and we’ll just plunk along with it and yeah.

Tashan remembers an incident from Walton’s grade 8 year when Poggy intervened:

And this one teacher that was the sub [substitute teacher] for the day that had them actually through the whole week well they were put into the library and they were supposed to be doing this pamphlet. And before you know it, Walton was not doing the pamphlet. He tried to explain to the school teacher [substitute] that this was not the work that was given to him at the beginning of the week from the regular teacher. That he could not do it. And she more or less took the piece of paper off of the desk and swatted him in the head and called him "retarded." And before you know it, he was like flying off the handle, got very, very upset emotionally. They put him out into the hall and they ended up calling his sister, Poggy, to come and calm him down and before I knew it, I ended up in the school.

Both Tashan and Poggy were continually being called into school to deal with behavior issues. She said:

Because of the frustration level he [Walton] was in, there was no way he could calm himself down to go into a different classroom by that time. Because he [Walton] would get so angry and so upset. And he would be crying and screaming and yelling and it was not a very good scene. So we just got to the point that I was more at school with him [Walton], than he was by himself and then my own daughter, Poggy, of
course her grades starting falling, because at least 3 to 4 times out of the day, she was pulled from her classes to calm him down or to take him to a class and she was late. Looking ahead to the future, Tashan expects that Poggy will become Walton’s advocate.

Poggy. Poggy describes her family as “the best family” and believes that they are “pretty great together.” She describes her brother Walton as a big [300 pounds], tough boy that for the most part is happy but when “he’s upset, all you have to do is make him smile and he’s having a good day after that.” She spoke of Walton “always playing video games because they cheer him up and kind of make him you know have something to do where we live.” She believed that Walton “is like the main person that pretty much brings all of us [family] together.” When she described herself she said that she’s “more the one that probably makes everyone in a better mood all the time. I’m the funny one.” Poggy revealed a very protective side and saw her younger brother as her responsibility, even into the future; her future was her brother’s future—where she goes, he goes. Her primary concern was protecting Walton.

Poggy seemed to see herself as the primary advocate and protector of Walton. As she said: “I used to get in a lot of fights because people used to pick on my brother.” She continued: “I remember I use to see people pick on him a lot. And I got into a lot of trouble because I’d be very protective because I knew Walton was really special.” She realized when she was in grade 4 that Walton had a disability and “that he would need more help in life. Poggy decided that it was her:

Duty to watch out for him, especially at school, because mom wasn’t there right, I mean mom couldn’t come to school every day, and him and me, we were in the same
school. I was there 24/7 when pretty much he needed me the most. So I kind of took it
upon myself to look after my brother. And even now I’m still like that.

She expressed hope that her brother would be able to live an independent life:

Truthfully if, if Walton did want to go out on his own, which I can see this happening
too where he doesn’t live with his big sister. He wants to, you know, show probably
show us that he can do it....And it make us very proud but it makes us very scared too.

Although she hoped Walton will be independent she also stated that if he did move
away from Tashan: “I think he’d get very frustrated easily, worry about money a lot just I
think he’s better at home being for sure able to get food, you know, you don’t have to have
that many worries.” Poggy thought that if something happened to Tashan that she would
become the primary caregiver as she stated:

Because I’m, I mean there’s Albert [stepfather] and Nanny [grandmother] but
Nanny’s not all there, Albert’s getting older and you know he, I’m pretty sure he
doesn’t want to look after a Walton boy growing up as a teenager. He gets very
frustrated too with kids but he’s a great dad, he really is. But I think Walton would be
more happy to live with me if something did happen to my mom.

Poggy said that she is planning on moving out of her parent’s home within the next
month after this interview and she will get a part-time job and finish a course needed to
graduate from high school. Poggy then plans on attending college and wants to “do health
care so I can go to the old folks home because they make really good money.” Poggy had
made a pact with Tashan that “no matter what happens to either of us, Walton would be
looked after, Walton would be happy, Walton’s pretty much our life.”
Poggy recognized the possibility that her brother might live with her in the future and makes sure that Walton approves of her boyfriends. She said that if Walton didn’t approve of her boyfriend, she did not consider the individual. Poggy believes Walton will want to move out from home soon and states “it scares her [Tashan], it scares me, it terrifies me but at least if he’s with me I know I can keep an eye on him. That’s what I more so think about.” She thinks Walton has a chance for a good quality of life “if he finds a job.” She thinks a job situation would be difficult for him as “he gets very emotional, very frustrated. He likes doing his own thing and being quiet and left alone. He’d need a quiet place.” She said she thinks he possibly could get a part time job at the recycling depot for bottles.

Poggy said she has no understanding of provincial supports or services. She expressed concerned that funding would become an issue if Walton moved in with her after she left home. She stated: “I more so worry about him having his own money you know and being happy and me having my own money but for sure I’d want to support him more than anything.”

Researcher.

I am a middle-aged parent with an 11 year old son who has Down syndrome. I know that my son will never be capable of protecting himself or becoming self-sufficient in adulthood. My question is, who will protect and care for my child when I have breathed my last breath? I have been married for more than 15 years and have two children, my son aged 11 and daughter aged 15 years. I am surrounded by nature—lakes, forests, and parks—in beautiful northwest British Columbia. Occasionally I go for a walk through the forest with its views and smells to escape from my daily life. I walk to slow down my inner dialogue—tasks, to do lists, and the reality that I am a mother of two children working a full-time job so
that I can support my family. I am a hard worker in all aspects, a worker bee and planner, always with an eye to the future. I am an advocate for my children, a friend, a daughter; I am continually striving to enhance my educational credentials so that I can earn more to support my family. I live in the present but worry about the future.

Our son has sleeping issues (he bangs his head against the wall while sleeping), uncontrollable bowel movements, respiratory problems, and safety concerns in terms of running into traffic and approaching strangers. As a family unit we understand that maintaining our current income level is crucial in order to meet our family's needs, so both my husband and I work fulltime. Our daughter sustains the family too in that she provides daycare for her brother which makes it possible for my husband and myself to go grocery shopping, run errands, attend meetings, and socialize. Our son requires special provisions because of his medical conditions, and safety concerns, and I have requested aid from the BC Ministry of Children and Family Development for support services. I began this study wanting to find out more about the BC social programs and policies and how our family could access them now and in the future.

My husband and I have set up our work retirement plans, but we have no provisions for any sustained future income for our son. Savings are an issue as we are trying to accumulate enough savings for our son's future prior to our retirement. We are also trying to secure a permanent home for him. We believe our son has the right to choose where and how he lives in the community, and that an institution is not a home.

My focus is on the quality of my son's future life. I fear the world my child is growing up in is not geared for those who are unable to fend for themselves but, rather, is a world in which the fittest survive. When I began my research I was ignorant of the supports
available for individuals with disabilities in the society in which my family lived. All our energy was expended on the care of the family which comprised keeping a roof over our heads, providing a sound moral base for our children, and ensuring that their health, education, and physical wellbeing was looked after. A reflection from a weekend writing session summarizes my thoughts:

Today I am feeling like I have made some headway into the overall picture of our family’s predicament. I realized that I am always looking for the overall picture, in order to define the family plan of today. Enlightenment came when I was researching the history of housing mentally disabled individuals of the past in institutions, and the current move to a model of community integration. In British Columbia, the mentally disabled were moved from institutions to group homes, family homes, and independent living arrangements or, more recently, to shared home arrangements. I realized that the current neoliberal narrative has set up a housing situation that places the financial burden on the families, knowing that the families will never want their child to suffer. Families are placed on waitlists for housing until funding becomes available. But with limited funding and information, families are left bearing the brunt of the load.

When I began my research, I wanted to hear the voices of other parents and siblings caring for intellectually disadvantaged individuals in situations similar to mine. The interviewees referred both explicitly and implicitly to the public discourse about advocacy, and what it means to a parent or sibling caring for an individual with an intellectual disability. Their narratives were woven around the themes of advocacy, responsibility, and caring. I gained an understanding of how other parents/siblings see the world, and heard their
perspectives on current and future housing options for their family members with intellectual disabilities. Underlying my study was my desire to explain how parents/siblings caring for an intellectually disadvantaged individual experience the social system in British Columbia. I now understand why the information I was viewing from newspaper articles and conversations with a few other parents had created a sense of panic for my son's future. Reviewing interview data provided a means of understanding how other parents/siblings maneuvered the British Columbia provincial system in order to access information, resources, and funding.

**Emergent Themes**

Twelve subthemes emerged from the data analysis that included examination of topics such as: parental advocacy, family fears, supports for family home arrangements, northwest issues, future housing, limited knowledge, funding issues, sustained care, safety, preparations, quality of life of caregivers, and solutions. As a result of the findings specific areas were explored: the experiences of the family caregivers; researcher's experiences as part of subcultural group; lessons from Canadian history; the present and the future in British Columbia; and recommendations.

**Theme 1: Parental Advocacy.**

Parents were the prime advocates for the child's rights regardless of age of the dependent family member. Alexis sought information and fought for services. Sasheen located independent living arrangements and ensured her son Cliff was registered along with working out his financial needs. Candice planned for her daughter Lilly's future well-being by sourcing out services in her son's community. Tashan and Poggy located their own
resources to care for their family member. Mary and Anne hoped for the best which in their view was that Alex would stay in the group home.

Alexis believed that the community of parent advocates needed to band together. She thought together they could advocate more effectively as one voice. As she states:

She is the only child, she is the only grandchild. So she has no real, true blood cousins, or cousins. She has my friends, all my friends are older and their children are all grown up and are having children. So she’s kind of this island on her own, and I, I find it very difficult. I feel like I’m an island. Like, us as a family, there’s nothing that, uhm, there has been nothing that has helped us to become a community of parents with special needs kids. That’s what I think is missing.

Alexis’ need for community was her primary concern along with her belief that a community of parents advocating for their children would ease the load of one parent standing alone fighting for her child. Alexis is a planner and wants to ensure that Jasmine has a good quality of life.

**Theme 2: Family Fears.**

For all of the participants, it appeared that family fears primarily stemmed from the uncertainty of funding and the inability to access information regarding services. They all knew the government was not providing adequate funding for supports and worried that funding could become non-existent.

Candice worried about who would become Lilly’s future advocate:

I know it’s a lot to think about really and I don’t know what we would really do. I mean if something happened to both of us. She can’t live by herself and there is nothing in place, there’s no where she could go here, so there’s no alternative really.
Candice was looking into the option of moving Lilly to elsewhere in BC where her brother currently resides.

Alexis also worried about Jasmine’s future. She was able to see beyond her own personal circumstances to describe the sense of isolation most parents of a person with a disability must experience. She said:

*Whereas I feel like you, of this continual feeling of being in quicksand. Not knowing what is next, what’s, what’s down the road. You know that is a disaster waiting to happen… and I am not alone. I know I can’t be alone because if I feel this way there must be parents who are not savvy to some Ministries or guidelines and understand the way things work who are probably feeling like they are in the middle of the lake on a lily pad. You know they are going down for a third time, is anyone noticing? Where I don’t think that has to exist. There, tell me every child that goes to school goes to the Child Development Centre is a known parent of a special needs child. We’re not hiding in the corners anymore. The children are going to school; the children are out there in the community. Why isn’t it that they, we are so isolated? Alexis elaborates in her fears of what would happen to her daughter once she was gone. She wondered who would look after Jasmine, and about what kind of life she would have:*

*If she needs help, dealing with the community when I’m gone which is my next fear what happen, I can, right now I can get her to a point I hope that she can have friends, and she can have activities, that she can do as best that I can do. Uhm but then when I’m gone what does she do? Who’s gonna to take care of my child? Who I don’t know will be able to take of herself. Who’s, who’s gonna ensure that she has a life*
after we’re gone. Because she doesn’t have siblings, and she doesn’t have uhm, uhm, extended family you know when, when my husband and I are gone…

Mary and Anne worried about maintaining Alex’s housing arrangement. Mary was exhausted from the years of advocating for a residential home for Alex. She had to resort to abandoning Alex before CLBC would find a home for him. Although she is satisfied with his current placement, the experience of “abandoning” him was very emotional, and created a sense of guilt. Also, she is not confident that his group home placement will continue.

Sasheen worried about Cliff getting into a permanent housing placement with supports and services to ensure he was cared for. Although she has done everything she can to secure a residential placement for Cliff, Sasheen continues to worry about Cliff accessing the placement before she can no longer advocate for him. She fears that her health will fail before Cliff is accepted into the residential placement for which she has waitlisted him.

Tashan sees Walton getting older and worries about his future as he has “a grade 2 education, did finish off grade 7 but I mean he reads and writes in a grade 2 setting.” Tashan has taught Walton basic life skills [grocery shopping, cash a cheque at the bank] but does not think this will be enough as Walton is very dependent on routine and she can’t see him thriving in a busy place.

She also expressed worries about his financial security. She said she’s: “Scared like in the next 5, 6 years, I don’t want him, having to flip burgers at Greasy Spoons for 9 bucks an hour to try to support himself.” Tashan does not believe Walton can live on $9 to $10 dollars an hour and she asks: “How is he going to support himself?” Tashan believes Walton does not have skills needed to maintain a job. She said: “How do you put him into a workforce when he has no skills?” Tashan plans on putting Walton into the life skills program at the
college at the age of 17 but does not see him holding a job as he cannot handle being around many people at once. Over the long term, she worries: “What if something happens to my husband and myself? That’s the scary part, like who is going to take care of him.” Tashan continues: “Like it is a big world out there and when they get out there on their own, it’s scary. Yeah.”

All participants in this study feared what would happen to their child when they would no longer be there to advocate for supports and services. Services, housing, and quality of life all required securing funding and no participant knew whether funding would exist when required in the future. The years of advocating and providing care for their intellectually disabled family member, I felt, had drained the participants of energy.

**Theme 3: Supports for the Family Home Arrangement.**

In all the families but one, the disabled family member lived at home with his/her parents. Most families were researching current or future housing options for their intellectually disabled family member well-being. Only one family member [Alex] lived in a group home accommodation and that was provided only after the parents [Mary] abandoned their child [Alex]. George was in a home share residential option with Grace. Cliff was on a waitlist and resided with his mother Sasheen, with limited supports. Walton lived with Tashan and her husband and she was not entertaining the option of a group home setting. Lilly lived with Candice and her husband and received supports and services from CLBC. Alexis and her husband cared for Jasmine, and received supports and services from MCFD for medical and respite.

Tashan spoke of continued care for Walton as long as she was capable as she did not believe a group home provided enough freedom or quality of life for Walton. Poggy,
Walton’s teenaged sister, looked into the future and moved towards educating herself so that she would have the skills and financial resources to look after Walton in the future. Poggy ensured that her boyfriend met the approval of Walton as she thought Walton might live with her in the future.

Alexis was busy advocating for at home supports and services as Jasmine was many years away from transitioning to a residential home option. Although recently given a terminal diagnosis, Alexis is making plans towards establishing a microboard. A microboard is “a small group of committed family and friends (a minimum of five people) who join together with the individual [with disability] to create a non-profit society (board)” (Vela Canada, 2014). Vela Canada (2014) microboard is created to help with planning, brainstorming ideas, advocating for and monitoring services, facilitating connecting with community, ensuring safety, and possibly access funding and deliver services.

Grace is still hoping for a letter stating that George will transfer to her daughter’s care when she can no longer take care of George. Sasheen is on a waitlist for an independent housing option for Cliff and hopes that he [Cliff] gets into the unit before her health worsens. Mary and Anne are happy that Alex is in a group home and their hope is that he does not transition to another model of housing as they believe his current home is a place he prides himself in calling ‘his home.’

This study has shown that parents advocating for residential housing options for their intellectually disabled family member are not accessing supports in a timely manner. As seen in the situation with Mary, Alex was on a waitlist for 11 years before she had to abandon him and say “I can no longer care for my child.” Mary’s family was exhausted and could not wait a day longer. I felt during the interview, that this act of abandoning almost broke Mary’s
heart. All I can hear her saying is "they kept calling and every time I [Mary] had to say that I [Mary] can not take my child [Alex]. The BC government has prioritized spending at the expense of family caregivers’ quality of life.

Theme 4: Northwest Issues.

Northwest issues varied from lack of access to professional services, lack of accommodation to access services and inflexibility of policies based on extraordinary situations. Alexis said that very little accommodation was made for her when traveling to BC Children’s Hospital in Vancouver for specialist appointments. Tashan identified the lack of supports for Walton when he transitioned to high school. Candice mentioned options for housing presented to her at a workshop that she knew would not be available in the northwest.

Alexis said she had experienced a lack of access to professional speech therapists in the northwest region. As well, she had been required to travel to Vancouver for assessments and other services for Jasmine. She identified the lack of accommodation for northern travelers to Children’s Hospital in Vancouver as another issue particular to the northwest region.

Alexis described her frustrating encounter with the At Home program. This program pays for speech and language therapy, but only with a certified speech pathologist. Alexis researched who in the northwest is a certified speech pathologist and found out that the only certified speech pathologists work at the school district. The school district has a policy that does not allow speech pathologists to work privately for school aged children. Alexis returned to the personnel of the At Home program and conveyed this information but received the response: “That is the way the program works.”
The At Home representative told Alexis that hundreds of individuals with disabilities travel to Vancouver for services. Alexis stated: “That’s very nice, but us travelling to Vancouver every other day so that she can have speech and language isn’t gonna work, is it.” Alexis continued to advocate for her daughter to have access to services, but said: “They will not budge on their policies because their policies work for Vancouver, Victoria, big cities. But they don’t work for Hub City. Oh, well.” According to Alexis the final response from the At Home representative was: “That’s too bad you can’t access it. You chose to live there [Hub City].” Alexis defended herself in saying that her job was in Hub City and moving was not an option. Alexis didn’t see herself moving to Vancouver [her job was in Hub City] and believed that all children in British Columbia regardless of location should have access to the same services.

Alexis saw similarities with Children’s Hospital in terms of the lack of accommodation for northern travelers. She noted that although she lives outside the Vancouver area, the hospital personnel insist that she call them “by one o’clock of the day before you have surgery” to confirm the surgery will go ahead. Alexis explained to the hospital personnel “I can’t call you at one o’clock, I’ll be in the air,” not to mention she has to buy the ticket ahead of time. Alexis explains that she has no choice once the ticket is purchased. She told them: “I have to buy the ticket and get on the plane before I can confirm with you that I actually have a date for Jasmine.” And then Alexis has to be concerned that once she arrives the surgery might be cancelled. She is exhausted at this point in telling the story as she is reliving an episode with Jasmine on one such trip, “I have just entertained an entire room of people, travelers, with my child’s antics. And I got on the plane and we are finally here and if you tell me that I don’t have an appointment, I’m going to blow a gasket,
or they’re gonna be putting me in a funny room.” Alexis states: “And looking around me, I feel like I’m all by myself on this little wheel.”

Tashan also identified issues with the availability of appropriate services in the Northwest region, based on her experiences with her son, Walton. Within 3 months of Walton transitioning to grade 8 he was removed from school due to inability of the school system to support Walton’s needs. Tashan explained that his routine was disrupted and with his brain injury, “he could not comprehend where he was supposed to be, what teacher?” Tashan tried to find additional help but noted:

Now there is nothing out in our community anywhere from here to Pine City - around 10 hours by car away. Pine City is the only other resource place that has the brain injury group. We have a support group here for the brain injury group but not anywhere closer than Pine City that actually visually go in and take him and have him in assessments or to do different things that they do in their offices.

Tashan was frustrated that Walton has been sitting at home without schooling or since he was in grade 8. She stated: “There is nothing by the time they hit into grade 8 if there is not the funding for ASA teachers, there is nothing for them. So he just got lost in the system.”

Candice spoke of information provided to her on residential housing options:

They presented the different options and people commented on them and what they thought their use was and whatever. You get a lot of these workshop things and a lot of government groups come and they do their little chats but nothing really happens up here.

Candice further stated: “There is no housing here to speak of at the moment and she is too advanced to go into a group home with severe people in it and yet she’s not advanced enough
to live on her own. So where would she go, there isn’t anywhere for someone in her situation to live.” Candice continues to research options to move Lilly to the community where her son lives.

**Theme 5: Housing – Future.**

Participants spoke of future housing options for their family members and information provided to them by Community Living British Columbia. The following section summarizes the range of thoughts and concerns expressed by participants.

Grace commented on future housing and her thoughts about consistency and stability in housing. George has now resided with her for over 20 years and he is integrated with her family. Grace is aging and knows that George has health issues that will shorten his life span. Her thoughts about housing George in the future rely on the willingness of her daughter to care for George. She said:

My son-in-law and daughter said if anything happened to me where I couldn’t take him they would probably move in here. They’ve got a much bigger house than I do so uhm but they would probably at first move in here to stabilize him and then slowly get him to stay at their house. But will the Ministry allow that, I don’t know. They said they will and it’s in their records but to say something and do that. I’ve worked with the Ministry a long time so do I put a whole lot of water behind that? No.

Candice is a parent who currently cares for her child Lilly in her own home and receives community service supports to allow Lilly to participate in society. She states that her daughter “never could really live alone” and she does not have confidence in CLBC to provide sufficient safeguards to ensure Lilly is adequately provided for. Candice is concerned
with future advocacy efforts when she can no longer be the watchdog and therefore is planning on asking a sibling [her son] to take on this role.

Candice believes Lilly needs to live within “a safety framework” and knows her daughter “would need some caregiver there all the time.” Candice has received some information from CLBC on housing options for Lilly but thought that the likelihood of the Ministry moving forward with getting the houses built “was another story.” She further commented that the government’s range of housing options were not likely to be implemented in the Northwest region of BC: “Really the options weren’t for here in Hub City.” Candice suggested that Lilly could go into a group home, but is concerned about who would advocate to ensure her daughter was properly cared for. Candice said:

Who advocates for people in the group homes now? Their parents aren’t here, they don’t have relatives here. I mean the Alternative Community Services staff is excellent and they really do try to help but they’re limited because they’re not really supposed to be interfering in their lives that much.

I asked Candice if she had thought of the home sharing option and she said that she thought it was too temporary as she saw “constant changing and being bumped around from foster home to foster home. I don’t know if that would be a really good thing either.” She stated that finding housing is an issue as there are others with more severe disabilities requiring accommodation in Hub City. She said: “So we haven’t really looked into these things that much” as Lilly “is not really a problem to us.” Candice is looking for information on housing and knows of individuals with disabilities that have their own little kitchen area, bathroom and bedroom. However, she said: “we wouldn’t really know how to find out that stuff but I would like to know more about that.” Candice stated that her “family is stable, more or less
and she [Lilly] doesn't do well with changes that much. She [Lilly] likes things, you know, pretty consistent.” Therefore Candice believes Lilly’s brother would be the best caregiver to take care of Lilly’s needs in the future.

Alexis discussed the future housing prospect for her daughter Jasmine as:

I mean, what do I see: group homes, uh, I, I think we’re old enough that there’s gonna be an issue. As you experience yourself, there is gonna be an issue of how old am I and who’s gonna be looking after who? You know? Uh, will she live with us, will she want to? Will we want her to live with us?

Alexis has tried going to the Ministry to discuss options but was told that there was no money available: “I tried to go through the Ministry to talk to them about some of the needs that I felt Jasmine needed. Yeah. Oh, there’s no money for that, and there’s no money for that, and there’s no money for that.” Alexis did comment that she had questioned ten years down the road whether Jasmine would stay at home and if so: “Am I going to be able to handle her… as she’s no longer, I think it’s nineteen, no longer going to be uh to get the service of respite… so where does she go from there?”

Alexis mentioned daydreaming about the possibility of Jasmine living with a roommate in an apartment. She speaks of questioning their choices about their current home and location, as she thinks about Jasmine’s future:

What do you do? Sell your life and hope that you can create a new life for yourself somewhere else? … Maybe we could buy a house that had two floors. Maybe I could buy an apartment building, ish, you know like a duplex or whatever. Maybe I can, you know, somehow swing where we’ve got two houses on a property. Or maybe we need to, you know, and my husband the same thing, we kinda, we wonder are we
doing the right thing, staying where we are, we’re out of town a little bit. Should we move into town, would it better, would it be easier, would it make more sense?

Alexis was worn and tired when I met with her for interviews. She worked on ensuring that her present home was set up to accommodate Jasmine and that Jasmine had a good quality of life. Alexis has recently been diagnosed with a life threatening ailment. Her prognosis is not good, and therefore her worries are no longer down the road but have become more immediate issues to be resolved. Alexis is currently working on establishing a microboard to ensure Jasmine has advocates in the future. Housing plans for Jasmine are still in question.

Sasheen is a single mom who lives with her son Cliff. She has her son waitlisted for an independent living arrangement. She speaks of limited homes for placement of people with intellectual disabilities in Hub City. She states:

They have those houses, and that’s what he’s still on a waitlist for. Yeah. So there was pretty much, he’s not going to get into, there was one place where they have a one room for somebody with autism but not intellectually disabled and that’s I guess been empty for the longest time but unless you fit those criteria you can’t get into it. Cliff currently lives with her [Sasheen] and she states that: “His standard of living will definitely go way down too if he goes [and lives independently].” She is concerned about her health and the current waitlist for housing that Cliff is currently on as she states “Yeah, suitability and availability, so we’re just waiting around for someone to move out of the other housing which could take who knows?” Sasheen knows that if she is not there to advocate for Cliff, he will not get services.
Sasheen began communicating with CLBC when Cliff was 18. She kept phoning and asking: “What’s up with the housing and when?” She said that she advocates for a “decent place for him to live.” Sasheen believes that as long as her health is fine she’ll continue to advocate, and states:

I’m trying to get ahead of it a little bit so that he’s sort of set up so that I’m not sick and unable to help him and he’s all of a sudden in a new place and everything else. Right, so you know I am going to get sick and that’s for sure. So where is he going to be when that’s happening? If he could already be established and all that, that would be great. Instead of having me sick and we moved and all of a sudden he’s on his own and dealing with everything at once.

Sasheen feels that CLBC prioritizes waitlists for housing for individuals with intellectual disabilities based on crisis. She said: “They take people who are, have no, are homeless and all this other stuff right so unless you drop your kid off at Emerg [emergency], I don’t know if that will happen?” My overall impression of Sasheen was that she is a woman with limited energy but who has a lot of love for her son. Sasheen did not believe the individuals with intellectual disabilities or their families had much of a voice with respect to services. She said:

I mean you know it’s people without a voice that it’s easy to cut their money back because are these folks voting, I guess their families are voting or I don’t know how much power there is as far as politics go but, yeah.

Mary painted a different picture with her son Alex who lives in a group home with three other disabled adults. Mary said she believes Alex is happy in the group home but also knows that staff members become worn out due to Alex’s behavior issues, and burn out
quickly: “He’s [Alex] very high maintenance and needs a constant turnover of staff.” She believes Alex should remain in the group home, and has told that to CLBC. Community Living BC has approached her family to see if Alex could move into a home sharing arrangement but her family decided that, “at this point in his life he needs to be where he is, in the group home. Simply because there’s fresh staff coming in all the time and they are not going to wear down as fast.” She continues in saying that he also needs a stable home:

I’ve been told that it will not change because there are people that live in that home that have been in there for 30 years type of thing. So the group home that he is in is pretty stable. And that is actually where I would like to see him stay, is in the group home.

Mary for a long time had her son on a waitlist for moving him into a group home. It was not until she said she refused to care for him that CLBC placed him in residential care facility. Interestingly, is another participant, Sasheen, spoke of individuals being “dropped off at Emerg.” as a means of forcing CLBC to place an individual into a residential home. For Mary, unfortunately, after waiting 11 years for CLBC to place Alex, she was in crisis mode. After years of pleading with CLBC to provide adequate respite, Alex’s family was left with no option but to abandon him.

I was fortunate to interview another family member, Anne, Alex’s sister. Anne thought that Alex was doing well in the group home setting that he lived in. She believed that the government needed to maintain this housing arrangement. Anne had the following comments regarding housing:

I mean it depends on how the government changes right like if they all of a sudden say no more group homes these people have to go, like I mean it’s hard to say if he’s
going to end up in a foster you know an adult foster care situation, where he might be happy. You know, I know that some of the, the individuals in town have gone into adult foster care because of cutbacks in group homes. Uhm and I mean it just all depends but you always wonder when he goes into adult foster care, is he being taken care of properly. Right.

Anne did not see her sibling role as caregiver for her foster brother. She was caring for her own immediate family and believed that the care of her brother should be the government’s responsibility. As she stated: “I mean my hope is that he ends up in a uhm you know if that were to be the case that he end up with somebody that would be able to you know take care of him properly.” Anne continued, saying: “I hope that these group homes don’t end up being completely non-existent.” She has had experience working in group homes and believes “That’s their home, they love their home. And that’s the thing. It’s their space.” Anne knows Alex needs supports and cannot live on his own. She believes that he [Alex] is content: “I know my brother’s happy, it’s his home, I have my own home. Yeah. My roommates… They all eat supper together.” She said that the residents all share the same kitchen, watch TV together, go shopping, and go to activities in the community where “they get to then mingle more with some of their other friends.”

Tashan believes her son will continue to live with her for now:

I feel like he will probably live with me for the rest of my life. Hopefully, and then after that I mean, you know, you just, you never look that far ahead. He’s in his teen years and he’s still with us and he would love like he always talks about it with like a couple of his friends or whatever.
Ultimately, Tashan believes that “it is up to my husband and myself to secure a home for him,” and that Walton will “live with us for the rest of his life or the rest of our lives, I think.” She also believes that living with them will allow him to not “to worry about rent and mortgage and taxes and stuff.” Tashan mentioned having other family members that currently receive a disability pension and how they struggle to make ends meet with a minimal amount of money left to go towards groceries after rent and utilities are paid. She notes: “That’s scary to know that you know near the end of the month you’ve got to go to the Salvation Army for a food basket because there is not enough to live on.”

Walton’s sister, Poggy, speaks of caring for him in the future. Walton, she says, is a “big boy” and that he would like to live independently with her family or possibly close friends. She agrees with Tashan that Walton should not live in a group home as “he doesn’t like being around a lot of people, like I said, he likes quietness.” She further commented that, “he gets frustrated and I’m scared that if he’s out on his own and something like that happens, he’s gonna get all frustrated and something bad is gonna happen. Like end up you know getting evicted or something because of his anger or because he lashes out at people.”

Poggy knows that her brother Walton would like to live independently and she would like to support him in moving out but also realizes that Walton is unable to assume this responsibility: “I don’t think he’d be capable or able to.” Poggy knows that Walton is easily frustrated and is unsure if he could hold a job. She is planning on moving out within the next month and ultimately wants Walton to move in with her but is hesitant because financially she could not support him. Poggy believes Walton’s best home presently is living with his mom [Tashan]. Poggy cares deeply for Walton and wants to protect him but she knows that at the present she is preoccupied with taking care of herself.
Overall, participants varied in their feelings regarding the future housing options available to their intellectually disabled family member. However, each participant waited on the government’s decision as to where their family member would be placed. Grace waited for a written response from government that her daughter could take George as a foster parent when she is no longer able to provide for him. Candice prepared for her son to take on advocacy and care for Lilly when she could no longer care for her daughter in their home. Alexis utilizes all her energy to deal with advocacy for family respite and building friendships for Jasmine. Alexis has begun building a microboard but still has not grappled with future housing for Jasmine. Sasheen has researched and advocated for Cliff to gain independent and safe housing. Cliff remains on a waitlist for housing and Sasheen hopes that her health issues will not worsen before she gets Cliff in an independent living complex. Mary has secured housing for Alex but worries about the future and possible government cuts. Mary hopes her daughter Anne will take on responsibility for advocacy. Anne has knowledge of the group home setup but most of her energy goes towards her own immediate family. Anne is hoping that the government continues to house Alex. Tashan believes that Walton should stay with her now and in the future. She believes that Poggy will take on Walton’s advocacy when she is no longer able to. Poggy is a young teenager who loves her brother Walton. She realizes that Walton needs to stay with his mom Tashan for now. Poggy is also pursuing a career in health care that will aid her in taking on the care of Walton in the future.

**Theme 6: Limited Knowledge.**

Lack of information was a key theme identified by the participants with the exception of the two siblings. The participants were provided with minimal information on housing
options for people living in the Northwest. In addition, information on supports and services were provided on a need to know basis. Families were left to provide care and housing for adult children, leaving them with a sense of isolation.

Limited knowledge of the policies and programs was a gap identified by many of the participants. As stated by Alexis, our system is like “wading through quicksand.” She further states that: “I’ve got exposure to all that [government programming] and this is like trying to pull teeth, trying to find out what is available.” She also mentions that:

You have the intellectual part of your child, your academic part of the child and it’s a constant worry because you’re fighting with a system that you figure you shouldn’t have to fight with because you know aren’t we all there for the best interest of the child.

Alexis identifies the lack of transparency regarding supports and services:

Why does it have to be a secret that there are things.. uhm. I actually heard someone say “well we don’t tell parents what their child can have because then they would want it all.” I'm going how ridiculous does that sound? It’s like saying OK I’m not going to tell you what cars available but you can see there’s a, a Volvo in the driveway so maybe you’re going to ask for a Volvo but you don’t know there’s any other car out there so you’re going to go for a Volvo because that’s all you know.

Candice also spoke of limited access to information. In particular, she had been seeking information regarding Registered Disability Savings Plans. The lack of access to information furthered the sense of isolation and having to take care of everything all on their own of which the participants spoke.
Theme 7: Funding Issues.

Funding is the primary theme of this study. Without funding, families are left to fend for themselves and try to make do with their own resources. Families are continually told that funding is limited, and waitlists exist.

Alexis identifies that she was told that program information is not shared with her because she might want too much:

And what, and it seems to me that the programs that are out there are not asking me as the parent, “What do I want?” What do I want for my child? What does my child need? They’re in, they’re from the top down, what programs there are out there, from the top down telling me what’s available, for instance, the Ministry of Children and Family special needs. They’re saying this is what is available but they are not talking to me about what I think my child needs. I have spoken to the regional director and talked to him about why should, why shouldn’t my child have the best of what’s available. And by the way, why aren’t you telling me what is available? You know. Alexis was extremely frustrated with the BC system as she tried to advocate for Jasmine’s needs. She felt that she was not part of the consultation process and was not provided with information to advocate once decisions were made at the BC government level.

Tashan identified issues with appropriate funding for Walton once he turned 18 years of age. Tashan researched the possibility of Walton living on his own and found that:

There is nothing after that [age 18] unless he goes on a social assistance disability which is out at $898 dollars a month. He’s allowed up to $400 dollars a month rent and that’s if he’s paying $400 a month rent so if he gets some place like in the low,
they do have the low income places. But the hydro and the natural gas in place are $200-300 a month. So he’s supposed to live on $70 a month for groceries.

She believes Walton would stay in the family home while she could care for him: “I feel like he will probably live with me for the rest of my life.”

Tashan was not comfortable with placing Walton in a group home as she stated “I don’t want to put my child in a place like that.” Tashan was concerned that Walton would never receive CPP disability. She didn’t see him as having the potential to obtain and keep a job as he did not have any skills and had behavioral issues.

Candice was concerned about the cuts made to Lilly’s adult program services:

They’re always cutting constantly. Most of the things she does are Alternative Community Services related. They’ve made changes over the years to the number of people that they have in the groups or how many different things they have for them available and all of this kind of stuff. Because there is always cuts.

In addition, Candice thought funding for residential housing options for Lilly were resourced from soft funding, which could not be depended on over a sustained period of time:

Yeah, I don’t really know. And again we have the problem even if we do secure a place in an apartment building or group home that’s overseen or whatever we have the problem that funding could be cut, that could be gone after we’re gone and set it in place that could disappear.

Overall, participants were frustrated with the limited amount of funding available for them to access supports and services. Participants felt that there was a top down approach to money allocation relating to services. Participants thought that they were not part of the consultation process that identified what types of supports would be made available. In
addition, participants felt that supports that were available would not be adequate to ensure basic needs, such as accommodation, meals, and so forth would be met now and in the future.

**Theme 8: Sustained Care.**

All participants were concerned about likelihood of the government sustaining the current level of care for their family member with an intellectual disability. Their fear was the level of future advocacy that would be required to maintain care and who would take on the role. None of the participants believed that the government would ensure their family member would be cared for once they could no longer advocate on behalf of their child or sibling.

Alexis's primary concern was: “Who I don’t know will be able to take of herself. Who’s, who’s gonna ensure that she has a life after we’re gone? Because she doesn’t have siblings, and she doesn’t have uhm, uhm, extended family you know when, when my husband and I are gone…” Alexis was extremely emotional at this point during the interview. Interestingly, she did not look to government to advocate.

Candice thought along the same vein in that she did not see the government providing a sustainable home for Lilly and therefore was looking at her son to take on the advocacy role. Sasheen was concerned that her health would fail before she secured an independent housing arrangement for Cliff. She hoped he would have supports and everything would be maintained after she could no longer advocate for him. Tashan did not have any faith in the BC system as shown by the fact that she did not make any efforts to look into residential options but instead calculated income Walton could receive and made plans to secure housing on their own property. Poggy hoped that there would be additional funds available to support Walton but feared that there would be none and she did not know how she would...
support him. Mary and Anne hoped that Alex could maintain his residence in the group home. Mary also hoped that Anne would advocate for Alex in the future.

On the theme of how care and housing would be sustained in the future, again it was clear that none of the participants expressed the expectation that government services would be adequate, or even an option in some cases. Family caregivers appeared to feel very much on their own in providing for their disabled child or sibling’s future.

**Theme 9: Safety.**

An overarching theme within this study for families was safety for their dependents. Parents in this study said that their family members with an intellectual disability were extremely trusting to the point of compromising their safety.

About Jasmine, Alexis stated that, “she’ll go with anybody. I mean, if she recognizes you as somebody that she might know, she’ll go with you. No problem. You know, uhm there have been children who have taken advantage of her, and you know, she doesn’t see anything wrong with what they’ve done.” Alexis only realized that children had taken advantage of Jasmine when one night she was putting her to bed and, “she, she gave me a kiss, at, you know, night Mommy, gave me a kiss what? She gave me a piece of tongue.” This occurred in grade 1. Alexis states that the “inhibitions that my child has is going to be different than what other kids have. If it feels good and, and other people are happy with me then it’s okay, where it is not.” Trying to convey this message to Jasmine is difficult but now she has a list of people that are allowed to give Jasmine a good night kiss, never with tongue. The incident happened on school grounds so Alexis brought the issue forward to the school. Alexis worried about her daughter Jasmine’s safety within the school system as she advocated for educational measures to be placed in the school. She said to personnel at the
school: “Look, this is what happened. Uhm. Have you not been doing the good touching and bad touching, have you not done that program?” And they went, “Oh, I don’t know.” Alexis realized they had not, but now the school does have a program in place.

Tashan and Poggy also worried about safety measures within the school system for Walton when he was still attending. They said he had experienced bullying and discrimination. Walton ultimately was pulled out of school as there was no one-on-one care and he became a danger to himself and others. They worried about his temper, behavioral issues, and his need for routine and quiet. Implicit in their comment was both a concern for Walton’s safety, and also concern for others’ safety, should his temper get out of hand. Poggy described how she was called into school to calm him down so he would not become upset.

Candice mentioned Lilly’s unpredictable behavior in the area of everyday living skills. She gave an example: “If the sink tap was on and the water in it was overflowing she would have to think about what to do with that situation.” Candice thinks that sometimes Lilly has “a little block, like the common sense factor of what do you do?” An example Candice used was: “If something is on fire, do you just look at it or do you go out of the house like you should and go get some help? She [Lilly] doesn’t speak very clearly. So she’s a little hard to understand.”

As well as Lilly being at risk in daily life situations in the home, Candice worried about Lilly and strangers approaching her when she was on outings. “If they were to talk to her or say to her that she needs to come with them, she probably would.” She worried that Lilly may wander away. She sometimes would, “maybe leave where you are to go to the washroom or to go somewhere else in the store, without telling any person, staff or family
where she’s going.” Lilly lives with Candice and her husband and she is “not verbal enough to tell somebody if there is a problem or to go someplace, into a store, if she has a problem, or anything like that, she’s not at that level.” Candice believes: “So she really can’t be left on her own completely, she would really need to live in a group home situation where there might be 2 or 3 moderately disabled people with a supervisor in there 24/7.”

On the topic of safety, Grace also mentioned the risk of strangers approaching George and potentially luring him away, for example by asking him to “come for coffee.” Grace also worries that George approaches strangers. Once he approached a woman walking down their street and jumped out of the bushes saying: “Give me your money.” Luckily the woman recognized him and told him to go home, and then reported the incident to Grace.

Grace also spoke of George and his medication as a safety issue. She mentioned an incident of when he was on one type of addictive medication and broke into a neighbor’s house hoping to find drugs. She further identified a time when, “he pulled a knife on me several times cause he wanted a pill and I always hid his pills [addictive prescribed] in a big safe, in my bedroom, with the bedroom door locked and he would take a ladder, once broke the bedroom room to get in.” George is older now and is off the addictive prescribed medication. Grace is only concerned about George’s well-being and has never wanted him removed as she considers George to be her child. George persists in behaviors that Grace continues to curb, such as him eating inedible products such as cigarette butts. Grace is worried about the future housing arrangement for George and fears for his safety. Clearly, her account also indicates times in the past when he has presented a threat to others, including herself.
Mary and Anne spoke of Alex, and how he has endangered himself and other people. Mary commented on a neighbor that exposed himself to Alex:

It really shocked him and he was really affected by it and he’s still affected by it to this day because he can’t, his processing is not the same as somebody who… I guess if you are exposed to something like that even if you are, say normal thinking person then it’s going to have an effect on you.

Anne described her brother Alex as always placing himself in dangerous situations before he was placed in a group home. Alex endangered himself by running out into the road, and he:

Was endangering other people too because he could cause some car accidents. Because somebody might be trying to avoid him, if he ran on the road so it was not even only for himself I could see that they were sort of trying to protect other people as well because you know anybody could get hurt from that, right.

Anne spoke of Alex living in a group home and being safe: “He [Alex] doesn’t always make safe choices. He doesn’t understand all the safety rules. Uhm. He just forgets them, so it’s good that he has that support to help him uhm just to maintain his safety, more than anything. It helps.” Anne added that:

Well he doesn’t always understand that you have to look both ways when you cross the road. He might just run out in the road. Right. He doesn’t pay attention to some of those safety rules. And talking to strangers, he’ll talk to anybody. He’ll tell anybody his whole life story. If you, you know, he’ll talk about anything.

Safety was paramount to all participants as they voiced concerns of the vulnerability of their intellectually disabled family member. Participants felt that mechanisms needed to be
put in place to ensure that their disabled adult child would not be placed at risk of abuse. In addition, they needed assurances that their intellectually disabled family member would have procedures set in place to ensure safety of self and others.

**Theme 10: Preparation.**

It was interesting that the words most used in this study were “going, because, think and don’t.” Preparations that these family members were making was because they had little faith in the system presently set up for their family member, and even less confidence that services would be forthcoming once the parents could no longer provide advocacy.

Alexis worked on gathering information but hoped someone could provide her with a plan:

So, the future? It would be nice if it was gently introduced at an earlier age. So, we would know what we needed to prepare. I'm more of a preparation person than spring it on me. If you spring it on me, you know, the stress level goes right through the roof. If I know that I have to, you need to do this, we need to have this in place before we can apply. I don’t think that, that is going to happen. I feel like I’m, out there on my own, churning around like a hamster on a wheel.

Alexis was beginning to look into Trusts and Wills and microboards. Alexis’ concern was that sourcing information was draining her energy and that she felt like she was “wading through quicksand...It is quicksand. And not only that it changes. So, if I expend the energy to figure out what’s gonna happen, then in two years from now, three years from now, it’s gonna change any way.” So she resorted to, “put that on the back burner and we’ll worry about that, but we’re still thinking, continually how, what’s gonna happen to her?”
Tashan and Poggy thought that they alone could take responsibility for securing a home for Walton. Mary and Anne hoped that the current group home that Alex lived in would suffice for the remainder of his life. Anne specifically hoped that her own children remained healthy and that “everybody is able to you know, kind of, you know, be able to uhm just you know live out a couple of their dreams.” For her, her family’s happiness and future was a priority, and she relied on government care to provide for her brother.

**Theme 11: Quality of Life for the Caregivers.**

Quality of life was not stated as a primary concern by most family members in this study. It seemed to me as a researcher that this subcultural group focused on securing the basic needs of the family members with the intellectual disability but there was very little mention of quality of life for parents.

Alexis identifies that her focus is on day to day living as she stated: “We’re so busy with the day to day surviving that, and I’m, one of the things I have consciously tried to do is it’s cheap to go swimming.” Financially they have had to reduce expenditures and emotionally they have no energy to entertain friends. In one word Alexis sums it up as “isolating” in that she no longer wants to engage with the community. She stated: “And I don’t want anything. I don’t want to go anywhere or do anything.”

Grace worried and felt powerless to secure a home for George as she was designated as a caregiver only. Grace thought her quality of life was good and didn’t see George as impacting her life negatively. She said:

My family has certainly accepted him, has accepted him as one of us but all families don’t and he’s always in your face. You know. So, but, but he is my main man. Uhm and I know when my husband died he was really concerned for George and I
promised him I would keep him forever. So. Not that it is a promise to him but I want to, I wouldn’t let him go.

Grace found that she could not just jump in her car and go someplace as she states “you’re pretty bound to home.” Grace enjoys being with George and brings him with her for most of her holidays.

Candice spoke of her quality of life as it related to Lilly’s care in that she didn’t need to dress or lift her. Candice said as long as those issues didn’t exist that their quality of life was good. She did expect that could transition as she ages and begins to look at retirement. She stated: “Yes it probably will be a problem because we would like to maybe move too. Retire some place. We may want to sell our house and move to a different place which of course uproots her completely. So we don’t, we don’t know. We’re kind of sitting on the fence with all of these things.”

Mary stated that having Alex has affected their choices and quality of life:

I think it’s made us more tired, sooner. And yeah, because Todd had to actually retire, uhm, because we had, we couldn’t leave him at home by himself. So he had to retire so he could stay at home so it has affected his pension so that way yeah it has affected our quality of life. And uh, Ah, sadness, frustration, uhm just anxiety, yeah.

Mary’s family experienced extreme anxiety when they had to abandon Alex after pleading with CLBC to provide him with a residential home. She recalled:

With the social worker phoning me every day to say ‘come pick him up, he’s not sick, you have to come pick him up.’ And I’d say, ‘No I don’t have to pick him up because I can’t take him home, I can’t take care of him properly.’ So that was all that stuff anxiety and... Yeah.
Sasheen worked on securing an independent living placement and associated her quality of life with Cliff’s in the following statement: “I think our quality of life is pretty good.” She relates quality of life to income: “Our income and our ability to afford our home and all that stuff is fine.” For Sasheen, however, her quality of life is impacted by the worry about Cliff’s unknown future.

Poggy talked about her quality of life “kind of revolves around my brother [Walton].” In her family, she saw her brother as the individual that “pretty much brings all of us together.” Whereas Tashan really struggled with the additional weight of caring for Walton and this has affected her own well-being:

I feel like Walton is in his teens now and I feel some days like I’m 80. Because of everything that has gone, I’ve aged, I think double fast. More so than what he has. Just with everything, dealing with schools and financials and the medical part of it and everything else I just feel like I’ve aged drastically, because of his disability. And I said that I think everybody in our family feels it.

I think Tashan sums up the frustration when she describes her day:

Physically, mentally, I’m tired. I’m tired with always being you know, you get up in the morning, it’s got to be the same routine with him, you set goals in one way for like with Walton, I try to set goals with him. When he doesn’t reach those goals of course he gets frustrated, I get frustrated. I find that the everyday care part of it, because he only eats 16 different types of foods. You gotta watch when he goes into the bathroom because he doesn’t know the difference between hot and cold, in the tub. So you’ve gotta make sure that he gets in and he gets out. He knows how to shut everything off. It’s the struggle of worrying when you’re out of the house and I do
leave him with his sister, uhm. You know that he doesn’t get frustrated, that he
doesn’t fly off the handle with the anger part. His issues that way. So it’s the worry.
Like you’re constantly worrying from the time you get up to the time you go to bed.
Is he eating Okay does he, you know, is he mentally capable of staying 10 minutes so
that I can take a break. If we’re out, outside, you’ve got to watch he doesn’t wander
off; you’ve got to watch that he doesn’t talk to strangers; you’ve got to watch that you
know he’s not going to hurt himself or hurt anybody. So it’s like a struggle every day
from the time you get up to the time you go to bed, you just worry yourself sick.
What is going to happen to this child? You know.

It was not a surprise to me that quality of life for the participants was not their
primary concern. The participants were female, including the two siblings. Mothers were the
primary caregivers. As Esquivel (2014) states: care is commonly associated with women and
the word itself is “loaded with moral meanings concerning notions of duty and love…These
associations are not innocent; they have concrete effects in shaping different policy agendas
and institutional responses to care and care work” (p. 423).

**Theme 12: Solutions.**

Many of the families identified solutions that could be implemented. Some of the
solutions they identified were planning, investing, provision of information, and guaranteed
sustained funding.

Alexis identified measures that she undertook to try to circumvent future obstacles:
That’s that’s probably what we do all of this for, is, our whole lives are centered
around what’s it going to be like for her. We have to get her to read, so that she can
read. Um, you know, what’s going to happen if she gets an eviction notice, if she gets
an application form she has to be able to read. Panic, panic she has to be able to read. Then we’ve got that and the next panic sets in. You know, ‘What’s the next thing that we need to worry about?’ So, we worry that number one: she is not going to have a network of friends.

Alexis is looking to build friendships for Jasmine as she wants her daughter to “be able to have the life that I’ve been able to have [with her friends].” She addresses the sense she has of being all alone in the caregiver situation:

And looking around me, I feel like I’m all by myself on this little wheel. Are there other people in this, I even said to the respite house, I cannot be the only parent of a child who is younger, who needs a friend.

She sees that a possible solution to this problem is within the schools: “Where is the avenue to meet, for these children to meet? ‘Cause they’re all from eight, nine different elementary schools.” Alexis stated that the current school setup for Jasmine is not conducive to her daughter developing a network of peers:

She’s on her own in a classroom, one of ten classrooms in eight elementary schools in this system. So, what chance does she have of meeting, and creating this bond that you and I have, or were able to have with kids her own age and own ability level. So, I’m back to that again. That’s, see that’s where my focus is.

Alexis identified a need for families caring for a dependent individual having to band together to advocate for their family members with disabilities:

And I have been saying that since practically day one. Unless I can find a parent, ‘oh, you have a special needs child, would you like to come for lunch?’ There is nothing out there; if you keep us separate, then we’re powerless, it seems. If you give us an
opportunity to get to know each other, we can create our own power or community because basically that’s the friends that she’s going to have.

Alexis knows that the database of parents exists:

As parents of special needs children, all of our children go to the doctor. From that point there ought to be a way of creating a community from which to make the richness of life for our children. The friendships, the, the future is being denied them in so many ways because they don’t have access to other children like them and I’m hoping of course because of Special Olympics that that’s going to be an avenue but there’s got to be more than that.

Advocacy requires information. She also sees the need for government services to be more proactive instead of reactive to crisis situations:

So I wish for, for the community of special needs parents more advocacy that is proactive rather than when life falls apart that we, we so we so somebody picks up the pieces. Instead of it falling apart and imploding why isn’t there a proactive ‘Oh Alexis you have a special needs kid, you need to be part of this association, you need to come and find out about this information. You need to know, you need to make this plan or what is it that you feel you need?’ That’s pro... the proactiveness of positive growth.

Alexis identifies another way to improve the situation would be if someone from the ministry [MCFD] would talk to her about future planning for her daughter:

Like, is anyone of the illusion that this isn’t going to be a worry? You know, guess I get caught up in getting through this week. You know, what is she gonna do? What sports, and the everyday mother things that I have to deal with, as well as the
extraordinary stuff that I have to worry about; the school, the meetings, and all that kind of stuff. I would like somebody, if, if, she has supposedly a social worker, why is it we’ve never talked about the future?

Alexis thinks that another possible solution would be a manual to guide her through the process:

I don’t know anything. Nobody’s ever given me a book even. If they gave me a book half the worry would be over. I can read the book that says: these are the options that are available to you. You know, is my daughter going to be um, living in an apartment somewhere on minimum, poverty level?

Alexis thinks that the solution for her family is being left in her hands, and that there seem to be very few social supports available:

If I tie up all the physical, educational and social uhm parts of her life and I try to give her some basis to bounce into the future with, you know, uhm have I done it well enough? Is there more that I could do? Are there more supports out there that I need? And the answer to that I’ve tried all that I can and know the supports don’t seem to be out there unless you happen to meet someone who has another piece of information.

Ultimately Alexis feels that the formation of special needs groups can be organized by parents at grassroots level, and that this will be the most realistic solution:

We need to band together to demand a life for our kids. I mean, I mean at one time didn’t parents do that for your regular average, intelligent child and that’s how come we have a public school system. Every child has a right to one. If we don’t band together, then all we are is talking in the wind. Because they don’t have to listen to us because we’re one voice and one voice has a tendency to get lost. I mean, I really do
think that we as a disbanded community need to band together to create a voice for our children in other, in all aspects of their life.

Anne wanted a guarantee that her brother Alex could maintain his current living arrangement in the group home. She wanted a government commitment in ensuring that the current group home model would be maintained as a protection of human rights for individuals with intellectual disabilities:

I think, his most important thing to him is that he has his room, he has his game system and his music, and he has, you know, he can call his friend anytime he wants because it’s not long distance. Right. So they can talk on the phone....And I hope that these group homes don’t end up being completely non-existent. Because I’ve worked with those clients and that’s their home, they love their home. And that’s the thing. It’s their space. They have their room, it’s like their little apartment. But somebody helps them, if they need help you know with things. Right. And they will come in the kitchen and they will help cook the meal. Because they, they want to. And they have chores and they are proud. Right.

Anne believes that the group homes must be maintained for the well-being of the people who live there:

So, and that’s why I kind of think that when they start, if they get rid of these group homes they’re going to be hurting some people feelings that there, I don’t know if they are really considering how the people that are residents of those homes how they feel about it.
Candice is another parent who has worked hard in ensuring that Lilly is educated, prepared for the workforce, and for participation in society. For all Candice's efforts, she still saw the need for additional supports and services for Lilly:

She reads and she writes and she does computer typing. She doesn't understand math. She also does unpredictable things, like if the sink tap was on and the water in it was overflowing she would have to think about what to do with that situation. She'll do things all of a sudden that you don't expect her to do. ...She's pretty good, generally, at what she's doing but every now and then there is a little block, like the common sense factor of what do you do. If something is on fire, do you just look at it or do you go out of the house like you should and go get some help? She doesn't speak very clearly...She really can't be left on her own completely.

Candice thought that Lilly needed to live in a group home with “2 or 3 moderately disabled people with a supervisor in there 24/7.” However, she was concerned about the lack of guarantee from the government that Lilly’s funding would be secured:

Then what would she do? So, I don’t know, I mean there are no guarantees so, that would help if there was a guarantee that she could stay where she was. If she had an apartment with two other ladies or in a group home and they were looked after by somebody living with them or whatever and that would go on forever. But there are no guarantees for that so that would help. So if there was a plan, a plan and a guarantee that they had the funding secured for the rest of their life...

Unless the government guarantees that funding is secure for the future, caregivers must try to find other options to ensure their child is cared for in the future. Candice therefore
has made preparations for Lilly to move into the community to which her brother has relocated.

In addition, Candice has set up a Registered Disability Savings Plan (RDSP) as a future source of income for Lilly:

We have an RDSP set up for her. We set it up actually as soon as they opened. I’m amazed how many people haven’t and it’s so easy to do. Have you done it? Because you don’t even need to put in a lot of money to it if you just open one and put in $25 dollars you’ll start getting the $1000 dollar bonds right away. You don’t even have to put in any more money. But if you can put in the $1500 a year, you’ll end up getting an extra $4500. So you’re making a huge return on this money. So for your $1500 it turns into $6000.

Candice suggested a good website to check out for additional information on the RDSP: “The Plan site is a really good place to go for people to look and get information from.” Candice believes this is a good measure for savings set up by the government but thought that it has been funded with ‘soft money”: “And the government is going to pull this, I’m sure, they haven’t said, but it’s only a matter of time before they stop doing this so people really should be getting on it.” Candice would like to see this program remain.

Participants were in general agreement that the BC government system did not provide a guarantee that they would look after their intellectual disabled adult child family member now or in the future. Solutions varied from transferring care of disabled family member, to siblings to RDSP’s or to setting up a microboard.
My Experiences of Government Supports

In this section, I describe my own experiences in trying to access government supports. Accessing government supports for my family has been frustrating and at times enriching. I have found that as my son grows older, information is becoming more limited and less forthcoming. The current services I access require an extensive amount of paperwork for which I cannot find the energy. My concerns are similar to the participants in that I fear supports will not be in place for my son in the future.

Finding out I had a child with an intellectual disability and dealing with the initial shock was difficult. Our primary concern on hearing the nurse say that our son had Down syndrome was “who will care for him in the future?” Initially, some supports and services were provided by the Child Development Centre (CDC) such as speech specialist, occupational therapy, physiotherapy, and so forth. Our initial encounter with the CDC was a home visit by an employee to inspect our home and assess how we were coping with our new disabled baby. The CDC worker made me feel like I was being investigated by Social Services. She went through my house inspecting and dictating procedures to me. At that point I decided I needed to understand the system that my son was part of. I proceeded to figure out the system by joining the CDC board. Luckily the CDC was undergoing a Commission on Accreditation of Rehabilitation Facilities (CARF) process. I provided input into the process of new family admittance into the CDC. This process was one of the most enriching experiences I had ever had. The CDC worked with me to ensure family needs were being met.

Unfortunately, a few years later— a year before my son transitioned to kindergarten—we moved to Hub City. My son was waitlisted for services from the CDC in
this city. I knew we only had a year before his services would transition to the school district system so I did not get involved with the CDC in Hub City to figure out why waitlists existed.

In Hub City, the school district to which my son transitioned does not support services such as physiotherapy, occupational therapy, and speech and language therapy. I tried to advocate for services and even today continue to wait for these services. I have asked different professional service providers for supports but I have not been able to locate anyone that can provide information on the unsupported services.

Our son was a challenge for us as a family as he would bang his head during the night. Initially we got up and held him so he would not injure himself but as the years of sleepless nights accumulated we decided we needed support. We visited an MCFD social worker and respite services were provided. Unfortunately, the respite services were not adequate; our son returned home on numerous occasions with injuries he received from other children in the respite home. We pulled our son out of the respite home and he no longer receives these services. The process to receive other services has been exhausting; our last request to MCFD for diapers was met with: “Check out the website for eligibility and contact the 1-800 number along with the paperwork.” We have not had the time to do this yet, but maybe next year.

Overall, I feel the services provided by MCFD are limited and if the current support is any indication, I don’t even want to think about the future.

The History of Government Supports

In conducting the policy analysis component of my study, I reviewed documents pertaining to the history of government supports in British Columbia for intellectually
disabled individuals and their families. Then I examined three components: timeline, perceptions about the nature of disability, and federal laws and policies pertaining to people with disabilities. I looked at the chronology of critical developments of disability policy in Canada; British Columbia provincial laws and policies put in place to care for intellectually disabled individuals and their families; and what context the lived experiences of this study's participants provides in understanding the current policy position of the BC government.

**Canadian/Federal Supports.**

Table 3 outlines the history of disability in Canada. It provides a context of how Canadians' view of disability has changed from a law and order model to a welfare state charity model and finally towards a human rights model.

**Table 3: Chronology of Canadian Events Relating to Disability History**

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>Mid 1800's</td>
<td>People with mental illness (no differentiation made between intellectual disability and mental illness) typically either put in jail or cared for at home.</td>
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<tr>
<td>1860-1890</td>
<td>Person with intellectual impairments, needed protection was the main justification of the asylum model of care; Belief in importance of collectivism, respect for authority, and acceptance of the need for state intervention. Disability policy development was part of the evolution of collectivist social policy.</td>
</tr>
<tr>
<td>Early 20th Century</td>
<td>Law and order; institutionalized.</td>
</tr>
<tr>
<td>WWI</td>
<td>Hospital and disability pensions for war veterans established; rehabilitation programs aimed at treatment and training; and injured workers training assistance.</td>
</tr>
<tr>
<td>1914-1950</td>
<td>Provide workers' compensation scheme.</td>
</tr>
<tr>
<td>1920-1970's</td>
<td>Individual medical and vocational limitations viewed as main obstacles to full participation in society. Treatment and support services to improve ability to perform jobs. Those unable to work received some compensation.</td>
</tr>
<tr>
<td>1929-1972</td>
<td>In Canada, Alberta &amp; British Columbia were the only two provinces that enacted legislation authorizing involuntary sterilization - Eugenics. Over 2800 people were sterilized under the authority of the Alberta's Sexual Sterilization Act. Movement to ensure more 'fit' members of society had children while 'undesirable elements' were bred out of the population. Alberta sterilized ten times as many people as British Columbia.</td>
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<tr>
<td>1940</td>
<td>Unemployment insurance Act (First federal welfare plan in Canada)</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
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<td>------</td>
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<tr>
<td>1957</td>
<td>Federal Hospital Insurance and Diagnostic Services Act.</td>
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<tr>
<td>1960's</td>
<td>Canadian government enacts welfare policies based on: Equality of condition (social minimum); Equality of opportunity (education); and Equality of consideration (human rights). Welfare state policies introduced.</td>
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Aimed at returning people with disabilities without other resources to the workplace; enabled provinces to recover 50% of vocational training costs. |
| 1965 | Canada Pension Plan.  
Federal-provincial agreement providing national system of social insurance (took form of either a retirement pension, for those in paid employment, or a disability pension).  
Canada/Quebec pension plan - contributory pension scheme that provided a national system of social insurance to the paid labor force—specifically, for people in retirement, widows and widowers, orphans, persons with disabilities, and children of disabled contributors. |
| 1967 | Medical Care Act provided universal access to hospital services and physician care. |
| 1970's | Disability does not stem from individual limitation but from the failure of the social environment to adjust to the needs of people with different abilities.  
Emphasis placed on enhancing participation in communities by increasing access to buildings, transportation and employment.  
By 1970 all provinces were receiving grant aid from the federal government to develop health-care, education and social welfare programs. There was general support for universal, equitable, publicly administered programs in health and post-secondary education. |
| 1971 | United Nations General Assembly – Declaration on the Rights of Mentally Retarded Persons – intellectually/developmentally disabled person has the same rights as other human beings. |
| 1972 | The western provinces, especially BC and Alberta, had been actively enacting eugenics. End of eugenics (sterilization) movement in Alberta. |
| 1977 | Federal-Provincial Fiscal Arrangements and Established Programs Financing Regulations, to control costs associated with open ended, federal-provincial matching grants. |
| 1980 | Canada's goals begin to shift from a welfare state to a welfare society.  
Financial redistribution alone would not create a true collectivist society and that all citizens had the right to be accepted for what they could contribute.  
Changes in attitude towards people facing discrimination were as important as financial redistribution. |
| 1982 | Aims of a welfare society were reflected in the Charter of Rights and Freedoms.  
*Charter of Rights and Freedoms*: women, native people, visible minorities (non-Caucasian), and people with disabilities. |
1985 Charter of rights and freedoms, Section 15, Equality Rights:
15. (1) Every individual is equal before and under the law and has the right to the
equal protection and equal benefit of the law without discrimination and, in
particular, without discrimination based on race, national or ethnic origin, colour,
religion, sex, age or mental or physical disability.
(2) Subsection (1) does not preclude any law, program or activity that has as its
object the amelioration of conditions of disadvantaged individuals or groups
including those that are disadvantaged because of race, national or ethnic origin,
colour, religion, sex, age or mental or physical disability (Canadian Charter of
Rights and Freedoms, 1982).


Current disability supports provided by the federal government are as follows: “Registered
Disability Savings Plan, the Disability component of the Social Development Partnerships
Program, Canada Pension Plan Disability, the Enabling Accessibility Fund, the Opportunities
Fund for Persons with Disabilities, labour market agreements for persons with disabilities,
and post-secondary education assistance measures for students with disabilities” (Human

The Canadian government historically has worked to enhance the rights of
individuals with intellectual disabilities as noted in the 1982 Charter of Rights and Freedoms
legislation. Current supports provided by the federal government are noted above, but the
ultimate protection in providing a safe place to live is the mandate of the provincial
government.

British Columbia/Provincial Supports.

British Columbia’s history on housing individuals with intellectual disabilities started
in 1872 with the first asylum model for the insane and transitioned with the human rights
movement and closure of institutions to what we have today, community residential housing.
British Columbia history of housing individuals with developmental disabilities is
summarized in Table 4.
Table 4: BC History of Housing Individuals with Developmental Disabilities

<table>
<thead>
<tr>
<th>Year</th>
<th>Description of Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1864</td>
<td>Infirmary for women opened in Victoria – includes a few female “lunatics” as patients. Most mentally ill people are left to fend for themselves or, if deemed dangerous or troublesome, are locked in the crowded city jails of Victoria and New Westminster.</td>
</tr>
<tr>
<td>1872</td>
<td>Royal Hospital opens: BC’s first asylum for the insane. Menzies and Atchison (2009) described the asylum as “ramshackle Victoria Lunatic Asylum (a former ‘pesthouse’) on expropriated Songhees First Nations lands on the north shore of the capital city’s inner harbor” (p.1).</td>
</tr>
<tr>
<td>1873</td>
<td>BC’s first legislation regarding mental illness: Insane Asylum Act.</td>
</tr>
<tr>
<td>1878</td>
<td>Due to overcrowding a new asylum is built: Provincial Asylum for the Insane (PAI) in New Westminster (BCMHSUS, 2013). Now known as Woodlands.</td>
</tr>
<tr>
<td>1883</td>
<td>Asylum residents are put to work in the gardens: work therapy.</td>
</tr>
<tr>
<td>1884</td>
<td>North (East) wing added. Eight new patients admitted classified with the following disorders: nervous trouble, masturbation, injury to head, intemperance, fright, and unknown.</td>
</tr>
<tr>
<td>1886</td>
<td>Asylum garden produced 20,000 lbs. of vegetables, mostly through patient labour. Resident population 65.</td>
</tr>
<tr>
<td>1894</td>
<td>Commission of Enquiry revealed widespread maltreatment of patients. Superintendent resigned.</td>
</tr>
<tr>
<td>1897</td>
<td>Hospitals for the Insane Act: Mentally ill persons could be committed to hospital under an Urgency Order, which requires two medical certificates; PAI renamed to Provincial Hospital for the Insane (PHI).</td>
</tr>
<tr>
<td>1899</td>
<td>PHI population surpasses 300. In the absence of social services, the hospital is housing developmentally disabled people and unwanted, physically handicapped children along with psychiatric patients. Complaints are heard of serious overcrowding, poor hygiene and living conditions, and inadequate care. Resident population 234.</td>
</tr>
<tr>
<td>Early 1900’s</td>
<td>BC’s immigrant population booms in the early 1900s. By 1924, Essondale became the administrative centre of the province’s public psychiatric system.</td>
</tr>
<tr>
<td>1904</td>
<td>To relieve overcrowding, 48 male patients are transferred to a small asylum in Vernon, and the BC government purchases 1,000 acres in rural Coquitlam as the site for a new mental hospital – the beginning of Riverview Hospital. Resident population 349.</td>
</tr>
<tr>
<td>1905</td>
<td>Using mostly patient labour, housed on-site in temporary buildings, the Coquitlam site is cleared and diked, and Colony Farm is established to grow food for the PHI.</td>
</tr>
<tr>
<td>1913</td>
<td>The Hospital for the Mind (Essondale) is officially opened, taking 300 of the most seriously ill patients (all male) from the overcrowded New Westminster facility.</td>
</tr>
<tr>
<td>1916</td>
<td>Weekly dental service begins. Resident population 518.</td>
</tr>
<tr>
<td>1932</td>
<td>PHI concentrated on ministering to the cognitively disabled, particularly children (and by the 1950s it was correspondingly renamed as the Woodlands School).</td>
</tr>
<tr>
<td>1933</td>
<td>BC adopts a sexual sterilization law similar to Alberta</td>
</tr>
<tr>
<td>1940</td>
<td>BC’s Mental Hospital Act is amended, deleting all references to “lunatic” and “insane”</td>
</tr>
<tr>
<td>1942</td>
<td>Electro-convulsive therapy (ECT) introduced, followed by sulfa drugs, then psychosurgery; all BC’s mental health facilities are reported as overcrowded.</td>
</tr>
<tr>
<td>1950</td>
<td>Provincial Mental Health Services are amalgamated; New Westminster’s Provincial Hospital for the Insane is renamed Woodlands School, repurposed as a residential facility for the developmentally disabled.</td>
</tr>
<tr>
<td>1951</td>
<td>Essondale reaches its peak population of 4,630 patients. Pennington Hall opens, providing recreational services to patients.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
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<tr>
<td>1953</td>
<td>School for Mental Defectives Act proclaimed.</td>
</tr>
<tr>
<td>1955</td>
<td>Improved medications, opening of community mental health centres, boarding homes, and general hospital psychiatric wards, results in the start of a decline in Essondale's patient population.</td>
</tr>
<tr>
<td>1959</td>
<td>Essondale’s last major residence opens, Valleyview 300. Tranquille tuberculosis sanitarium in Kamloops converted to residential facility for developmentally disabled.</td>
</tr>
<tr>
<td>1961</td>
<td>Highest resident population (1436) at Woodland’s.</td>
</tr>
<tr>
<td>1965</td>
<td>BC Mental Health Act introduced.</td>
</tr>
<tr>
<td>1966</td>
<td>Essondale is renamed Riverview Hospital, although Valleyview continues to operate independently until 1986.</td>
</tr>
<tr>
<td>1970</td>
<td>Beginning of relocation of residents to group homes, community placements.</td>
</tr>
<tr>
<td>1973</td>
<td>Northern Training Centre opens in Smithers, BC. Centre offered residential, co-educational program to help mentally challenged adults learn skills that could help them become more independent.</td>
</tr>
<tr>
<td>1978</td>
<td>Woodland resident population decreases to 890 residents.</td>
</tr>
<tr>
<td>1979</td>
<td>Sexual Sterilization Act repealed.</td>
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<tr>
<td>1988</td>
<td>The BC Mental Health Society is established and takes over management of Riverview; the society’s provincially-appointed trustees are replaced by a community-based board of governors in 1992.</td>
</tr>
<tr>
<td>1990</td>
<td>The Mental Health Initiative introduces a comprehensive plan for the development of mental health services throughout the province. It focuses on replacing Riverview with smaller, more specialized regional facilities.</td>
</tr>
<tr>
<td>1994</td>
<td>Riverview establishes Canada’s first Charter of Patient Rights. After investigating patient complaints, the BC Ombudsman releases a report titled “Listening – A Review of Riverview Hospital”. The two events signal a change in Riverview’s relationship with its patients and family members.</td>
</tr>
<tr>
<td>2001</td>
<td>The BC government announces a new administrative structure for health services, comprising five geographically-based regional health authorities plus the Provincial Health Services Authority (PHSA), which is responsible for specialized, province-wide services.</td>
</tr>
<tr>
<td>2002</td>
<td>The aging institutional buildings at Riverview are to be gradually phased out, replaced by new smaller tertiary care facilities located in each of the five geographic regions of BC. Riverview patients will be transferred to facilities within those health regions in a carefully planned “bed for bed” transfer process. Kelowna murder-suicide: Maurice, Belva and Reece Baulne. Family rejected for funding to help parents care for son Reece at home. The tragic murder-suicide of a Kelowna family has helped galvanize commitment to find options for B.C. families caring for mentally disabled children, says Children and Families Minister Gordon Hogg.</td>
</tr>
<tr>
<td>2003</td>
<td>Provincial Government apologizes to former residents for incidents of mental, physical and sexual abuse it deems did likely occur over many years at The Woodlands School. $77.5 million (12%) budget cut to adult community living services (BC CLAG, 2011, August 11).</td>
</tr>
<tr>
<td>2005</td>
<td>With patient transfers to new regional facilities continuing to reduce Riverview’s population, the 75-year-old East Lawn building is closed. Community Living Act; CLBC established to empower people with developmental disabilities.</td>
</tr>
</tbody>
</table>
Canada has emerged from a law and order type of approach to managing individuals with intellectual disabilities in the mid-1800’s to a country that heralds protection of rights for the most vulnerable population. Monies are required to protect the rights of this population but the current economic situation in British Columbia is not providing sufficient supports and services. Instead, the BC government is transferring the responsibility onto families. This study’s findings reflect the struggles that families are facing.

**Current Situation of Government Supports.**

The MCFD and CLBC supports currently in place for families are limited. Waitlists for supports and services continue to be an issue as identified by participants in this study. Frustration regarding lack of information is a prominent theme discussed. CLBC presents itself as a business, as it introduces efficiencies in its work, and supporting policies and procedures. CLBC’s cost saving measures of cuts to community living (e.g., closure of group
homes) has created crisis situations with many families. Prioritizing savings to programs before investing in supports to families has created a piecemeal service plan to families leaving them worn and tired. The system is in continuous flux creating confusion for families. Policy is going in the direction of closing group homes to save money at the expense of the well-being of individuals with intellectual disabilities. Families are left to advocate for the few monies CLBC provides.

Families in this subcultural group have experienced shifts in government setup of services within the last few years. Services for individuals with intellectual disabilities a few years ago were through CLBC and then changed in 2009 to the MCFD for children 0-19 years and to CLBC for adults 19 years of age and older. Most participants understood bits and pieces of the MCFD and CLBC programs and services but most felt like they knew very little about the overall services and policy framework. A statement by Alexis sums up the feelings of most of the study participants: “I don’t know what’s out there.”

Participant Evaluation

As a means of verifying the results of this thesis, I asked one of the study participants to review the manuscript submitted to the thesis committee prior to the defence. The participant made the following statement:

Read the whole thing again last ... We are sooooo on the same page! You know your topic and it shows... All this needed to be said and it showed how vulnerable not only our kids are but us as caregivers as well. We throw our hearts out there sharing our fears and we truly believe that the government is deliberately ignoring us.
Chapter Five: Discussion and Conclusions

The purpose of this study was to gain an understanding of what families caring for an individual with an intellectual disability are experiencing as they navigate the current social framework in locating housing in northwestern British Columbia. Eight participants were interviewed and a thematic analysis was used on the data to determine significant issues that these families are facing while trying to locate and secure a home for their intellectually disabled family member. In this chapter, I will talk about the experiences of family caregivers. Then I will discuss my own experiences, using the interviews as a lens to show how my own understanding of the housing context has developed, and also using my own experience to better understand the participants' experiences. I will discuss the current BC policy framework and provide recommendations for possible solutions to alleviate family pressures of caring for an intellectually disabled adult child family member. In addition, I will discuss limitations within this study and the implications of research results.

The Experiences of the Family Caregivers

Individuals with intellectual disabilities are not moving from family homes into their own places due to:

A supply 'crunch' within the developmental services residential system; the formal residential services system for people with intellectual disabilities has simply not kept pace with increasing demand in recent years. Other factors include the high cost of housing on the open market and the low incomes of people with intellectual disabilities, difficulties securing the needed supports for disability beyond the family home and other issues of a financial nature. (Crawford, 2008)
Families have become the primary caregiver for their family member’s lifetime until they are no longer able to provide care. This study presents the voices of families caring for an intellectually disabled individual and their lived experience in the context of the current BC policy framework. The main issues arising from the caregivers’ experiences dealt with: fear of inadequate housing options and supports; safety; and the need for advocacy by parents in order to ensure supports and services were attained and maintained.

Participants’ words most frequently used in the interviews were “going,” “think,” “because” and “don’t.” Participants described a lot of their experiences as going towards something, thinking about outcomes, explaining why things were a certain way and why things could not be another way.

The differing ages of the participants provided a means of viewing how MCFD and CLBC have been transitioning adults at 19 years of age into residential housing options across time. This study shows that participants do not have a smooth transition plan from the family home to an alternative residential housing option. In many cases, family members with disabilities remain in their parents’ home rather than transitioning into other housing. In the No Place Like Home report Crawford (2008) stated that “compared with adults who do not have disabilities, those with intellectual disabilities are much more likely (38% compared to 18%) to be living as never-married adult sons and daughters with one or both parents” (p. 9).

Access to residential care facility options is limited and waitlists for transitioning youth have become commonplace in recent the last decade (Crawford, 2008). The BC government states that it is essential to reduce costs but seems to believe it is appropriate to offload the expenses to the families of intellectually disabled individuals. Elderly parents

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continue to provide care for intellectually disabled family members but at what cost to them in terms of health and quality of life?

Older participants were extremely weary of the government system. Grace (65-69 years of age) said that unless she had something in writing she would not believe any verbal communication. Grace hoped that her daughter would be allowed to provide supported home share for George (35-39 years of age). Candice (60-64 years of age) was a true warrior in the sense that she fought to have Lilly (30-34 years of age) attend regular school instead of special needs. Lilly lived at home with her and Candice had fought for supports to ensure Lilly had a good quality of life. Candice did not look to the government to advocate for Lilly, but rather to her son. Mary (60-64 years of age) had to abandon Alex (30-34 years of age) in order to ensure he was admitted into a group home. Mary had been on a waitlist for 10 years, and only made progress when someone mentioned to her that abandoning Alex would be the only way the government would take over housing Alex.

Two participants were on the cusp of transitioning to supported homes for their children. Sasheen (45-49 years of age) was waiting for a residential option that would provide Cliff (20-24 years of age) with safety and accessibility to amenities. Tashan (40-44 years of age) did not consider any government residential option as accessible as she thought each of them would impinge on Walton’s (15-19 years of age) freedom. CLBC’s literature claims that it provides supports to “eligible adults to live as fully and independently as possible in the community” (Queenswood Consulting Group, 2011, p. ii). However, these study participants reported that in their situations, these services are not adequate or available.
It is important to note that CLBC caseload projections are highly unpredictable and difficult to budget for as numbers of transitioning disabled members are based on both youth [known] and adults currently living with families [unknown]. I was surprised that information was unknown on this population, as individuals with intellectual disabilities have numerous health issues and I would think records exist in our health care system. As well the Ministry of Education through the Individualized Education Plan (IEP) keeps records on number and nature of disabilities prior to the transition to adult-based services. As stated in the Queenswood Consulting Group (2011) report “it will continue to be challenging to estimate both the number of older clients who will present for services in the course of a year, and the cost of serving each year’s new cohort” (p. ii). The numbers are important as they relate to funding and waitlists for housing of transitioning youth. The request for service list is based on “the highest established need, within a fixed budget cap” (Queenswood Consulting Group, 2011, p. ii). I think that this means that transitioning youth or older adults only get priority if families are in crisis. As seen with Mary, she was in crisis mode and had to abandon Alex in order to receive services. Otherwise, they wait like Sasheen, and hope that residential placements are available before their health fails.

Transitioning youth planning is not considered until disabled family members are 15 years of age. One participant, Alexis has a child under the age of 15. During the interview Alexis had not begun to look at residential options for Jasmine. Alexis was concerned about community and respite services for her family. When I probed a bit further about possible housing options, Alexis thought that a group home was not an option for Jasmine as she knew of the group home closures. Recently, Alexis told me she was looking into a
microboard option where a board of directors [chosen by Alexis] would advocate for future supports of Jasmine.

Parental advocacy of this subcultural group is crucial to supports and funding of intellectually disabled individuals. Parents are the warriors in this group as they are the true advocates. I found it interesting that in a country that proclaims that human rights of individuals with intellectual disabilities are protected, that their right to adequate housing was not protected. Parents were the only ones continually fighting and advocating for resources to support their disabled family member now and into the future. All parents had done their homework regarding supports and services and all knew that waitlists and funding were issues. All participants, with the exception of the siblings, had sourced the system for supports. It is interesting to note that the system had not provided the information to support them, that they had to solicit the information from MCFD and CLBC themselves. I found that this did not align with the Canadian vision of the welfare society and the Charter of Rights in Freedoms as people with intellectual disabilities do not seem to be protected and their rights upheld.

Participants advocated as follows. Alexis sourced information and fought for services. Sasheen sourced independent living arrangements and ensured Cliff was registered along with working out his financial needs. Candice planned for her daughter Lilly’s future well-being by sourcing out services in her son’s community. Tashan and Poggy sourced out their own resources to care for their family member as they were concerned that Walton’s freedom would be impacted if he moved into a CLBC residential option. Mary and Anne hoped for the best in that Alex would stay in the group home. Therefore, the parents have done their part in seeking services and a home setting for their disabled child who has reached or soon
will reach adulthood. However, the BC government, as represented by MCFD and CLBC, is not providing adequate support and information to parents to alleviate their fears of housing options for their intellectually disabled family member in the future.

Provincial budget priorities are always at the forefront of government cuts. The Ministry of Family and Social Development, CLBC’s main funder, ultimately mandates CLBC initiatives. An example is CLBC’s Savings Initiatives Tracking Template (SITT) whose goal is to create a master list of all contracts, track progress, and identify outcomes. CLBC’s SITT resulted in the group home closures of “64 homes in staffed residential services, with 169 people moving into different residential arrangements” (Queenswood Consulting Group, 2011, p. 21). Furthermore, CLBC is promoting a “conceptual shift towards meeting disability related needs by ensuring that family, community, and other “natural” supports remain in place and are not supplanted by funded services” (Queenswood Consulting Group, 2011, p. 27). The BC government is shifting its responsibilities of care for this subcultural group to families. Government publications rationalize these cuts in services as due to current financial restraints. The literature also implies that family placements are preferred.

BC parents with children and youth with special needs rallied in 2001 when they formed Moms on the Move. The rally was initiated to protest plans to cut services by over 20% to vulnerable children and families (Moms on the Move, 2014). Moms on the Move (2014) said that “And now the level and quality of crucial services is being further eroded as the Province seeks to balance its budget on the backs of BC’s most vulnerable children, adults and families” (p.1). Another parent rally by Moms on the Move was also initiated in
2009 once again to protest more cuts. Without the advocacy of parent groups, it seems that the rights for intellectually disabled members of society are not protected.

A particularly important theme emerging from the interview data was the need for advocacy by parents in order to ensure that supports and services were attained and maintained. Some families felt isolated from their own subculture group and felt that if information could be shared, advocacy could be done collectively. Families feared that if they were not able to advocate for their dependent family members, minimal to no supports would be provided. The results indicated that family/caregivers felt unsupported and uninformed. They felt that minimal information was supplied by the government, as summarized by Alexis in a conversation with CLBC personnel [incident occurred while CLBC was still in charge of youth] “well we [CLBC personnel] don’t tell parents what their child can have because then they would want it all.” In terms of information sharing in the Northwest, CLBC provide workshops, but not on options available in this region. In particular, Candice mentioned that in the Northwest a workshop was presented on residential options but she knew it was not for the northwest residents.

The Northwest has a smaller population base compared to bigger centers and I have not seen funding for residential housing options available. I participated on the Hub City housing board a few years ago and advocated for supportive housing but was told that no funding was available to support such an option. The board mentioned the need for supportive housing as a priority in the final report on housing needs in Hub City but also mentioned that lack of funding made this option unattainable during this period.

In the No Place Like Home report Crawford (2008) mentions that more efforts need to be made to develop housing options for intellectually disabled individuals. He suggests that:
Unless and until more such housing and supportive arrangements come on stream, too many families will continue to be responsible for providing housing and social support far past the time when most people leave the parental home and establish homes of their own. And until such a time, too few people with intellectual disabilities will have places that they can call homes of their own. (p. 32)

Funding is always at the forefront of planning, and without committed funding from government, individuals with intellectual disabilities and their families are left fending for themselves.

Most of the parent/caregivers conversations implied that they were still sourcing out information on housing options. There was an obvious gap in support from both MCFD and CLBC in providing obtainable solutions for the housing and support needs of their intellectually disabled family member. Families/caregivers realized that they needed to know the system, meaning CLBC and MCFD, in order to access and advocate for supports and services. Families knew that supports were limited and only allocated to individuals needing immediate attention. I felt an underlying intense competition for limited resources by parents as they advocated for their own family member. Parents only had the energy to advocate for their family member and not the population as a whole and therefore the competition element was introduced.

When asked about their knowledge of provincial and federal policies and advocacy groups, the participants primarily spoke of CLBC or MCFD and supports they provided. They were generally unaware of any other relevant provincial support organizations or other means of advocating for their family member. I felt that the time demands on parents along with their limited energy left them isolated from the support of their subculture group. Such a
group could provide them with information and advocacy tactics. The participants felt that the government supports of which they were aware was dictated from the top with little to no input from the users of the supports. It seemed that they felt like charity cases begging for supports. I felt this created a stigma and impacted their willingness to speak out about their lack of information and services. I found it interesting, that when invited to speak in this study with anonymity, I had to limit interview time due to the massive amount of lived experience they wanted to contribute. Anonymity provided a freedom; I felt that it was like the first time they had ever been given a voice.

Safety was paramount to all participants as they realized that their disabled family members are extremely vulnerable within society. All participants knew that their dependent family members would need some sort of safety mechanism in place. They knew that their child would not have the sense or skills to protect themselves and could easily be taken advantage of (e.g., enter a car if someone asked them to without hesitation). Participants were very aware that some sort of sustained care needed to be in place for their family member's well-being and protection of rights. Some participants worried about the shared home residential option as it did not offer any permanent housing solution. Also, it lacked checks and balances to protect these vulnerable citizens. Because there is little surveillance, abuses could go unreported. Mary who had Alex in a group housing option did not want him to move and hoped that the government would maintain their commitment to keeping him in this home.

Ultimately, fear of the unknown has left these parents afraid of the future. This subculture group found comfort in anonymity as they knew that this was a way of “making waves” without potentially having their current or future funding cut. The changing delivery
system and priorities of the BC government have left parents fearful. The BC service
delivery model appears on paper to align with policy guidelines but after reviewing the
interview data, I see that it does not. Parents are unsure of future supports as CLBC
consistently states that funding is limited and the needs of this subculture group are only
growing. The BC system claims to be transparent but as identified by Alexis, “it is like
wading through quicksand.”

My Experiences

The information gathered in this study has aided me in becoming a better advocate for
my son. It has taught me that, historically, Canada has cared for its intellectually disabled
citizens but within the last few decades a shift has occurred such that the provincial system
no longer is adequately fulfilling this role. The BC provincial system has shifted the locus of
responsibility to families and community. My reaction in response to reading the policy
literature and engaging in the interviews regarding supports available has been emotionally
intense. As a newcomer to this subcultural group, I never knew that our government would
not take care of our most vulnerable citizens. I have reflected on my own future and the
heavy load that I have to carry in seeking services for my son that ought to be provided
automatically under the Canadian Human Rights law.

I have a very rich experience because I am involved in gaining supports for my son.
However, I have been hesitant to cite all my experiences and interactions with support
organizations for fear of compromising my own access to supports. I have been
uncomfortably aware of the possibility of backlash if I am too outspoken. My only thought
all along was that I needed information and that ‘forewarned is forearmed’. I am the advocate
for my family and I believe that the best way to advocate for my son with an intellectual
disability is to get information about the British Columbia system. In doing this research I have learned that services and programs are dictated from the top government structure and this structure has limited funding, resulting in waitlists for housing. I have learned that British Columbia is politically driven by a neoliberalism mindset and that this mindset brings with it a charity model approach to service delivery. As I listened to other parents’ stories about their experiences, I came to understand that I must be up front and center in advocating otherwise my son will always be at the back of the lineup, which to me equates to the homeless shelters, the streets, the jails or the psychiatric institutions. Unfortunately, at a recent parent/service provider meeting, I heard other caregivers express similar conclusions.

The process of doing this research has provided an opportunity for the participants to share their experiences. In this way, they can be a voice for others going through the same issues identified in this study regarding the barriers and strategies for securing a home for their disabled child in the future. In a recent parent/service provider meeting that I attended (September 24, 2014), concerns were raised regarding access to information, wading through program and services paperwork, and waitlists for housing and support services once paperwork was completed. People at the meeting also addressed the gloomy outlook for the future. Families are already at a reduced capacity of coping due to the weight of caring for an intellectually disabled child. Adding this additional layer of paperwork is often beyond the family’s energy and resources to complete. Many parents at this meeting were left with a feeling of helplessness and hopelessness as they heard stories of individuals with intellectual disabilities living in seniors’ residents, homeless shelters, on the streets, in jails and in psychiatric units. Some families shared that they had heard of CLBC being a voluntary
service that families had to approach to beg to receive services. In addition, information was shared that most families remained on waitlists for years as funding was limited.

**Present Policy Framework in British Columbia and Expectations for the Future**

The current situation in British Columbia is that CLBC provides the supports and services to families with intellectually disabled family members. CLBC provides limited information to parents as pointed out by the majority of the participants in this study and has a top down approach to the delivery of supports and services.

The shifts in disability policy in Canada have transitioned from “conceptualizing disability as a challenge to law and order, to viewing disability as a medical and/or economic deficit and then as a sociopolitical issue” (Jongbloed, 2003, p. 203). Each model presents a different idea of what society owes people with disabilities. Current policies in British Columbia, pertaining to the intellectually disabled individuals, have left families with limited access to supports and services. The main issues arising from the caregivers’ experiences in this study dealt with: fear of adequate housing options and supports; safety; and the need for advocacy by parents in order to ensure supports and services were attained and maintained. Endless waitlists and lack of access to supports must be a priority if we want to avoid additional systemic failures such as the Baulne (Moore, 2002) and Robinson (Baziuk, 2014) families’ murder-suicides. The next section provides recommendations that could alleviate families that are getting little support, leaving them feeling alone and isolated.

**Recommendations**

Lack of access to services has created many gaps for families caring for intellectually disabled family members in areas of: planning, information, and supports. Policy changes are needed to correct these gaps and the BC government needs to provide adequate support and
funding to families as they transition their child, with an intellectual disability, for the entirety of their life. It was evident in this study that families are exhausted and in great need of immediate supports and services – not merely the promise of them at some future date. In addition, at the municipal level, communities need to support families. This may be in the form of providing space and communication services for the formation of support groups or advocacy meetings.

A bottom up approach to planning must be the foundation of a new planning framework. Families are the care providers for individuals with intellectual disabilities and they are the ones who should be empowered and funded to create life plans to ensure homes and supports for their dependents. If self-advocates have the mental awareness to participate in the planning they should be included in the planning the course of their lives. Of course, the funding needs to be in place to support the various options that family caregivers may consider, and be consistent with and accountable to the stated policies.

Providing information to parents and self-advocates is an important way to empower this subculture. Information is power, as I have come to realize through this research. For me, an example is my access to scholarly journals and articles, policy documents, and literature in general. If I had to pay for each research article online, I would not have been able to back up my research findings. This would have therefore lessened the validity of my academic research.

Government needs to take on the responsibility of sharing information and providing independent advocates that are not part of the MCFD and CLBC agencies delivering the programs. This could be someone like the current representative for British Columbia Children and Youth, Mary Ellen Turpel-Lafond, an individual who is an independent
advocate who supports children, youth and families who need help in dealing with the child-serving system. The Child Advocate reports directly to the Legislature and is independent from the Ministry. My recommendation is to increase her portfolio to include adults with intellectual disabilities, to develop a care from crib to grave model. In addition, I recommend providing families and self-advocates with a regional independent representative (and the direction for this could be provided by the Child Advocate) for families in each Region of the province. These individuals, who would report outside of MCFD or CLBC, would be charged with providing face to face advice on how to maneuver the system.

The government needs to further develop support systems for the care of this subcultural group. Supports are needed at the level of family, community, and the provincial government. This group of caregivers is aging and tired. A child is normally dependent for up to two decades, not for a lifetime. These parents generally must care for their disadvantaged children until the parents are no longer physically capable. In some cases, they reach a point of exhaustion and desperation, as seen in the cases of Mary, and in the Baulne murder-suicide (Moore, 2002), and the 2014 Robinson murder-suicide (Baziuk, 2014). Parents speak of wanting their child to die before them as they fear that the system will let their child suffer when they are no longer there to advocate on their behalf. We cannot leave these families to cope alone as the tragic incidents of murder/suicide, albeit extreme, can eventually seem like the only way of bringing these families rest.

Ultimately, a paradigm shift needs to occur in which parents join together in advocacy to protect the rights of their children against a very powerful government system that treats them as welfare recipients rather than as equal citizens with rights. It seemed to me, as a researcher, that many of the parents appeared to believe in the pre-1960’s charity
model where this child was theirs and their responsibility alone with some hand-outs available if they begged long enough and were moved off the waitlists. It is disappointing to see this regressive shift in provincial policies. In the current political context, it seems that the social safety net has been dismantled and that parents and, to a lesser extent, the community is now responsible for the wellbeing of intellectually disabled family members.

Limitations

The primary limitation of this study is the lack of voice from persons with an intellectual disability. Families providing care could only provide a small glimpse of the vantage point of the intellectually disabled member. In addition, I wanted to include fathers and sons in this study but only mothers and daughters participated even though I cast a large net to encompass mothers, fathers and siblings. As a result the voices of fathers and brothers are not represented in this study. One more group not represented in this study is parents and siblings of low income groups as none came forward. Other limitations ranged from fear of disclosing information that might negatively impact access to services, the difficulty of maintaining anonymity in small towns, and a general reluctance to share information on such a vulnerable subcultural group.

With respect to the hesitation of family members to disclose their personal experiences, I am aware that families with members who have intellectual disabilities are constantly advocating for funding to ensure their family members with disabilities are protected. Therefore I anticipated that some family members may be reluctant to share details or critical opinions due to a fear of repercussions such as reduced services for their disabled child or sibling. As a parent of a child with a disability, I can understand the possible concerns parents might have about disclosing information to an arms-length researcher. As a
means of alleviating concerns, I invited parents to review transcripts or summaries of information they shared in interviews and asked them to remove any information that they did not want to be included in a public report. This option was outlined in my informed consent form. Additional details about ethical procedures and ways to limit potential or perceived harm are discussed in the Methods chapter.

An additional limitation was added after this research was initiated: my fear as a researcher about repercussions by government agencies, and a potential impact on the supports for my own family. I found that I did not share my own experiences in as much detail as I might have because of this risk. Secondly, I identified the need to include adult self-advocates in the discussion of protecting their rights as contributing members in our society. This demographic was outside of the scope of my current study.

Further Research Direction

The voices of family members are not normally acknowledged or listened to when policy initiatives are set up. These interview descriptors are an excellent indicator of what individuals with intellectual disabilities and their families are experiencing, and how it is affecting their quality of life. CLBC, in its beginning stages, was set up on a good foundation with parents and government officials establishing the groundwork for programming, delivery of services, and identification of necessary supports. Unfortunately, the financial budget constraints were prioritized at the expense of the human rights aspects in making decisions for this subculture group. This is illustrated by the forced closures of group homes even though this housing approach appear to work well for many people with intellectual disabilities and their families.
Additional research is required on where individuals with intellectual disabilities are being housed. To understand the current reality of family members and self-advocates, a quantitative account of services applied for and services actually supplied needs to happen. The BC government should be required to supply these statistics in their annual budget audit, and the statistical report should be made publically available. To get an overall picture, and as a way to plan for the future, a quantitative study using these statistics should be initiated to identify the following information. How many disabled family members are receiving services, what type of services, and are they adequate? What are the actual numbers of intellectually disabled individuals living with family members and is this voluntary? What are the actual waitlist numbers? How many have advocates that understand the British Columbia system and have a voice to advocate for them? How many are living in placements (e.g., group homes; shared living; family) and is the placement by choice? How many are living with aging parents and are not accounted for on the CLBC system? How many are living on their own with assisted-living supports? Are the funds and services they are receiving providing them with a good quality of life? Are they able to receive income from jobs to sustain a good quality of life? How many are residing in homeless shelters? How many are residing on the streets? How many individuals with intellectual disabilities under the age of 65 are living in a senior's home? How many are in psychiatric units? How many are incarcerated?

Once this information is compiled and shared with the public, it will serve as a platform to substantiate the areas requiring greater allocation of funding in order to care for these individuals. Provincial government and family/caregiver/self-advocate representatives need a bottom up approach as outlined in Critical Disability Theory, in which the users of the
system determine solutions and direct how government secures funding to protect the human rights of individuals with intellectual disabilities, as agreed to in our Canadian Charter of Rights and Freedoms. In addition, an independent advocate that reports to the Legislature should be appointed. The independent advocate's office can have regional representatives providing families/caregivers and self-advocates information and resources to aid them in securing services they deserve.

As a researcher and as a parent I would advocate moving this agenda forward by creating a parental advocacy network preferably funded by government. The network could be set up like the Canadian Union of Public Employees (CUPE) National with locals in regions across the province. As CUPE is set up, workshops for educating members could be initiated, lawyers savvy to legislative requirements could be put in place to provide advice or advocate for rights, and so forth. The CUPE union was set up to safeguard rights and freedoms; this might be a possible template to be pursued in the future.

Implications of Research Results

This research provided a multi-dimensional and dynamic picture of the housing options of individuals with intellectual disabilities in the current British Columbia economic climate. It enhanced my awareness, as a researcher and a parent, of how other families have coped with maneuvering through the current policy social service framework of the British Columbia system. This study provided information regarding housing options for adults with intellectual disabilities and the challenges of accessing those services. The study also placed the current policies within a historical background of disability and how it has been defined and resourced in Canada and British Columbia. This research provided a means for family members and for adults with disabilities to be heard through the voices of their family
members acting as their advocates. Knowledge gained from this study will provide information to other families experiencing similar obstacles and challenges, and also will provide direction on lobbying for changes in provincial housing policies. It is my hope that this research will come to the attention of government bodies and encourage them to provide adequate, timely, and secure funding for housing for individuals with intellectual disabilities. Greater awareness of the inadequacies of social services may also serve as a lever for political change.

Concluding Remarks

Families are intimately involved in the care of their children and siblings with disabilities and for the most part work to create a fertile ground for their social, physical, and educational growth. They can speak to the issues facing people with intellectual disabilities with the knowledge of lived experience. Individuals with intellectual disabilities are vulnerable, and society needs to devise strategies to maintain their economic well-being and quality of life. This research will add to the body of knowledge that can help sensitize society to the needs of individuals with disabilities. In addition, it will provide a voice, and a face, to those within our society whose needs should be considered in future government policy and funding decisions.

One of my concerns is as a researcher and parent, that we are seeing burnout from this subcultural group in providing lifelong support for their disabled dependents. Did we not see this a decade ago with the murder suicide of the family in Kelowna? Once again, there has been a recent murder-suicide of a Prince Rupert mother who was unable to receive supports from the British Columbia government and ultimately resorted to end her own life and her son's life. How do we alleviate the load on families so they do not turn to desperate
measures? How can we facilitate the process of applying for funding supports and services and reduce waitlists?

Beyond the family home, it remains a question as to where their intellectually disabled family members will be housed later in life. Families remain waitlisted for CLBC residential supports such as staffed residential (e.g., group homes), shared living, or supported living housing. At a recent parent/service provider meeting in September 2014, participants relayed stories of individuals with intellectual disabilities living in senior’s homes, homeless shelters, on the streets and in jails. In addition, one of the participants commented on a shared living housing arrangement that had led to neglect. The participant identified that an individual had been locked in an unclean room with only a mattress [no sheets] on the floor. The only reason the incident of neglect was reported was through follow-up on separate reports of abuse of young children in the same residence, received by the MCFD. The social worker reported the incident of an individual with a developmental disability also living with the people [shared living contractors] that had questionable living conditions. Prior to the investigation, the people running the shared living arrangement had been rated as a good provider so this was a surprise to CLBC. Safety becomes the next big factor that parents fear: where are the safety mechanisms to keep these individuals safe?

It is my opinion and fear that the British Columbia system is returning to a time in history when individuals with intellectual disabilities were living on the streets. Are we moving back towards a welfare/charity system where individuals with intellectual disabilities need to beg for funding? The Community Living British Columbia 2014/15 to 2016/17 Service Plan (CLBC, 2014b) annual report stated that:
As of December 31, 2013, CLBC had open files for 15,735 adults with developmental disabilities. The majority of adults receiving services are living in their family home and are being provided a combination of community inclusion services and respite. Of the group of individuals living outside of their family home, 5,703 adults are receiving residential and community inclusion services while 861 adults are living on their own with assistance in activities of daily living and receiving community inclusion services. (p.6)

This means that only 42% of adults with developmental disabilities for whom CLBC has a file are receiving residential services or living on their own. The majority of individuals with intellectual disabilities live with their families. Moreover, in the Community Living British Columbia 2014/15 to 2016/17 Service Plan (CLBC, 2014b) it states that CLBC does not have all individuals with developmental disabilities accounted for in their current plan.

Community Living BC suggests that there are many potentially eligible adults living independently or supported by their aging parents who are not recorded in these statistics. As well, the report states that: “caseload growth due to new adults over age 19 registering with CLBC is forecasted to be 300 in 2013/14 and the next three years” (CLBC, 2014b, p. 11).

Waitlists already exist and with improved health care, individuals currently receiving supports will continue to use the system funding for many more years to come. With a forecast of additional newcomers into the system, where will the funding come from to support all who are in need of services?

Families can be good advocates for their family members but it is important to note that not all families are effective advocates for their disabled children, and not all are able to provide caring, supportive environments. Therefore, policies and social networks have to be
designed to also create independent advocates for individuals not represented by a
supportive, caring family as well as for families who feel isolated and powerless. As a
researcher and a mother of an individual with an intellectual disability, I will continue to
lobby government for the rights of my child as he grows into adulthood and into the care of
society. The findings of this study will make me a more effective advocate for my son and
for other individuals who are seeking secure and humane housing for their intellectually
disabled family member in adulthood. Because of my personal involvement in the issues I
plan to continue to interact with both my research participants (if they wish to stay in touch
beyond the end of the study), and with other members of this subculture group, and I will
make a point of sharing my knowledge. I plan on presenting workshops and possibly writing
articles to continue promoting public awareness of this subcultural group and their fight to
maintain their human rights within society.
References


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Rioux, M. H. (1994). New research directions and paradigms: Disability is not measles. In M. H. Rioux and M. Bach (Eds.), *Disability is not measles: New research paradigms in disability*. Roeher Institute (pp.1-2). North York, Ont.


Appendix A: Research Participant Information

Research Participant Information Letter

You are invited to participate in a Master of Education – Multi-disciplinary Leadership thesis study entitled Securing a Home for Adults with Disabilities in British Columbia: A Family Perspective. The research is being carried out by Deidre Quinlan under the direction of Dr. Judith Lapadat through the University of Northern British Columbia (UNBC).

Why is this research being done?

The reason for this research thesis is to better understand a family’s experience and perspectives of locating a home for their disabled family member once he or she reaches adulthood. I am interested in what is happening to families supporting an individual with an intellectual disability as they locate and secure a home now and in the future. I will gather their thoughts, feelings, reflections, and experiences regarding their preparation of past, present, and future housing options for their family member living with a disability. The voices of families in my research can contribute towards a description of the lived experiences of families of individuals with disabilities and provide direction towards rethinking the nature and impact of our politics, policies and law.

Why I was chosen?

You are being asked to participate in this study because:

- You are currently a parent or sibling of an individual with an intellectual disability
- You are 19 years of age or older
- You will be involved in locating a home for a family member with an intellectual disability or already have in the past located a home for a family member with an intellectual disability
- You are willing to participate in this study’s research process voluntarily

What is involved?

If you agree to voluntarily take part in the study, you will be asked to:

- Participate in an interview that will last about an hour. The interview will focus on perspectives and experiences regarding housing options for your family member living with an intellectual disability. The interviews will be audio tape-recorded so the material can later be analyzed by the researcher. You may ask that the tape recorder be turned off at any time.
- Later, I will invite you to read the transcript of your interview. This will involve a short interview lasting about 30 minutes. You will be able to add any information and let the researcher know if you want to elaborate or clarify or ask for material to be omitted.
What are the benefits and risks involved in taking part in the study?

One potential benefit of participating in this research is you may feel rewarded by discussing your stories and experiences of locating a home for an intellectually disabled family member. You may also feel satisfied in knowing that you are contributing to research and providing knowledge to the community. A potential risk is that it may be uncomfortable to talk about your experiences of locating a home for an intellectually disabled family member. You will be provided with a list of resources that you can access for additional support if you would like it.

You can refuse to answer any questions and you may stop the interviews at any time. Your participation is completely voluntary. If you choose to withdraw from the study during the interview, the tape recordings and any information you provided will be destroyed.

How will my identity be protected? (Anonymity)

Your interview will be transcribed (typed word for word) by the researcher. Transcripts will be identified by a code number and not your name. Any information that might identify you will be removed from the final research document.

How will my information be kept private? (Confidentiality)

Everything you discuss during the interviews as well as the forms you fill out will be kept confidential. This means that your information will not be shared with others. There are instances where I would have to report certain types of information. For example, if you are in need of protection because you tell me that you are going to harm yourself or others, if you suspect that a child is being abused or neglected, or if you are involved in a legal court case and the court orders a release of information. Only myself and my supervisor will have access to the information. Your information and tapes will be stored in a locked filing cabinet at the University of Northern British Columbia for five years after the successful thesis defence and then will be destroyed.

How will I be compensated?

- As a way to show my appreciation for your time and effort, you will be given a $10 gift certificate for coffee after you have completed the minimum 45 minute to one hour interview. You can withdraw your information I have collected for this study if at any time you feel you no longer want to participate.

What will be done with the results?

The completed research will be presented for my thesis defence at UNBC. It is anticipated that the results will be presented at conferences, to community organizations, and published
in professional journals or reports. Participants are invited to attend the final thesis defence. The Researcher will notify participants of the date of the defence. If participants choose to attend the thesis defence, this researcher can not guarantee anonymity of the participant.

You can obtain a copy of the research results by contacting the researcher, Deidre Quinlan at (250) 631-7693 or quinlan@unbc.ca, or Dr. Judith Lapadat at lapadat@unbc.ca.

How will my information be destroyed?

Data from this study will be destroyed five years after the successful thesis defence. Hardcopies will be shredded and electronic data will be erased from the hard drive.

Who should I contact if I have more questions?

Please feel free to contact the researcher, Deidre Quinlan at (250) 631-7693 or quinlan@unbc.ca if you have any questions. Any concerns about the project should be directed to the Office of Research at the University of Northern British Columbia (250) 960-5820 or by email: reb@unbc.ca.
# Appendix B: Research Participant Consent Form

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Do you understand that you have been asked to be in a research study?</td>
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<td>Have you read and received a copy of the participant information letter?</td>
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<td>Do you understand that you are free to refuse to participate or withdraw from the research study at any time?</td>
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<td>Do you understand the benefits and risks of participating in this research study?</td>
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<td>Do you understand that the interviews will be audio recorded?</td>
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<td>Do you understand that some of your actual words may be published in written form?</td>
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<td>Has the issue of confidentiality been explained to you?</td>
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<td>Do you know what resources are available for additional support?</td>
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<td>Do you understand who will have access to the information you provide?</td>
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<td>Have you had an opportunity to ask questions about the study?</td>
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This study was explained to me by: __________________________________________

Printed name of Research Participant: ________________________________

I agree to participate in this research study:

______________________________ Date

Signature of Research Participant
Appendix C: Poster

Participants needed for UNBC Research Study:
A Family Perspective on Housing Options for Individuals with Intellectual Disabilities

RESEARCH STUDY: A FAMILY PERSPECTIVE ON HOUSING OPTIONS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

The reason for this research thesis is to better understand a family's experience in British Columbia of locating a home for their disabled family member once he or she reaches adulthood. I am interested in family members' perspectives about the process of locating and securing a home. The voices of families in my research will reflect the lived experiences of families of individuals with disabilities and help us to rethink the nature and impact of our politics, policies and law.

For more information, please contact Deidre Quinnlan at 250.861.7563 or email: quinnlan@unbc.ca

All calls will be kept strictly confidential.

Deidre Quinnlan, Principal Investigator
Dr. Judith Lapedat, Supervisor
Appendix D: Interview Questions for Parent/Sibling/Caregiver

1. Describe your family (who they are)?

2. What quality of life do you see for your child with an intellectual disability in the future?

3. What preparations have you made to ensure your child has a home in the future?

4. What experience do you have with provincial policies and program for housing within British Columbia?

5. What quality of life do you see for yourself and your immediate family members in the future?

6. What, if anything, might aid your family in securing a home for your child with an intellectual disability?
Appendix F: Graphical Overview of Study Design