

**SUSTAINING SERVICES AND SUPPORTS FOR INDIVIDUALS  
WITH DISABILITIES AND THEIR FAMILIES**

by

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We accept this thesis as conforming  
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## ABSTRACT

The research question explored in this thesis is: *How can the services and supports provided by the Community Living Restructuring Fund (CLRF) be sustained?* The CLRF had \$24 million to provide creative initiatives and innovative projects that would offer more choice to individuals who live with developmental disabilities and their families. As of July 2005, the funds have been expended. The fund has had cost-saving benefits for the Ministry of Children and Family Development, while also increasing the decision-making power of individuals and families with disabilities to make choices for their own lives. This study examined how the positive aspects of the fund might be sustained to provide significant learning in terms of how community partners who came together benefited the community in supporting individuals with developmental disabilities and their families. The findings validated the benefits of implementing ongoing supports and services for individuals with disabilities and their families.

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LIST OF ACRONYMS

BC:	British Columbia
BCACL:	BC Association for Community Living
BCMCFD:	BC Ministry of Children and Family Development
CLBC:	Community Living British Columbia
CLRF:	Community Living Restructuring Fund
CLTSC:	Community Living Transition Steering Committee
MCFD:	Ministry of Children and Family Development
WHO:	World Health Organization

## CHAPTER ONE – FOCUS AND FRAMING

## Introduction

In 2001 the British Columbia (BC) government initiated a review of the delivery of all government systems. For the BC Ministry of Children and Family Development (BCMCFD, n.d.a), the review was to determine the mandate, the options for service delivery to individuals with developmental disabilities, and an implementation strategy. In a paper released in October 2001, the Ministry identified the challenges of cultural change within its organization: “We have to change the way we think” (BCMCFD, 2001, p. 9). The Ministry laid down the challenge for organizations such as the BC Association for Community Living (BCACL) to move “from funding programs to funding individuals” (p. 6). For example, the Ministry moved forward with the creation of a modified form of individualized funding for children with autism.

Embedded in the review was the intent to reduce costs to a ‘sustainable’ level, as outlined in the government’s budget documents. All of this must be accomplished within existing budget targets. From 2002-2003 to 2005-2006 the “Ministry’s budget will decrease by 19%, or \$305 million. It is critical that the Ministry meet the target while maintaining or enhancing the quality of life for many of BC’s most vulnerable children, youth, and adults with developmental disabilities and their families” (BCMCFD, 2003, ¶ 3).

In 2002 the Honourable Gordon Hogg, Minister for Children and Family Development asked people in the community living movement to meet and develop a plan for making changes to the way that services are provided to people with disabilities and their families. As a result of this request, the Community Living Coalition, an unprecedented coalition of individuals, families, and service providers, came together to develop a plan to address BCMCFD’s request

for a core review (Community Living Coalition, 2001). Accordingly, BCMCFD formed the Community Living Transition Steering Committee (CLTSC), which included self-advocates, family members, staff who work for service providers, and staff who work for the MCFD. The Steering Committee worked together from April 2002 and in October 2002 submitted its report *A New Vision for Community Living* (CLTSC, 2002) to the Minister. This report was to be the basis for changes to improve the services and supports for people with developmental disabilities and their families.

Based on the report of the CLTSC, the decision to transfer funds to a new provincial organization called Community Living British Columbia (CLBC) was announced in October 2002 (CLTSC, 2002). This organization is called the “new Authority” (p. 8).

On March 31, 2003, the Ministry of Children and Family Development (MCFD) approved and provided a \$20 million restructuring fund that was held in trust by the Victoria Foundation. The purpose of the fund was to support creative initiatives and innovative projects that would provide more choice during the transition of Community Living Services in BC to (a) adults with developmental disabilities, (b) families of children with special needs who are eligible for Community Living Services, and (c) service providers. These funds have enabled families to keep their loved ones at home through home renovations or through the purchase of equipment not available from other sources. The funds are also used to assist organizations in providing innovative programs or to improve services for the individuals whom they serve. It was understood that these funds would be expended over a period of up to two years (BCMCFD, 2003).

The nine-member Community Living Restructuring Fund (CLRF) Advisory Committee was appointed by the BCACL, the Interim Authority for CLBC, and the MCFD to oversee,

review, disburse, monitor, and provide direction on the allocation of the CLRF grants and to ensure fair and equitable access to all eligible applicants.

Because the \$20 million was expected to be expended by April 2005, in January 2005 the CLRF Advisory Committee submitted a proposal to Stan Hagen, Minister of Children and Family Development, requesting continuation of funding for the CLRF. The proposal included a request to consider strategic investment in a permanent endowment to address the ongoing needs of individuals who live with developmental disabilities in this province. The submission included background information on the fund, success stories, and the financial benefits to individuals/families and service providers supported by the CLRF. This resulted in an additional \$4 million being granted to the CLRF in May 2005.

However, in July 2005 the committee was at a point where the funds would be fully expended over the next couple of months covering applications received up to June 30, 2005. The committee was able to process applications for those months but had to announce that no further applications would be accepted after July 1, 2005. A large number of outstanding applications could not be considered, and many inquiries from potential applicants continued to be received regarding the status of the fund. The longstanding needs of the community had not yet been met. While I worked as a consultant with this committee for over 10 months, I began to recognize that the committee's overall objectives were congruent with my own personal values pertaining to the quality of life for individuals with disabilities and their families. The thought of not being able to support families and individuals who need support is extremely disconcerting. As a result of the \$24 million being depleted, I decided to explore the following research question: How can the services and supports provided by the CLRF be sustained? The sub questions are as follows:

1. What supports and services do individuals/families/service providers consider to be valuable?
2. How have services been provided in the past?
3. What options exist for sustaining the supports previously provided by the CLRF?
4. What risks are associated with the loss of such funding?
5. What would be required to pursue other options?

Having worked as a consultant with the Victoria Foundation CLRF, I had the opportunity to observe and directly work with community partners, Ministry representatives, the Victoria Foundation, and families and individuals who are directly being served. In my past role as a consultant I have had many opportunities to learn, observe, and participate in informal conversations, dialogues, and interviews while following policies and procedures established by the committee, which added immense value and insight into this project.

#### The Opportunity

In this project my team of colleagues included (a) co-chairs of the CLRF, (b) community representatives from the Interim Authority of CLBC, (c) representatives from the BCACL, (d) representative from the MCFD, (e) a consultant who has life experiences because her own child received Community Living Services, and (f) a consultant who has had over 40 years' experience working in the Ministry with children and adults with disabilities. Additionally, the trust coordinator from the Victoria Foundation provided insight into the financial and monitoring aspects of the fund and carried out the granting requests of the Advisory Committee. Hence, the opportunity to learn, develop, and access years of life experiences was endless in terms of the experts available as resources and partners in working collaboratively to find possible answers for the question under study.

Furthermore, my ongoing communications with families, individuals, and community professionals also provided an excellent avenue for assessing and understanding the impacts that the CLRF has had on its ability to be empowered and provide a better quality of life for individuals with disabilities and their family members. According to Bridges (2003), one of the persistent problems during a transition is the difficulty that decision makers and those who implement decisions have in remaining clear on the precise impact of their decisions and actions. I believe that in conducting this project I have captured and reflected upon the decisions that were taken, which has fostered an understanding of the significant difference that the fund had made.

An exploration of the unique informal opportunities for learning in an environment that consists of so many key stakeholders from diverse work environments in itself was very interesting. This project allowed me to gain an understanding of the various roles, policies, and mission and values that each stakeholder brought to the CLRF committee and to explore the uniqueness and diversity associated with having such a dynamic group of people around the table making decisions.

This project was a leadership stretch primarily because the role of working in a Community Living environment was a fairly new one for me. Throughout my personal and professional life experiences I had not had many direct opportunities to work with individuals with disabilities or to support families who have children with disabilities; hence, the prospect of understanding and being able to empathize with the challenges and support the needs of these individuals and their families was an excellent opportunity for acquiring additional knowledge.

### Significance of the Opportunity

As of September 14, 2005, the CLRF had approved grants totalling approximately \$24 million. The results of these grants for enhancing the quality of life while dramatically reducing the costs of serving individuals who require Community Living supports and services have been very encouraging. As the government is well aware, the cost of keeping a child or adult with a developmental disability at home is considerably less than the cost of placing that person in a third-party residential setting. Therefore, it only makes sense for the Ministry to continue to support the community-based funding structure and enable families to remain whole or individuals to remain in their current chosen residence. Of the 734 grants that were approved to individuals and families, the vast majority of applicants have stated that the grants will now enable the family to care for their child/adult far into the future (CLRF, 2005a).

The following is a summary of the savings according to the CLRF grant statistics from April 2003 to September 2005 (CLRF, 2005b).

1. Agencies (including non-profit and for-profit service providers and family model homes): The first \$5 million granted produced annual savings of approximately \$3.3 million from community living agencies while providing equal or better-quality services than had existed prior to receiving the grants.

2. Individuals and families: It was assumed that when significant grants were issued to individuals or their families for renovations, 60% of those individuals avoided residential placement. From this assumption, minimum annual savings of \$6.2 million were extrapolated. For grants issued to young children, it was assumed that savings were not realized but that quality of life was enhanced.

3. Individuals reintegrated into the community from Willow Clinic: In addition to the above savings, grants were also issued to successfully reintegrate eight individuals into the community who had previously resided at the Willow Clinic Institution. Savings from this reintegration were estimated at \$1.2 million annually, and the quality of life was enhanced immeasurably.

4. Overall savings: In summary, the total estimated annual savings from the \$24 million investment in the CLRF was \$10.7 million, an overall payback on investment of 2.24 years. This would not be a one-off, but an annual savings each and every year until conditions change.

As demonstrated in the above examples of savings, many stakeholders have been positively impacted by the community-based funding structure. Through informal discussions and statistics on grant recipients, it has become clear that bringing community partners together to be involved in the decision making of Community Living funds continues to be a benefit for all involved.

#### Systems Analysis of the Opportunity

From a systems perspective, the organizations and structures involved in supporting community living in BC are going through a period of change and transition. A major element of the joint plan by the Ministry and community representatives to transfer funds to the community is the recognition that individuals and families drive much of this change.

Over the past two years the MCFD, the CLTSC, and the Interim Authority for CLBC have been working towards devolving community living services from the Ministry to a provincial authority known as CLBC. To date, thousands of hours have gone into the effort, both by these entities and by volunteers who are committed to transforming community living services delivery.

In November 2003 the MCFD appointed an independent panel to assess the state of readiness of the Interim Authority for CLBC and the MCFD to devolve community living services to a permanent authority in June 2004 (Boyd, 2004). The panel concluded that devolution of services could be accomplished successfully by June only if the parties resolved three key outstanding issues related to accountability, service delivery, and services for children with special needs. These challenges needed to be addressed by January 31, 2004, as did the development of a comprehensive project management plan outlining actions that were to be completed.

Based on the BCMCFD data in 2004, 7,839 families were receiving a range of community living supports and services for children with special needs, including those with a developmental disability. Of this figure, 514 children were receiving residential services through BCMCFD Community Living Services. As of July 1, 2005, CLBC had served over 17,000 children and adults with special needs. Based upon April 30, 2005, CLBC (2005a) data, (a) 9,627 adults were using either residential or family and day support services, or both; (b) 5,037 adults were using residential services (2,830 in staffed residential; 2,207 in family model homes/semi-independent living situations); and (c) 4,590 adults were using family and day support services.

Budget cutbacks to community living services are an ongoing concern. Individuals and families have voiced their concerns to MLAs, the Minister of Children and Family Development, and the Premier. As a result of these efforts, the cuts were reduced from 23% to 11%. However, there was more work to be done to ensure adequate funding to support children and adults with developmental disabilities and their families (BCACL, 2005).

The Interim Authority for CLBC laid the foundation required to successfully devolve services from the Ministry to CLBC. In preparation for the eventual legal transfer, the provincial

legislature passed the Community Living Authority Act in October 2004, which established the statutory basis for CLBC's mandate. CLBC was officially given authority on July 1, 2005, and became a Crown agency with a proclamation of the Community Living Authority Act (CLBC, 2005b).

The BCACL has taken a lead in supporting and promoting the participation of people with developmental disabilities in all aspects of community life. The BCACL has been long established (50 years of service completed in 2005) and has historically provided strong advocacy for change in services for individuals with developmental disabilities (BCACL, 2005). For example, in a public statement by BCACL in 2002 pertaining to the abuse of residents living at the Woodlands Institution, which was confirmed in Dulcie McCallum's (2002) report, the BCACL president at that time, Claudia Semaniuk (2002), stated:

We have waited many years for the recognition of abuse that took place at Woodlands and institutions like it. We have waited many months for the release of this report.

Meanwhile, former residents of Woodlands continue to struggle with these issues as they age, and some have died with no recognition of the injuries they experienced. Now that government has completed the initial step of confirming that abuse occurred, it is critical to move forward without further delay. (p. 2)

In designing a process to address institutional abuse, the most important guiding principles were to empower former residents and to do no further harm.

CLBC is now responsible for the new governance model and in July 2005 had a budget of approximately \$600 million from BCMCFD. My project explains how the CLRF fared amidst the 'change' process, which was an interesting phenomenon in itself, and what an effective model of partnership in action and community-based decision making it has been. This

partnership model has the potential to save an enormous amount of money for BCMCFD, as well as facilitating the continued support of service providers, individuals, and families who require community living services.

### Organizational Context

The Community Living Coalition was formed in October 2001 to respond to the MCFD's core review process. The groundwork had been laid in the community living movement decades earlier with the formation of the Woodlands Parents Group, who were successful in closing institutions such as Woodlands, Tranquille, and Glendale and relocating their loved ones to the community. More recently, the Individualized Funding Family Coalition was formed to provide a new model for service delivery for individuals with developmental disabilities. Members of these groups came together with others dedicated to creating a new vision for community living.

The Community Living Coalition (2005) "is an open and inclusive gathering of people, families, professionals, and organizations dedicated to empowering individuals and families to make decisions about how they lead their lives in the community" (§ 1). By October 26, 2001, these efforts led to the coming together of several groups and individuals at the invitation of BCACL's Executive Director Network to discuss a unified approach and response. The group decided to pursue two avenues with a common theme and purpose: first, the development of a coalition to respond to the provincial government's Core Review of Services and Programs; and second, the launching of a series of province-wide meetings to bring together families and service providers to discuss the key elements of the response within the context of the looming service cuts. Ultimately, the various groups agreed to unite loosely as the Community Living Coalition to present a strong, united voice to government. On November 1, 2001, the coalition was created and began to meet twice weekly to refine the work of the various groups and

develop a single community-driven, family-led response to government. The coalition's immediate goals were as follows:

- to address threatened cutbacks to community living services and supports,
- to develop a new governance structure for community living, and
- to promote Individualized Funding as an option for individuals and families. ¶ 6)

On November 5, 2001, the BCACL Board of Directors met to discuss participation in the coalition and agreed to support its efforts to emphasize the importance of a new governance model and to ensure that services for children and adults stay together and that current funding levels for community living supports and services remain intact.

The first major issue that the new coalition addressed was the threat of severe cutbacks to community living services. During the next few weeks a media campaign was carried out to alert the public, politicians, families, self-advocates, and other stakeholders to the potentially devastating impact of such cuts. During November and December 2001 individuals and families across the province visited, wrote to, telephoned, emailed, and faxed their member of the legislature and Cabinet members to tell them how they felt about cutbacks. Feedback from that campaign indicated that many MLAs were deeply affected by those efforts and became more aware of the realities faced by families and individuals and the serious impact that budget cuts would have.

On November 30, 2001, the Community Living Coalition (2005) presented a proposal to the Minister of Children and Family Development. In this proposal the following was included:

We believe the time has come to transform the system of services and supports for people with developmental disabilities and their families. We envisage a system:

- in which individuals with a disability are full citizens of their communities

- which honours and encourages their contributions
- which places trust in the capacity of individuals and families to lead their own lives effectively, . . . to meet the challenges they face, . . . and to develop their own support system
- that changes dependence on government into a community partnership of the public, private, and civic sectors.

BC families and communities have always accepted their collective responsibility to care for each other. We have pioneered creative responses to our social obligations in the past and we want to build on that success.

With government we want to share responsibility to usher in a system of supports that strengthens families and builds resilience in individuals; a system that builds capacity in our communities.

We want to partner with government in restoring the prominence and leadership that has built BC's reputation as a caring community.

We want to be part of a province that ensures a good life for everyone with a disability.

(Community Living Coalition, 2001, ¶ 2-6)

The coalition represents an unprecedented coming together of families, self-advocates, service providers, and advocacy organizations. Since the presentation of the governance proposal to the Minister and the Deputy on November 30, 2001, the coalition's focus has turned to expanding representation at the table by reaching out regionally and to smaller groups of parents and service providers. Since that time meetings of the Community Living Coalition have expanded to regularly include family representatives from the Interior, Vancouver Island, and the

North; non-profit service providers from across the province; and representatives of private family care model homes and other private providers.

Based on Peter Block's (2000) assessment of "flawless consulting," I believed that this coalition would provide an appropriate environment for my research because it allowed for authenticity throughout (Block, 2000). Because my project involved working with various community partners, governmental representatives, individuals, and family members, it was of utmost importance that everyone involved remain authentic to the cause and purpose of the project to ensure that we were all working towards a common goal, and I believe that the environment was conducive to this purpose based on my experiences.

The involvement of various community partners, governmental bodies, and community members within the Community Living Coalition had provided a wealth of opportunities in researching my topic. Lorraine Ward, my Project Sponsor, mother of two children with autism, had been involved in the grassroots movement toward community governance and had participated since the early days of the Community Living Coalition to develop a new vision and service delivery model for people with developmental disabilities. She has been inspired by and learned from the "pioneers" of the community living movement: parents who have fought since the 1970s to close institutions such as Woodlands, Tranquille, and Glendale so that children like hers can lead a good life and be respected as valued members of the community. I believe that the involvement of Lorraine and the other pioneers from the Community Living Coalition in the research project provided diverse experiences and expertise to the research.

On December 11, 2003, Lieutenant Governor Iona Campagnola recognized Lorraine Ward and her fellow directors of the Interim Authority for CLBC at a reception at Government

House. Gordon Hogg (personal communication, January 22, 2004), Minister of Children and Family Development, forwarded a video of that reception and wrote:

Upon viewing the video, I was again touched by the heartfelt comments made by many board members. It is heartening to know that we share a vision of well-being and inclusiveness for people with developmental disabilities. I cannot emphasize strongly enough the value of the work you did toward realizing that vision. It has been both an honour and a privilege working with you. Thank you.

## CHAPTER TWO – LITERATURE REVIEW

The focus for this literature review includes three key areas of exploration for my research project: (a) understanding and managing developmental disabilities (b) determining the supports required for individuals with disabilities and their families and (c) examining service delivery models.

To support a community-based governance model in disbursing funds to individuals and adults with disabilities, it was important that I know the various definitions for *developmental disabilities* and attempt to understand what it means for an individual who has developmental disabilities. Additionally, it was important that I research how disabilities have been managed in the family and community.

As we move forward into an era of greater choice and recognize the need for self-determination by people with disabilities, it becomes incumbent on government and community groups to seek ways to directly involve people with disabilities in all processes that affect their lives. It was important that I examine the service delivery models from the past to the present, understand how service delivery and change models have evolved over the years, and explore individualized funding specifically.

#### Understanding Developmental Disabilities

As individuals and as a society, we have a duty to care for each member of our community. This is true irrespective of their physical capacity or mental reflection. All individuals have a fundamental right to happiness and an avoidance of suffering. We must avoid the urge to shut away those who are diseased or marginalized. To push them away would be to create more suffering. If we ourselves were in the same condition, we

would look to others for help. We therefore need to ensure that the sick and afflicted person never feels helpless, rejected, or unprotected. Indeed, the affection that we show to such people is, in my opinion, the measure of our spiritual health, at the level of both the individual and society (Dalai Lama, 2001).

The above quotation by Dalai Lama resonated for me, as it clearly emphasizes that we have a responsibility for others. The more we can focus on increasing the happiness and reduce the suffering of others, the more, ultimately, we will also benefit ourselves.

Through supporting those in difficulties and demonstrating greater compassion, we will be able to alleviate suffering and may empower some of the individuals needing additional supports.

#### Definitions of Developmental Disabilities

In my review of the literature on community living and developmental disabilities, I found a variance in the definitions of developmental disabilities from community agencies, government, and other researchers. It is important to note that the literature identified political and cultural contexts around which services are available for support. In my experience, it also appears that when people speak about developmental disabilities, they are not always talking about the same thing. In deciding whether an individual qualifies for developmental services, it is important to note which definition is being used, because this determines their eligibility for supports.

The BC government defined developmental disability as “measured intellectual functioning of approximately 70 IQ or lower, with onset before age 18, and measured significant limitations in two or more adaptive skill areas” (BCMCFD, n.d.a, ¶ 2). The government also indicated that an eligibility criterion reflects the internationally accepted definition of

developmental disability. It appears that the government's definition is more aligned with those in some of the literature; however, the government's claim to acceptability may not reflect existing international standards. In *Your Child Has a Disability*, Batshaw (1991) used the term *mental retardation* and listed three components: and intelligent quotient (IQ) below 70, a non-progressive disorder evident during childhood, and an impaired ability to adapt to the environment (p. 62). However, BCACL has a different definition:

A developmental disability is a life-long condition where people grow and develop more slowly than others. Individuals may have difficulty understanding abstract concepts or adapting to some of the demands of daily life. This disability varies greatly between individuals and may or may not be accompanied by other physical conditions. (BCACL, n.d..a, ¶ 4)

The Persons With Developmental Disabilities Partners Group (2002) in Alberta defined developmental disability as “a state of functioning that begins in childhood and is characterized by significant limitations in both intellectual capacity and adaptive skills” (p. 4). I researched the World Health Organization (WHO) for the international standard. WHO (2005) has not used an intelligence indicator to classify disability but developed the measure ‘International Classification of Functioning, Disability and Health.’ The United Nations has accepted this classification of disability, which appears to be placed within a functioning and contextual structure.

The WHO (2005) and other noted definitions are not centred on a specific IQ measurement, as is the case in BC. The meaning of *disability* and its English cognates has changed over the years, but whether it has evolved or gained precision thereafter is contestable. I believe that Pfeiffer (1999) summed it up well when he explained that the reason a definition is

important is because it is necessary to give meaning to the whole area of disability studies. Additionally, although disability studies have revealed several contradictory and complementary definitions, clarity requires that at least differing definitions be recognized and noted by researchers. It is also important to note that the BC government definition is used to identify those eligible for service and thus is a sub definition of the more general ones noted above.

#### *Studies Related to Developmental Disabilities*

A crucial aspect of community-based action research is that all relevant partners are recognized and involved in the process (Stringer, 1999). I was drawn to this collaborative approach of action research to focus on improving the quality of all participants' lives and providing direction for positive change (Stringer, 1999). The participatory nature further enhances the collaborative and cooperative relationships that exist between agencies, individuals, families, and government representatives.

Accordingly, the research on and new vision of developmental disabilities are varied and interesting. The BC government's transition of funds from the MCFD to a community-based governance model in 2005 was another indication of the government's move to empower families and individuals to take responsibility for and have choices pertaining to their lives (CLBC, 2004).

Crawford (2004) indicated that nearly 2.3 million people in Canada have provided support to family members because of their disabilities. Crawford defined *disability* as limitations in carrying out activities of daily living and participating in the social, economic, political, and cultural life of the community; and a *disability-related support* as any goods, service, or environmental adaptation that assists persons with disabilities to overcome limitations in carrying out activities of daily living and participating in the social, economic, political, and

cultural life of the community. The limitations of Crawford's research, *Some Relief: A Statistical Portrait of People Who Provide Support in Everyday Activities to Family Members With Disabilities*, were that he did not (a) include data for people living in Canada's northern territories; (b) portray the situation of people in those areas who provide support because of a family member's disability; or (c) present a detailed analysis of specific subgroups of people who provide support to differentiate, for example, parents who support children with disabilities from adult children who support aging parents with disabilities.

In other research, Kendrick (2001) stated that people with disabilities often are not seen as being fully human. He elaborated, "Our sense of what constitutes humanness seems to be unduly influenced by the loss or reduction of some kinds of functioning" (p. 4). These diminishments appeared to be taken as indicators of whether we are fully human. Kendrick also noted that when the humanity of some people is not seen as equivalent to that of others, it commonly means that they are treated "less well" in accordance with whatever sense of humanity is no longer seen as being present. This begs the question of whether our level of functioning is being used to define our humanity.

In another study, Diesfeld (2001) raised some important issues, particularly around the quality-of-life judgements that doctors make. Diesfeld provoked comparable questions to those of other researchers conducting similar studies: What is meant by *disability*? What purposes are served by its use? This begs the question as to whether it is possible to reach consensus on a general and unified definition of disability for individuals with developmental disabilities.

Although I have referred to only a few researchers such as Kendrick (2001), Diesfeld (2001), and Crawford (2004) in this literature review, all of the research that I read on this topic varied in terms of defining what developmental disabilities mean. It also appears that whatever

definition the researcher used determined how the study was conducted and that, accordingly, only those supports were explored that fit with the definition. No doubt ongoing research needs to be conducted to close the gap between a collective understanding of the area of developmental disabilities and the uncertainty of the definition, which might just reflect the instability of the concept itself.

### *Supports Needed for Individuals With Disabilities and Their Families*

Family members play a major role in providing support to children, siblings, spouses/partners, parents, grandparents, and extended family members who are born with disabilities or who become disabled sometime later in life (Crawford, 2004). Based on this role, people who provide support to family members with disabilities would benefit from occasional relief from caregiving and its attendant responsibilities.

Crawford (2004) further observed that these family members share much in common with others in terms of family size, home ownership, and other aspects, but they also have to deal with many challenges that most others do not face and, in most situations, do not require assistance to continue their support-providing role. Crawford's findings indicate that family support providers who need relief are twice as likely as other family support providers to have turned down a job offer in the past year (8% compared with 3.9%) and to have turned down a job promotion or transfer because of having provided disability-related support (8.5% compared with 3.4%) (p. 13). Additionally, because of their support-providing responsibilities, those who need relief are more likely to arrive at work later or to leave earlier (Crawford, 2004).

The BC government website on services for adults with developmental disabilities (BCMCFD, 2004a) presents information on the services that the government offers to support people with developmental disabilities in addressing their everyday needs and future goals Some

of these services include personal planning, community residential services, training and support services, home support services, home support programs, professional support services, and other resources provided through the BC Ministry of Human Resources.

BCMCFD (2004) identified the following factors that characterize a person's quality of life:

- Health and safety
- Personal power and choice
- Personal value and positive recognition by self and others
- A range of experiences which help the person participate in community life
- Good relationships with friends
- The ability to manage daily activities and pursue personal goals. (§ 12)

From various readings, personal observations, and interactions through my work with individuals and families, it is evident that the quality of life for these individuals depends on the services and supports that they receive. It is essential to recognize that quality of life can be enhanced and become more meaningful with supports that provide empowerment and safety nets.

#### *Moving Responsibility from Government to Community*

The move to a new governance authority will improve the lives of thousands of vulnerable people and their families. Consultation with more than 2,000 affected people and organizations showed broad support for community-based governance as a system that will be more flexible, less costly, and more sustainable in the long term while giving people with developmental disabilities more control over their own lives. BC has received Canada-wide and

international recognition for its innovative approach to supporting vulnerable people and their families (BCMCFD, 2004a).

On February 11, 2004, after a meeting between Minister Christy Clark and officials from the Ministry and the Interim Authority for CLBC, the MCFD and the Authority reaffirmed their commitment to a new community-based approach to serving people with developmental disabilities and their families.

In a discussion paper on community living services, the BCMCFD (2001) described the evolving thinking around why change to community living services is necessary. The three major policy and service objectives outlined include (a) strengthening individuals, families, and communities; (b) to reform service delivery; and (c) to deliver on the obligations to the government. The BCMCFD clearly outlined the need for change and confirmed its willingness to change. In reading this discussion paper, I recognized that the Ministry is very engaged in honouring and respecting the dignity of persons with developmental disabilities and facilitating their equitable participation in everyday life, as well as willing to accept responsibility for the lack of insufficient support and resources allocated to the area of community living services. I agree with the thinking behind this discussion paper and feel strongly that it has contributed considerably to the transitioning of services from the Ministry to the community-based governance model.

### Service Delivery Models

Even the progressive models of comprehensive community service systems retain[ed] a certain class of conception of need, . . . reflected in the belief that if we define a range of options, everyone's needs will eventually be met. While it is unrealistic that the range could ever be broad enough to meet everyone's individual needs, in the existing socio-

political context, it is a patent absurdity. There is also a lack of flexibility built into the system, particularly in funding mechanisms, which again tend towards broad classes of needs rather than the individualized entitlements. This makes it difficult to respond to changing or complex needs which don't 'fit' the standard classes. (Stainton, 1992, p. 17)

*Moving From Institutionalized and Traditional Model to Community Living*

The disability rights movement has been a primary example of a reform movement that has changed how individuals with disabilities are viewed and treated in society. Older social movements that occurred in the first half of the 1900s tended to be class based and oriented to gaining greater equity in income. But the "new" social movements that have been typical since the 1960s have focused much more on the issue of rights (Stroman, 2003).

Several authors wrote about the changes in service delivery protocol and policy that has marked the field of developmental disability since the 1940s. The first change was initiated by parents of individuals with a developmental disability who were seeking improved services for their children. The second change was the notion of civil rights for people with disabilities as a consequence of the 1959 desegregation movement. The third shift was the 1970s deinstitutionalization movement that assured public school education for children with disabilities (Whitehead & Hughey, 2004). The fourth change in service delivery protocol and policy was the current implementation plan to offer individuals and families alternatives that respect their choice in meeting their disability-related support needs and that they feel would enhance their personal independence and connection to community (BCMCFD, 2002).

The most recent change in service has been focused on breaking out of the system of social services, which has worked from the basic tenet that professional intervention is the initial and primary response. In his speech to the CLTSC, Minister Hogg (2002) stated, "Aside from

affordability, our approach has often been characterized as disenfranchising and disempowering those who best know what services and supports are required to assist persons with disabilities to independence—their families, their care givers, and their communities” (§ 3). BC has led the world in the embodiment of community living goals and ideals in supporting individuals and families. Our province was one of the “first jurisdictions in the world to close institutions and in the decade of 1980s created some remarkable means of supporting families” (BCMCFD, 2002, § 5). Twenty years later, the At Home Program and Associate Family Programs are examples of this thinking. The restructuring of the system from institution based to community based between 1977 and 1990 was characterized by the movement of people from large facilities to small congregate-care residential service settings commonly known as *group homes* (Whitehead & Hughey, 2004).

According to Stainton (in press), since the 1970s there has been a steadily growing focus in the disability movement on rights as the basis for supports and services. By the 1980s, Stainton explained, we began to see explicit protection for people with intellectual disabilities in a range of legal instruments. Examples of this would include the inclusion of *mental disability* in the Canadian Charter of Rights and Freedoms in 1982 and the Americans with Disabilities Act in 1990 (Stainton, 1994).

In 1975 a large institution in BC known as Woodlands School was analyzed by a group of families known as the Woodlands Parent Group. The common experience for all those involved seemed to be a closed, unresponsive service system whose funding policies and planning structures lacked flexibility and accountability (Salisbury, 1998). This group was committed to their children’s return to community life, autonomy, and dignity, and the parents identified alternatives such as individualized funding—funding that the government allocates to

a person—and providing a place for families and individuals to receive whatever assistance is necessary. However, the key point for these parents was the need to remain community based and independent from the government and direct services.

In 1976 a proposal to implement individual funding and to establish the Community Living Society was submitted and received government approval. This society was an independent vehicle that worked on behalf of individuals who wanted to leave Woodlands.

According to Salisbury (1998):

The real significance of the BC model, however, was that the combination of money and independent planning represented, *for the first time*, a radically alternative framework for achieving citizenship. People could think entirely outside of the “disability box” to address their needs. (p. 5)

With this information it became more evident to me that the CLRF mandate was congruent with the view that allows individuals with developmental disabilities and their families to “think outside the box” and encourages families to think of creative and innovative ideas to support their family member while maintaining their independence and dignity.

It also appears that one of the positive changes in the last 30 years had been the increased deinstitutionalization of persons with disabilities from long term care institutions to independent living, which has enabled many individuals to move into their own homes and receive required supports. This movement has provided a much richer and fuller life for the individual, family, and community.

It is important to note that supporting meaningful change toward individualized funding and support requires continued local and provincial involvement and expertise.

*Examples of Service Delivery Models*

In the mid 1970s the BC legislature mandated direct or individualized funding, but by the 1990s the government's commitment decreased as a result of bureaucratic and provider interference (Salisbury, 2000). The Community Brokerage Services Society and Microboards are two models that were developed, but, despite their success, they have remained small and relatively unknown. According to the B.C Coalition of People with Disabilities (1997), this may be because there has not been a broad community movement to promote individualized funding.

In 1989 the Vela Housing Society, a non-profit organization in BC, offered subsidized housing to people with developmental challenges in Greater Vancouver and started a pilot project with three microboards. In British Columbia, "to satisfy legal requirements of the provincial Societies Act a minimum of five people are required to incorporate the Microboard" (Vela Board, n.d. ¶ 2). These boards consist of a small group of individuals (family and friends) who work together to address the support needs of a person with challenges. Microboards have the option to oversee the provision of support services to people with disabilities, thus becoming the employers. Vela provides support to the microboard for this employer role. Microboards are able to access funding because they are registered societies similar to the Associations for Community Living (Lord, 2000). There are over 300 microboards throughout BC at this time.

Although microboards may be effective, it is not easy to determine the needs of the person being supported, especially if there are difficulties in communication. Additionally, it is also difficult to find the right staff. Hiring staff through networks is a possibility because hiring friends and relatives might not always work out.

The Community Brokerage Services Society is another example of the individualized funding and independent planning that occurred in BC as a pilot project for five years. The

project offered planning supports to individuals with developmental disabilities and their families, as well as assistance in accessing individualized funding. According to Salisbury (1998), the government cancelled the project in 1996 for the following reasons: (a) poor management, inconsistent leadership; (b) minimal support from key stakeholders and loss of clarity and consensus regarding project objectives; (c) brokers' lack of awareness of services and options and lengthy delays in planning and implementing services; and (d) the concern that brokers were often more accountable to personal networks than to individuals. However, families and individuals appreciated the recognition and role that they were given in planning and the opportunity to choose support staff and change service providers if needed. They also appreciated the administrative support to deal with the paperwork.

Small brokerage projects have also been developed in the United States and the United Kingdom, though in some cases the model had been compromised, especially in relation to the independence of the broker (Dowson & Salisbury, 1999).

Although the service brokerage model may have provided support and encouragement to families and individuals, it still required a broad commitment to implementation and strategic stakeholder alliances, and support and training for the brokers would be essential.

In Ontario the highly successful Direct Funding Program for people with physical disabilities conducts formal functional assessments of physical capacity instead of placing the individual's articulation of needs at the centre of a thorough process of peer review (Torjman, 1996). Appropriate payment is allocated for each component of established need, including social, recreational, and occupational needs as well as physical supports, and a total amount is determined. With the input of his or her personal support team when appropriate, the individual then purchases the required equipment and/or personal supports according to his or her own

preferences. In this instance, no two individuals would have exactly the same needs; thus, levels of support are determined on an individualized basis. In BC, we have the Choice in Supports for Independent Living (CSIL) program for physical disability.

Over the last 15 years the concept and practice of direct funding for individualized supports has continued to grow in Ontario. The Special Services at Home: Family Support Initiative continues to be a very popular and important family program. Since the mid 1980s families with children who have physical or developmental disabilities can receive individualized funds for respite, family support, community integration, or individualized supports. This program compares with the At Home Program offered in BC. Both have demonstrated that families appreciate having more control over supports in their lives.

Another example of a service delivery model in a global context is the Monadnock Self-Determination Project in New Hampshire. In 1993 Monadnock Developmental Services received a grant from the Robert Wood Johnson Foundation for a three-year pilot project, the focus of which was to implement a system that gave the control of supports to people with disabilities. The program had three overlapping goals: (a) to enable individuals and their families to control dollars without dealing with cash, (b) to change the role of case management to personal agents chosen by the consumer and independent brokers of services, and (c) to organize a response to a managed-care culture (Lord, 2000).

According to my review of the literature, because of the emphasis on informal support networks in the lives of people with disabilities, the project had a community-development component. It also managed to emphasize the provision of control over the way that dollars were spent without managing the money directly.

The above are only a few examples of service delivery models that I reviewed for the purpose of this study. They have all provided insights into the ways that services have been transferred to individuals and their families. Despite the challenges, efforts continue to be made to develop a culture of collaboration between key stakeholders. In BC the transitioning of responsibility from government to CLBC is a further indication of a radical change in the model of service delivery and support.

#### Individualized Funding: What Does It Mean for Families?

According to the Roeher Institute (1997), individualized funding (IF) is based on the principles of self-determination, choice, equality, and the right to make decisions that affect one's life. It is also based on the premise that people who have disabilities need money for basic living expenses, in addition to the expenses related to having a disability, which include equipment, homemaking services, and attendant services (Roeher Institute, 1997).

Salisbury (2000) defined individual funding as “the allocation of financial resources to individuals by governments on the basis of their specific, disability related needs and service/support requirements, thereby enabling people to purchase only those services they require” (p. 2).

Torjman (1996), on the other hand, referred to individualized funding as the provision of dollars to allow the purchase of certain goods and services. To arrive at an appropriate payment under individualized funding, an assessment is carried out with the involvement of the individual to determine the supports that are required and, in the case of service, how much assistance is needed. An amount is then determined, and the individual can then purchase the required supports. Torjman argued that, despite the strengths of individualized funding, the inherent weaknesses should also be mentioned:

1. Access: Persons with disabilities often find it difficult to obtain personal supports.
2. Eligibility: Needs assessment under individualized funding differs from traditional processes. The primary difference is that under a system of individualized funding, individuals with a disability play the central role in articulating their needs and determining the best way to respond to these needs.
3. Responsiveness: Traditional services are frequently unresponsive to individual needs. A major component of this is the restriction on where certain supports may be made available.
4. Myth of the market place: Despite the positive aspect of individualized funding, there are limits to what it can actually achieve, especially in the short term.
5. Quality control: The lack of standards for the quality of service is a concern.
6. Accountability: Monitoring the use of public funds that are given directly to individuals is an issue.

Individualized funding in Canada emerged in the mid 1970s in BC with the development of brokerage services as a response to the closure of the Woodlands Institution. “Normally brokerage services are independent of other direct services, enabling an individual to pick and choose from an array of available services and community opportunities” (Lord, 2000, p. 10).

The CLBC is the new authority and will have the legislative mandate and capacity to provide individualized funding as an option for those who request it. “Individualized funding will allocate funds directly to individuals, or in the case of children, to their parents or guardians, to provide the support necessary to meet the disability related needs and to assist individuals to become contributing citizens” (CLTSC, 2002, p. 25).

In my review of individualized funding it was apparent that this model is indeed a means or mechanism of attempting to keep families together and supporting individuals during transitions while reducing the cost of services from the traditional model of service delivery. Compared to block funding, it also ensures appropriate funding to meet the needs of the individual and allows for portability of services. Additionally, this funding provides opportunities for individuals, families, and communities to respond collaboratively and in a manner that best suits the needs of individuals with disabilities and their families.

According to Bleasdale (2001), individualized funding is currently regarded as one way of advancing community living for people with disabilities beyond residential models. Bleasdale explained that the model of individualized funding that has been promoted across USA, Canada, and now the UK has person-centred planning at its core. Person-centered planning is changing how people view the futures of individuals with severe disabilities. In fact, it is being referred to by some as a "paradigm shift" - a completely different way of looking at services for persons with disabilities (Bradley, 1994). The person-centered approach relies much less on the service system by organizing truly individualized, natural, and creative supports to achieve meaningful goals based on the individual's strengths and preferences.

#### Summary

With person-centred planning at its core, I believe that individualized funding for families would mean opportunities to develop innovative projects that would encourage community development, break down the difficulties around service provision, increase independence, and empower individuals with disabilities to participate in decision making. However, as indicated in the literature review, making the individualized funding available might be a challenge and require direct lobbying to establish it. Another significant challenge would be

to manage the complex contracts involved in receiving government funds and, in some instances, in being an employer (Bleasdale, 2001).

The literature review reveals the necessity of continuing to search for ways in which people can be treated better. As His Holiness the Dalai Lama (2001) and countless others have pointed out, we all long for happiness for ourselves and others. How can we continue to provide services and funds to support the quality of life for individuals with disabilities and their families? Moreover, how can we ensure that we maintain the dignity of these individuals and continue to incorporate an ethical foundation into all of the services and supports that are provided?

Individualized funding may not be the solution to full inclusion of people with disabilities in our society, however; it does provide the best opportunity for individuals to make their own choices and participate in the community.

## CHAPTER THREE – CONDUCT OF RESEARCH

## Research Approach

I conducted this project using a qualitative action research methodology. Action research is a systematic and emergent process that “focuses on methods and techniques of inquiry that take into account people’s history, culture, interactional practices and emotional lives” (Stringer, 1999, p. 17).

I chose the qualitative approach because it is human centered and takes into account the participants’ perceptions, values, and attitudes (Palys, 2003). Qualitative research assumes that reality is partly subjective and dependent upon people’s perceptions at any given time. This phenomenological approach to research made understanding human perceptions its major focus (Palys, 2003). As the researcher, I became more involved as part of the process, rather than staying distant.

In conducting this study, I also used policy-oriented research, which is designed to inform or understand one or more aspects of the public and social policy process, including decision making and policy formulation, implementation, and evaluation (Hammersley, 2000). Policy means choice that involves change, and policy by its very nature implies that we believe that we can effect change in some form or another (Russell, 1945).

The abovementioned is in contrast to quantitative research, which attempts to define the environment through statistics and raw data that uncover theories and facts (Palys, 2003). The challenge with quantitative research is its inability to capture human experience in any degree of depth. For example, quantitative methods could capture the percentage of people who are not

satisfied in their workplace; however, they would not be able to determine why they were feeling this way, whereas with qualitative methods, this depth can also be captured.

Community-based action research is the type of qualitative approach that I used to conduct this project. Community Living is made up of many stakeholders, individuals, families, and communities who can be impacted by the outcome of this research. The action research approach offered these stakeholders the opportunity to continue to work together for the collective benefit of the community. According to Stringer (1999), “Community based action research seeks to change the social and personal dynamics of the research situation so that it is non-competitive and non-exploitive and enhances the lives of those who participate” (p. 21).

This project followed what Stringer (1999) described as the three basic elements of action research: look, think, and act. Stringer suggested that the look, think, and act routine “should be read as a continually recycling set of activities” (p. 19). As a fairly new researcher, I found the idea of using action research exciting because it allowed me to fully engage research participants and organizations in their own research. It was important for me to keep in mind that I would be bringing my own biases, judgements, perceptions, and mental models of my experiences to this research process. Bias can be present from the perspective of the interviewer. Stringer cautioned, “A major problem with the interview process is that the questions are easily flavoured by the researcher’s perceptions, perspectives, interests, and agendas” (p. 68). As a result of my awareness of this, I was careful throughout my research to maintain objectivity.

I used Stringer’s (1999) methods and principles of action research to authenticate the information required for a comprehensive and well-developed research approach. Palys (2003) stated, “Gathering data is easy; gathering *meaningful* data is a whole other challenge” (p. 150). This statement resonated with me as I proceeded to plan the methodology for my research.

The methods that I used to conduct this research project included questionnaires, a focus group evaluation, and a file review.

### Project Participants

The action research involved the project sponsor, faculty supervisor, three groups of research participants, an editor, and myself as the researcher. Two groups of participants were required for the questionnaires, and the other group served in a dual role as both focus group and advisory group. The individuals who participated in the questionnaires included three individuals from the various stakeholder groups who had been involved in the initial stages of transforming community living and three families who had received funding from the CLRF. The questionnaires for both the family and stakeholders were worded slightly differently in order to capture the appropriate information required for the study. Both of these questionnaire groups were key sources for providing suggestions on ways to continue the fund which contributed to my suggested options in chapter five. The focus/advisory group included individuals who were currently part of the CLRF Advisory Committee, a Victoria Foundation representative, and CLRF supporting staff. In all of these groups the individuals had a stake in or influence over future goals and outcomes of community living services and supports in British Columbia.

I sent an initial letter of communication to all participants that described the project, what it was about, and why I was conducting this research. Upon receiving confirmation of their interest, I organized an exploratory meeting to inform them of the next steps, the timeframes, and other related information. Additionally, I asked all of the participants to sign a consent form prior to proceeding with the research (Appendix A).

## Research Methods and Tools

### *Questionnaires*

I used structured questionnaires to collect primary data on a specific topic, including feelings, knowledge, experiences, opinions, and behaviours. I developed the questionnaires in consultation with my faculty supervisor and project sponsor and administered them over a two-month period. I forwarded them to the participants by email, and they either emailed or faxed the completed questionnaires to me directly. The individuals who completed the questionnaires comprised a representative group of stakeholders who included families, government, and Community Living organization representatives. Stringer (1999) explained, “The interview and questionnaire process not only provides a record of their views and perspectives but also symbolically recognizes the legitimacy of their views” (p. 68). I believe that this was critical to my research because the views and perspectives that the participants offered contributed to authenticity and trustworthiness in the focus group discussion. Palys (2003) stated that allowing respondents to answer questionnaires on their own poses special constraints that the researcher must consider. First, the respondents must be literate in the language; second, researchers must ensure that the language used in questionnaires is appropriate for the sample group; and third, researchers who design questionnaires must anticipate possible ambiguities or misunderstandings. For the purpose of this study, keeping in mind Palys’ potential constraints, it was imperative that my questions be relatively straightforward and clear. Additionally, I ensured that I was available to clarify any ambiguities while allowing the respondents to answer the questionnaire in privacy.

My organization sponsor and I requested participation in the questionnaires via email and telephone.

The steps in preparing the questionnaire included scripting the questionnaire to ensure that the questions were consistent, which assisted in the analysis stage of the research. It was important to determine what information I required and, accordingly, to determine the general question content that would elicit the desired information.

Preparing and piloting the questionnaire allowed me to validate the format design and questionnaire length, as well as to test the questionnaire for flaws and misleading questions. It was also important to establish rapport. I needed to reach a balance between ease and over identification with the project participants. As the researcher, it was important that I make the participants feel relaxed so that they were willing to share their opinions openly in completing the questionnaire.

Additionally, as a researcher it was crucial that I avoid biases as much as possible, be sensitive, and allow more time than I might have expected for each project participant to complete the questionnaire. It was important to keep in mind that each project participant's responses to the same questionnaire were different.

In my opinion, the questionnaire was meaningful in getting at the story behind a participant's experiences, which further contributed towards the validity and reliability of the information for my research.

### *Focus Group*

For the purpose of my study, a focus group was a good methodology because it could be used in conjunction with other methods. Kitzinger (1994) stated that the focus group method is particularly useful in exploring people's knowledge and experiences and can be used to examine not only what people think, but also how they think and why they think that way.

I conducted the focus group evaluation during a scheduled CLRF meeting to avoid individuals' having to travel from their locations to Vancouver. The focus group was scheduled for three hours, and it was focused on evaluation of the wind-down process of the funding dollars from the CLRF being expended.

The process of gathering data included keeping a record of my observations and the discussion in the focus group, as well as tape recording the focus group; the Victoria Foundation representative, a CLRF consultant, and I then transcribed the tapes for data analysis. According to Morgan (1997), focus groups are a particularly useful method for exploring knowledge and experiences, and I believe that because my research participants had a history of being involved with Community Living, this was a dynamic process of compiling data from the questionnaires and further validating and authenticating the data with the focus group to explore options and potential recommendations.

Palys (2003) also explained that the usefulness of focus groups is not limited to exploratory research, but that the group could visit the analyzed and interpreted data to allow the researcher to explore further considerations and generate hypotheses by gathering alternative interpretations (p. 162). It was my intent, through engaging in a focus group with the individuals identified, that we would collectively generate ideas and look at alternative ways of sustaining the supports and services for individuals with disabilities and their families.

#### *Document Analysis/File Review*

I then analyzed and reviewed organizational and government documents from a longitudinal perspective to track the history, evolution, and development of the community living model and the transition from government-based to community-based service delivery. The

documents provided context to the research as a whole and contributed to the development of questions for the questionnaire and my understanding of the Community Living movement.

For the purpose of this research, I reviewed completed evaluation forms that individuals, families, and service providers who had received grants from the Victoria Foundation had submitted, developed an Excel spreadsheet that captured the data, which I then reviewed, sorted, and analyzed thematically. I sought consent from the Victoria Foundation to gain access and review the files, and I maintained confidentiality by not including identifying information in my analysis. I received access to review the files at the Victoria Foundation office, which is located in Victoria, BC. Because it was difficult to review the files in order of date, I did so according to the file resolution numbers, and the recipients remained anonymous. Out of approximately 700 files, I randomly selected every 14<sup>th</sup> or 15<sup>th</sup> file to reach a cohort of 50, and I then input the data into an Excel spreadsheet and sorted and analyzed them thematically.

### Study Conduct

I began the study by reflecting on my awareness of the existing services and supports available to individuals with disabilities and their families, especially the *lack* of services and supports. Through my work as a consultant for the CLRF, I became interested in the area of researching supports and services for individuals and their families and exploring ways in which the supports and services could be sustainable. Through further dialogue with Community Living agency representatives, CLRF advisory members, a Victoria Foundation representative, and a few others who had knowledge and experiences with the Community Living Restructuring Fund, I decided to explore how supports offered through funds such as the CLRF could be sustained. It was important for me to understand the supports and services that individuals and families value and, further, to explore how these supports and services impact their quality of life.

The next step involved conducting a formal and informal review of the various government and community documents on the community living movement and transition, followed by reviewing the supporting literature. At this stage I drafted the research question, along with the subquestions. I then constructed the questions for the questionnaire, which I then forwarded to my faculty supervisor and project sponsor for their input.

The literature brought many interesting insights to the forefront, especially regarding the huge discrepancies around the definition of developmental disabilities. It was evident that in many circumstances the definition identified not only the services used, but also the expectations of the recipients. In many instances, it was evident that the expectations the recipients had were not aligned with the supports and services that were available to them. This starting point was somewhat demoralizing; however, I continued with my research with the intention of reaching a deeper understanding of the possibilities that exist for change and support for individuals with disabilities and their families. Once I had collected the data, it was obvious that some of the literature that I had reviewed that had seemed relevant and disturbing was not as discomforting as I had thought because huge strides had been taken in how supports were being made available for individuals and families regardless of the various definitions of developmental disabilities. This step was very encouraging, because I realized that cycling through Stringer's (1999) different stages that he referred to as looking, thinking, and acting was a very necessary reflective process to gain an understanding of qualitative methodology or cycles of action research.

I solicited participation from three different groups of individuals to obtain a holistic perspective on the data. The focus group evaluation involved the members of the CLRF Advisory Committee, a Victoria Foundation representative who facilitated the process, and the

CLRF support staff. Setting up the focus group session was not complex because we planned to hold it during the time of a regularly scheduled CLRF meeting. The enthusiasm and passion of the members around the table was evident time and time again in terms of the learning and benefits that resulted from the CLRF funding over the two-year period. It was also a benefit to have the Victoria Foundation representative and another CLRF consultant taking notes to provide an opportunity to capture their outcomes. It was an interesting process to review the data and begin to sort, theme, and analyze in terms of thematic occurrences.

Fortunately, the questionnaires were very well received. All of the project participants selected from the families and stakeholders were very diligent in submitting their consent forms and completed questionnaires on time. The information that they provided added further insight into the positive movement towards supporting individuals and families and the need to explore ways to sustain these supports and services.

I summarized each questionnaire individually and then compared the overall data for emergent themes and points of concern, merged them into one document, and searched for common themes that emerged again. I noted the patterns that emerged frequently and produced one document of the research. Some of the information that I had collected through the questionnaires and focus group evaluation was of such significance and relevance to the study that I reviewed and summarized it in a narrative format to capture the essence of the stories and responses that the participants had offered. I also searched for and noted data that contrasted with an emergent theme and reported them in the results section as well. To determine patterns and themes in the participants' responses, I analyzed the content and summarized the data.

## Data Analysis

Glesne (1999) suggested that data analysis is the process of categorizing, synthesizing, searching for patterns, and interpreting the information. There are three main methods of gathering data from questionnaires and interviews: verbatim written notes, written notes of main points, and audio or video recording. For the purpose of my research, I used written notes of main points and audio recording when needed.

The questionnaire was particularly useful for qualitative research because it allowed me as the researcher to gather rich data and gain deep insight into phenomena. However, according to Stringer (1999), no matter which method is used to gather data, the key to data collection is to capture the experience of the other and to gather meaningful information.

After analyzing the questionnaire results, I conducted a focus group evaluation, which allowed for further interpretation of the data in relation to the research question. Morgan (1997) suggested, “The strength of relying on the researcher’s focus in a focus group is the ability to produce concentrated amounts of data on precisely the topic of interest” (p. 13), and “focus groups not only give access to reports on a wide range of topics that may not be observable but also ensure that the data will be directly targeted to the researcher’s interests” (p. 13).

Data collection also included organizational document analysis and government document reviews to assist in establishing a link between the research data, the historical context, and the devolution of community living. My review of the files at the Victoria Foundation provided further data in terms of the value of the supports offered to individuals, families, and service organizations.

Using researcher and assistant field notes, I collected data from the questionnaires and focus groups. To analyze the data, I reviewed my notes and then cross referenced them to those

that the CLRF consultant and the Victoria Foundation representative had taken for further clarity and validation. Accordingly, I looked for key words and phrases and then began to identify tentative categories and themes.

I asked some of the questionnaire and focus group participants to verify the transcribed data and to make any required changes (descriptive data). Once they had validated the transcripts, I proceeded to revisit the themes. This process involved searching for similarities and patterns that emerged from the participants' responses based on each of the categories and themes.

My faculty supervisor and sponsor assisted in determining the interpretive validity and transferability of the themes and categories that emerged from the data. This process contributed to triangulating the data to provide trustworthiness of the interpretation.

#### Ethical Issues

For the purpose of this research opportunity, the requirements set forth in Royal Roads University's (2004) *Research Ethics Policy* and Royal Roads University's (2000) *Policy on Integrity and Misconduct in Research and Scholarship* guided how I interacted with all those involved in the research to ensure that their rights and interests were protected. "Researchers must consciously consider and protect the rights of the participants to privacy" (Glesne, 1999, p. 122). Additionally, "respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity" (Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2003, p. i.5). This is important to me, and I believe that it was also important to all those involved in the study. Because I was working with various community partners,

government representatives, community agencies, and individuals with disabilities and their families, respecting their privacy and confidentiality was paramount in my research because we would frequently disclose or share information with each other; hence, it was essential that I put appropriate safeguards in place to maintain the human dignity and privacy of the individuals and families who were involved in the study.

“Respect for human dignity entails high ethical obligations towards vulnerable persons—to those whose diminished competence and/or decision-making capacity make them vulnerable” (Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2003, p. i.5). Based on my personal values and beliefs, it was imperative that I keep this guiding principle in mind in researching vulnerable individuals, which included children, institutionalized persons, or others who are vulnerable, to maintain their self-worth and dignity and avoid abuse or discrimination. In gathering the data, it was important that I set certain guidelines in seeking permission, support, and responses from immediate family members to allow them to offer input into the best care or plan for their child or family member. Palys (2003) also identified a “scientific obligation to do research in the best way we know how . . . and . . . a humanistic obligation to treat people with dignity and to safeguard their interests” (p. 81).

I informed the participants as clearly as possible what their participation in the research project would involve and obtained informed oral or written consent (Appendix B) in which I outlined the purpose and nature of my research, the purposes for which the data would be used, and how I would present the information upon the completion of my project. I also needed to ensure that the Advisory Committee members, staff, and other individuals involved in the research signed confidentiality agreements. I assured the participants of the confidentiality and

anonymity of the data and explained that I would store the data and destroy them upon completion of the project to prevent any ethical issues from arising. Having these discussions in advance helped to decrease the possibility of problems arising and ensured that the rights of the individuals would be respected and ethical considerations satisfied (Palys, 2003).

As a responsible researcher, I ensured that I did not breach any of the principles cited in Royal Roads University's (2000) *Policy on Integrity and Misconduct in Research and Scholarship*. As my knowledge of ethical issues and the methodology of my research became clearer, it was important that I keep ethical considerations at the forefront throughout the study.

## CHAPTER FOUR – ACTION RESEARCH PROJECT

### RESULTS AND CONCLUSIONS

#### Introduction

This chapter presents an analysis of the data gathered for this study. The purpose of the project was to explore the question, “How can supports and services for individuals with disabilities and their families, which had previously been provided by the Community Living Restructuring Fund, be sustained?” The findings came from data collected through a file review, a focus group evaluation, and family and key informant questionnaires. I analyzed the data for themes, and this chapter presents the findings and conclusions from that data analysis.

#### Study Findings

##### *File Review*

Demographic data from the file review include (a) age range, (b) city, and (c) region. I broke the data analysis down into four regions: Fraser Valley, Interior, Vancouver Coastal, and Vancouver Island. The total amount for the random sampling was \$1,443,071.19, which is approximately 6% of the total funding of \$24 million that the CLRF receives from the Ministry.

Of the 49 file reviews that I completed, 100% of the recipients noted that they had achieved the outcome that they had indicated in their initial application. According to the sample group, 50% of the funding was utilized for renovations and 50% for transportation through the purchase of vans and safe vehicles. The respondents reported that both the renovations and the transportation allowed increased accessibility, independence, privacy, and safe delivery of care; kept families together; increased capacity; and provided a safer environment.

Approximately 16.3% of the applicants from this sampling had acquired funding from other sources, 2.1% had made attempts but were unsuccessful, and 81.6% had not considered other funding sources. Some of the sources from which applicants received funding included the President's Choice Children's Charities, the Variety Club, and other children's charities. The 81.6% who had not applied for other resources, but needed funding over the level of the grant, used funds from their own savings, borrowed from friends and family, or continued to incur costs personally.

The consistent theme in all of the files that I reviewed was that because of the funding that they received from CLRF, many of the families were able to take their family member with disabilities on outings and attend necessary appointments. Additionally, the modifications and renovations eased the stress on the caregivers and parents because it allowed them to care for the individual with a disability in a much healthier environment. One parent explained, "These improvements will also allow our daughter to stay at home for the maximum amount of time to attend to her critical needs safely with dignity." Another recipient reported, "The funding provided a huge relief from back issues and joint issues due to the ease of transportation."

Broken down according to the four regions (Fraser Valley, Interior, Vancouver Coastal, and Vancouver Island), the results are as follows.

*Fraser Valley.* Within the Fraser Valley Region, the total amount disbursed from the sample files was \$463,875.02, or 32% of the total sample amount. The average amount disbursed was \$24,414.47, the highest amount was \$35,000.00, and the lowest amount was \$8,025.00. The average age of a child with a disability in this region who received funding was 12 years. As shown in Table 1, the majority of the requests for funding in this region were for \$25,000 to purchase vans to increase mobility and accessibility for individuals who use wheelchairs.

Table 1

*CLRF Funding: Fraser Valley Region*

Family (F) or agency (A)	Age	Geographic area of the province	Region	Amount received
(F)	13	Abbotsford	FV	25,000.00
(F)	14	Abbotsford	FV	25,000.00
(F)	5	Abbotsford	FV	28,086.00
(F)	15	Abbotsford	FV	25,000.00
(F)	16	Abbotsford	FV	10,450.00
(F)	n/a	Chilliwack	FV	28,335.52
(F)	7	Coquitlam	FV	25,000.00
(F)	14	Delta	FV	34,000.00
(F)	10	Delta	FV	25,000.00
(F)	7	Hope	FV	25,000.00
(F)	16	Langley	FV	32,956.00
(F)	19	Langley	FV	25,000.00
(A)	n/a	Langley	FV	8,025.00
(F)	14	Mission	FV	25,000.00
(F)	9	New Westminster	FV	25,000.00
(F)	9	New Westminster	FV	25,000.00
(F)	17	Surrey	FV	35,000.00
(F)	11	Surrey	FV	25,000.00
(F)	15	Surrey	FV	12,022.50
Total amount disbursed				463,875.02
Average amount disbursed				24,414.47
Disbursed as a percentage of sample				32%
Highest amount disbursed				35,000.00
Lowest amount disbursed				8,025.00
Average age of recipient				12.41
Number of applications by families				18
Number of applications by agencies				1

*Interior.* Within the Interior Region, the total amount disbursed from the sample files was \$230,029.00, which was 16% of the total sample amount. The average amount disbursed was \$46,005.80, the highest was \$115,029.00 and the lowest was \$25,000. The average age of the people in this region who received funding was 17.5 years. It is evident that the numbers of recipients were much lower; however, the ranges of disbursements for this region were much higher than those in the Fraser Valley. Again, it appears that the major need in this region was wheelchair adaptable vans. Table 2 provides a breakdown of the details for the Interior Region.

Table 2

*CLRF Funding: Interior Region*

Family (F) or agency (A)	Age	Geographic area of the province	Region	Amount received
(A)	n/a	Kelowna	I	40,000.00
(A)	n/a	Nelson	I	115,029.00
(F)	15	Penticton	I	25,000.00
(F)	13	Penticton	I	25,000.00
(F)	25	Penticton	I	25,000.00
Total amount disbursed				230,029.00
Average amount disbursed				46,005.80
Disbursed as a percentage of sample				16%
Highest amount disbursed				115,029.00
Lowest amount disbursed				25,000.00
Average age of recipient				17.60
Number of applications by families				3
Number of applications by agencies				2

*Vancouver Coastal.* Within the Vancouver Coastal Region, the total amount disbursed from the sample files was \$277,372.54, which was 19% of the total sample amount. The average amount disbursed was \$25,215.69, the highest was \$75,000.00, and the lowest was \$4,900.00. The average age of people in this region who received funding was 12 years. There is a huge difference between the lowest and highest funding for this region—\$4,900.00 for a full bathroom that allowed for private living in the basement and \$75,000.00 for creative and innovative options for individuals and families. The grant reduced the cost of services and supports by adding beds to an existing home and allowed several individuals to remain at home. Without the support of the grant, the agency would not have been able to make the necessary changes. The fund allowed three programs to amalgamate and improve existing living conditions.

The amounts received show that the needs also appear to be mixed in terms of supports requested for transportation and modifications to the home. Table 3 presents a breakdown of the details for the Vancouver Coastal Region.

*Vancouver Island.* Within the Vancouver Island Region, the total amount disbursed from the sample files was \$471,794.63, which was 33% of the total sample amount. The average amount disbursed was \$33,699.62, the highest was \$86,756.00, and the lowest was \$5,539.00. The average age of children with disabilities in this region who received funding was 14 years. Again, like the Vancouver Coastal Region, the difference between the lowest and highest amounts is huge. The highest amount provided creative options for an individual with significant needs to be supported in more independent accommodation. The funds also allowed a family to keep their daughter at home by providing separate accommodation with some supervision. The lowest amount helped to create a much safer and secure environment for a family member with significant needs. According to the funding requests, the needs for the Vancouver Island Region

Table 3

*CLRF Funding: Vancouver Coastal Region*

Family (F) or agency (A)	Age	Geographic area of the province	Region	Amount received
(F)	9	Burnaby	VC	25,000.00
(F)	11	Burnaby	VC	25,000.00
(F)	6	North Saanich	VC	25,000.00
(A)	n/a	North Vancouver	VC	75,000.00
(A)	n/a	North Vancouver	VC	23,545.00
(F)	22	North Vancouver	VC	4,900.00
(F)	n/a	Richmond	VC	18,000.00
(F)	16	Richmond	VC	25,000.00
(F)	5	Richmond	VC	17,546.75
(F)	16	Vancouver	VC	21,380.79
(A)	n/a	Vancouver	VC	17,000.00
Total amount disbursed				277,372.54
Average amount disbursed				25,215.69
Disbursed as a percentage of sample				19%
Highest amount disbursed				75,000.00
Lowest amount disbursed				4,900.00
Average age of recipient				12.14
Number of applications by families				8
Number of applications by agencies				3

also appear to be diverse. In the Island Region there were five requests for transportation supports and nine for renovations or home modifications. There was undoubtedly a higher request for support from families than for agencies. Table 4 shows a breakdown of the details for the Vancouver Island Region.

Table 4

*CLRF Funding: Vancouver Island Region*

Family (F) or agency (A)	Age	Geographic area of the province	Region	Amount received
(F)	18	Campbell River/VI	VI	29,000.00
(F)	4	Comox	VI	8,461.55
(A)	n/a	Cowichan	VI	35,000.00
(F)	17	Duncan	VI	25,000.00
(F)	11	Gold River	VI	25,000.00
(F)	20	Port Alberni	VI	86,756.00
(F)	8	Saanichton	VI	50,000.00
(F)	16	Sechelt	VI	25,000.00
(F)	18	Sooke	VI	28,655.21
(F)	17	Victoria	VI	25,000.00
(F)	18	Victoria	VI	18,382.87
(F)	17	Victoria	VI	25,000.00
(F)	7	Victoria	VI	5,539.00
(A)	n/a	Victoria	VI	85,000.00
Total amount Disbursed				471,794.63
Average amount Disbursed				33,699.62
Disbursed as a percentage of sample				33%
Highest amount Disbursed				86,756.00
Lowest amount Disbursed				5,539.00
Average age of recipient				14.25
Number of applications by families				12
Number of applications by agencies				2

*Family Recipients' Questionnaire Findings*

I forwarded a questionnaire (Appendix B) to three families who had been recipients of CLRF. Similar themes emerged from all three questionnaires. It was evident that the families immensely valued the funding that they received through CLRF to enable them to support their

family members through increasing independence and mobility and to keep their family members at home in a safer environment. Consistent themes emerged from the three questionnaires around the positive impact of the fund on their families and the decreased stress that the families had experienced because they were now able to provide transportation and adaptations to their home to meet the needs of the children in their care.

For the purposes of my project, I will focus on three emerging themes: (a) keeping families together, (b) increased mobility, and (c) enhanced quality of life.

*Keeping families together.* In all three methodologies that I used in this project, the common theme that emerged from the data collection was the impact of the CLRF fund on keeping families together. In my review and analysis of the three questionnaires that the families completed, it was once again evident that the funding played an integral role in supporting families in keeping their child or family member with disabilities at home. One participant reported, “We appreciated the fact that the CLRF was available to us to enable us to continue caring for our daughter in her own home.” Another explained, “The funding made life that much less stressful both financially and emotionally by providing supports to assist with the immense task of raising a member/child with disabilities. It prevented burnout for me.” According to all three participants, the biggest reward was the hope and encouragement that it gave them in being able to keep their family member at home because they were able to make the necessary adaptations and renovations to meet the needs of the individuals with disabilities. It was comforting for them to know that through the renovations and additional minor adjustments, they could accommodate their family member’s needs for years to come. One participant summarized it best: “What can I say? It eased so many burdens and allowed me to spend some quality time with my children, which was very unusual prior to this assistance.”

*Increased mobility.* Almost every participant from all three data-gathering processes made a reference to the impact of the increased mobility on the individuals with disabilities and their families. It was a common theme that emerged from the focus group, the questionnaires, and the file review. Many families were extremely limited in the outings in which their family members could participate together, and most of the participants expressed frustration with their inability to transport their own child to scheduled appointments. Without appropriate transportation, the families had to rely on external modes of transport, which in most cases were not very reliable and in some instances expensive.

Receiving funds through the CLRF to purchase or adapt a van that is wheelchair accessible provided the families with independence and flexibility in meeting the needs of their family member. The families no longer had to rely on external transportation, their family members with disabilities were able to be comfortably and safely transferred to their seats without much complication, and in some cases the family member with disabilities gained additional confidence as a result of being able to participate in community events. The funding also gave the families increased opportunities to go on outings and short holiday trips together. One participant stated:

The funds for the van have enabled us to be much more mobile as a family. We probably go out at least 75% more than we did before we got the van, and our daughter never gets left behind any more because it was just too hard to transfer her from her wheelchair to an adequate seat.

The data analysis showed that the increased mobility in many instances “opened up the world,” as one participant commented. The individuals with disabilities could be transported

safely in the van, participate in family and community events, and attend regularly scheduled appointments with ease.

*Enhanced quality of life.* After I had completed the data analysis, there was no doubt in my mind that the CLRF had enhanced the quality of life for the vast majority of the families who had received funding. In almost every instance, the participants reported that their lives had improved in terms of keeping the family together, reducing the burden on the caregiver/parent, being able to participate in more social outings, easing the stress on siblings to help, and, most of all, allowing the individuals with disabilities increased independence to meet some of their daily self-care as a result of the adaptations and renovations.

One participant stated:

The grant made an impact on our family. Not only did the grant give us a huge financial boost in purchasing the van, but it also improved our daughter's quality and enjoyment of life immensely with the additional support around installing a ceiling tracking directly from her bed to her toilet and bathtub. So we can see where her quality of life will be greatly improved.

Another participant was clear on the ongoing support that is required: "I think that it is imperative that families are enabled with support to make it possible to allow their family members with disabilities to remain at home and have an opportunity to participate actively as equal citizens in the community," and "This is a cost effective method and provides a quality of life for all concerned, prevents burnout, and greatly reduces the risk of injury to all concerned."

### *Key Informant Questionnaire Findings*

In addition to the family questionnaires, I sent a questionnaire (Appendix C) to three key informants, all three of whom have been and continue to be an integral part of the Community Living Transition Movement, as I reported in the methodology section of this project report.

It was evident that all three participants valued the CLRF, but did not necessarily restrict their thinking to the way that it was currently being executed. There was an overall consensus on the need for ongoing funding such as the CLRF; however, the challenges were how to provide similar ongoing funds and who would be accountable. Based on the information from the key informants, I examined the following three areas: (a) the major outcomes, (b) the risks to individuals with disabilities and their families, and (c) the advantages/disadvantages of fund.

*Major outcomes.* In reviewing all three questionnaires, I found a common theme that emerged in terms of the major outcomes. I asked participants, “What major outcomes were achieved through the CLRF fund?” and they identified the following: (a) increased support for families of children and adults with disabilities, (b) opportunities for families to keep their family member at home, (c) a wide variety of structured services to better meet the needs of the individuals who are being served, (d) resources to assist in service adjustments or redesign, (e) the ability of families to remain together, (f) enhanced quality of life for the individuals served by agencies and the opportunity to remain in or move to appropriate facilities, and (g) the ability of service providers to renovate to enhance the quality of life of those they support as well as to reorganize to streamline their operations and become more cost efficient.

These outcomes confirm once again the positive impact of the supports and services that the CLRF provides and the enhancement of the quality of life of individuals with disabilities and their families.

*Risks to individuals with disabilities and their families.* The participants' responses in the area of risk were mixed. The question that I asked was, "What are the risks to individuals with developmental disabilities and their families upon the depletion of this type of fund? Some of their responses included the following:

1. "A risk exists without this type of fund. Families who are desperate for renovations such as those which address mobility issues will decide they can no longer care for their loved one at home."
2. "Family units will break apart, and this will cause a financial burden on the service delivery system."
3. "No longer able to deal with issues which limit families to keep their loved ones at home."
4. "There are no risks to the families who have been supported by the fund and the risk to families who have not is they continue to be on lengthy waitlists for services and supports that even when they get them may not be what it is they want or need."
5. "The beauty of the CLRF was that it allowed those families who did receive the fund, to implement a new vision for supporting their family member. Without a fund of this sort, there is little hope for this to continue to occur for more families."

Once again, it was evident from the above responses that without similar types of funding, the risks for individuals with disabilities and their families will continue. In some instances, families will have very little hope of supporting their loved ones. In contrast, those who have received funding have a new vision for supporting their family members and renewed hope for the provision of adequate supports and services for their family members.

*Advantages/disadvantages.* The key informants' responses to the question "What are some advantages and disadvantages of this type of funding?" included the following:

1. Participant 1 explained, "The advantages are that it is arm's length from government, and the disadvantage is that there is limited accountability for how the funds are expended."

2. Participant 2 reported:

The advantages are that families get to determine what it is they need and want. In the past, the only real option they had was in their home or out of their home, and if it was out of their home, they had little or no opportunity to determine what the service model should look like that would best support their child.

The disadvantages of the fund is that it is difficult—especially in a short-term circumstance—to fully ensure that there is equity of access and distribution. Unless it is continuing, the families who are best connected are most likely to know about the fund and are most likely to get the supports to assist them in applying for the fund.

3. Participant 3 observed:

The advantages are that we are enabling families to remain whole and individuals to move to or remain in their chosen residential setting. Having the funds held outside government, enables the fund to carry over the past fiscal year end without being returned to general revenue. Having funds held by a foundation enables skilled investment so that the fund pays out more than the original principle amount. Decisions on granting are made by community representatives who are knowledgeable as to the needs of the community, who are not bureaucratic, who make decisions as a single body, and who are knowledgeable as to the other sources of funding which can be used as a first resource.

Utilizing a committee for making granting decisions is extremely cost effective and efficient.

The disadvantages are that, without an ongoing commitment to funding, those people who lack skills to apply or who are unaware of the fund and who likely are most needy are left behind when funds are expended.

From the above responses from the key informants, it is clear that there are many advantages and a few disadvantages of this type of funding. They also emphasize the need for families who do not have supports to be actively engaged or connected to support so that when these types of funds become available, they are equipped to apply for an appropriate grant.

#### Focus Group Study Findings

I asked the focus group eight questions from the evaluation form that the Victoria Foundation developed. This evaluation was part of the monitoring of the Strategic Investment Funds that the BCMCFD provides and that the Victoria Foundation holds in trust. The focus group consisted of the Trust Advisory Committee and the CLRF support staff.

Even though the participants addressed each question individually, the group later shared their responses and worked together as a group to combine and categorize their individual responses. Many of the responses were similar to others, but some involved independent ideas and issues. The group presented all of their ideas and made summary statements at the end of the exercise that the Victoria Foundation trust coordinator collected in a document.

Overall, the results of the focus group were positive, and I received the information that I sought. Through the two-and-a-half years of being involved in the disbursements of funds, the committee had made many observations and acquired a great deal of learning. For the purposes of this project, I will focus on the following questions:

1. How were the CLRF goals met?
2. What were some of the issues identified?
3. What were some of the important learnings from being part of the process?

#### *How Were the CLRF Goals Met?*

It was evident from the responses that the CLRF is a creative initiative that provides more options for individuals and their families because they play a role in the care decisions with regard to their family members. Additionally, a similar theme on the quality of life emerged as the families identified their own needs. One participant responded enthusiastically, “In my perception, families have *never* had an opportunity like this, and they were blown away. Someone actually cared enough to be interested and willing to help.”

Another goal that was met was the reduced costs of services and supports. Not only was this goal met, but also, as one participant remarked, “For the first time, creative solutions came from families themselves and not governments that typically tend to offer quick fix solutions that only work for a short time, if at all.”

The fund provided alternative support for people with significant needs. One member of the focus group stated, “The majority of families *want* to have their family members live with them, contrary to some beliefs.” In particular, the Trust Advisory Committee was proud to have been able to support the closure of Willow Clinic and to move individuals into community living. Others were moved back home with family members, and day programs were supported.

Other outcomes that the focus group identified included the following:

1. The fund supported movement to more independent accommodation.

2. Many other individuals were supported to enable them to stay at home with their families, and others were supported to move back home or to live with extended family members.
3. The committee also stated that the fund has allowed individuals with developmental disabilities to continue to live with their families. The CLRF has allowed families to remain whole and has supported many families who were strained financially, physically, and emotionally.
4. The fund assisted agencies in restructuring their services to meet the demands of the new system. However, most agencies saw the restructuring as being forced upon them by MCFD. The Trust Advisory Committee would have preferred more creativity. A number of applications from agencies could not be dealt with because the requests were large and often for very large capital building projects that would consume the fund or that did not reflect the vision of Community Living.
5. Some agency decisions seemed to be based on fiscal restraint rather than on enhancing the quality of life of the individuals being served. The CLRF helped some agencies to respond to the cutbacks required by the MCFD.
6. The fund assisted private care operators and family model homes in enhancing their property and increasing safety and accessibility for individuals living in these homes.

*What Were Some of the Issues Identified?*

The Trust Advisory Committee members noted in particular the fragility of parents and the decline in parental health when caring for high needs children. The number of single parents and grandparents or extended family stepping in to provide care and stability was also notable. According to one participant, “50 years ago, there were no supports, and parents and

grandparents were allowed to hit rock bottom and then their children were institutionalized.” The concern for the Committee remained that once this fund had been expended, what is there to support families with restructuring needs at home?

Another issue identified by the participants was around the area of housing. Housing issues continue to be major issues for those who live with developmental disabilities. Homes are not built for special needs and there no other source of funds to help families keep their loved one at home. Sometimes, only minimal changes are needed, however; those funds are not available.

The participants also noted that the number of individuals who live with developmental disabilities out in the community is now large. CLRF has provided community accessibility, mobility and safety for hundreds of individuals whereas before the Handy Dart system was the only option or life was limited to their backyards.

Another concern was around the complexity of families with multiple support needs. Some applicants had several children with high needs along with complex parental health concerns. This caused stress and plenty of anxiety for parents in making decisions around the best care for their child.

Lastly, the participants identified that not all families are connected with support agencies. Outside the Lower Mainland, access to resources is minimal or non-existent.

Most of the participants emphasized how the issue of families needing to stay together was so important. In most cases, it was a small cost compared to putting people into a group home situation. The payoff was not only in dollars, but in general happiness within the families themselves.

*What Were Some of the Important Learnings From Being Part of the Process?*

As the Trust Advisory Committee members reflected on the work that they had accomplished over the past two-and-a-half years in reviewing, disbursing, and monitoring the grants to recipients, they acknowledged that they had learned a great deal over this timeframe and considered the results of providing similar funds. Although no process is perfect, the committee members had worked hard to establish fair and equitable processes and policies to assist those who live with developmental disabilities in this province.

The following are some of the participants' learnings in terms of being part of the CLRF process:

1. The focus group participants identified the importance of allowing parents to express what they see as their needs in caring for their children and to discuss the high hopes that they have for the future of their children. The participants also observed that it has been possible to be prudent and achieve cost savings while enhancing the quality of care.
2. The Advisory Committee members have learned that 'contributing' towards large projects rather than funding in full streamlines the process and stretches the available dollars. They have also determined other sources of funding for some items and have requested that applicants apply first for those resources (e.g., At Home Program, Variety Club, and President's Choice).
3. The committee members recognized the importance of establishing maximums for some components such as flooring, bathrooms, and vans and ensuring that the items that are funded are generic or basic in nature rather than 'high end.'

4. The committee members commented on the importance of spending time on organizing policies and procedures. For example, the committee established a policy that renovations for younger children are expected to take place within the four walls of the existing premises, and grants are more modest in nature. Taking more time in the beginning to develop policies and terms of references and to prepare and implement a comprehensive communication plan are important future considerations.
5. The committee members identified the need to request that agencies submit financial statements with their applications so that the committee can determine financial need and utilize reserves where they exist.
6. Another important learning is the need to have support staff in place prior to reviewing applications to ensure that all required documentation is included in the applications, as well as confirm the applicant's eligibility before the review.
7. The committee members recognized the need for all future funding processes to retain the community-based decision-making process. Involving family members in decision making is crucial to success.

### Study Conclusions

In my research question, I had attempted to answer the research question: how to sustain supports and services for individuals with disabilities and their families, which had previously been provided by CLRF, however; it became more and more apparent that my research was taking me in a different direction. Through ongoing communications with families, listening to the compelling stories, completing the literature review, and reviewing the research stats that were sorted and analyzed, it was quite evident that much of the focus for the research was more directed towards “why it was important to sustain supports and services for individuals with

disabilities and their families as the CLRF had been expended?” My research findings continuously leaned towards validating the value and the positive impact that was made for the recipients and their families that had received funds through CLRF.

Study conclusions are a result of the review of literature on understanding and managing developmental disabilities, determining the supports required for individuals with disabilities and their families and examining service delivery models, with the research findings from the file reviews, family and stakeholder questionnaires and focus group. Three conclusions from the research study are outlined in the following pages. These conclusions include: 1) need for disability grants & individualized funding; 2) supports to improve the quality of life for individuals’ and families; and, 3) a community decision making model.

*1) Need for disability grants and individualized funding*

It became apparent in my analysis of the data from the file reviews, questionnaires and focus group research findings that all of the participants involved in this major project stated that the grants that individuals with disabilities and their families had received from the CLRF added value to their lives. Furthermore, there was an overall consensus on the need to continue similar types of funding; however, what could the funding process look like, and who could be responsible for disbursing them was not answered. The participants identified many advantages and a few disadvantages, but in all instances the message was consistent: there is a need to continue this type of funding so that families can continue to remain whole and their loved one’s quality of life can be enhanced. Throughout the study findings it was clear that individuals with disabilities and their families have been positively impacted by receiving a grant. As a result, some of them have a ‘new vision’ for the individual whom they are supporting. The fund has given families hope and kept them together. The major project findings concur with Salisbury &

Dawson (1999) & Torjman (1996) that families benefit from receiving disability grants and individualized funding supports, and appreciate and recognize the active role they are given in planning and choosing the supports they require for their family member. Additionally, all the family questionnaire respondents validated the positive impact the funding had on increasing the self-esteem and independence of the individual with disabilities. One of the project participants further emphasized the amount of physical and emotional stress that was alleviated by just making modest renovations in the home.

*2) Grants improve the quality of life for individuals with disabilities and their families*

Additionally, these individuals and their families could place no dollar value on the enhanced quality of life that they had achieved with their ability to gain independence, their increased mobility, and their ability to stay at home as a complete family unit. In some situations, individuals with disabilities gained increased confidence when having their own safe and reliable transportation which allowed them to integrate into and participate in the community.

The research indicated that providing grants for additional supports alleviates and reduces many of the stresses and burdens on parents/caregivers. Families are able to spend more quality time with their family members with disabilities, and fragile parents and grandparents are relieved of some of the stresses that heavy lifting and transporting cause. Bleasdale (2001) had explained that individualized funding is currently regarded as one way of advancing community living for people with disabilities beyond residential models. Bradley (1994) stated that the person-centered approach relies much less on the service system by organizing truly individualized, natural, and creative supports to achieve meaningful goals for families and individuals with disabilities. The study findings support these conclusions. Furthermore, the file

reviews confirmed the value added to the individuals and families that had been recipients of the funding. The funding allowed the family to remain whole and connected. One of the recipients stated that “the funding provided alternative support for an individual with significant needs” and another noted that the “funding reduced costs of services and supports, allowing for our son to continue living at home with us”.

### *3) A Community decision making model*

As indicated in the literature review in chapter two, individualized funding in Canada emerged in the mid 1970s in BC with the development of brokerage services as a response to the closure of the Woodlands Institution. With the research data gathered within the focus group and family questionnaires, it was evident that the CLRF as a community decision making model was one which was well received by families, individuals with disabilities, agencies and other involved stakeholders. One of the respondents stated that the application process empowered them to be self-advocates for the kinds of services that would best be suited for their daughter. It provided an opportunity to be involved in the decision making rather than being told that this is what they have to do.

As we continue to move into an era of greater choice and recognize the need for self-determination by people with disabilities, it becomes even more critical for government and community groups to explore ways to directly involve people with disabilities in all processes that impact their lives.

As noted in the literature review, in a consultation process by MCFD with more than 2,000 affected people and organizations showed broad support for a community-based governance as a system that will be more flexible, less costly, and more sustainable in the long term while giving people with disabilities more control over their own lives. Minister Hogg

(2002) emphasized in one of his speeches, “ Aside from affordability, our approach has often been characterized as disenfranchising and disempowering those who best know what services and supports are required to assist persons with disabilities to independence – their families, their care givers, and their communities” (¶3).

According to Salisbury (1998), “for the first time, the combination of money and independent planning provided a radically alternative framework for achieving citizenship” (p.5). He further noted that people could think entirely outside of the “disability box” to address their needs. One of the respondents from the family questionnaires concurred with Salisbury’s thinking, as he also felt that the grants provided an opportunity for their family to be creative in planning how to make the best of a situation.

This conclusion is further validated by a statement that was made in the CLRF Final Report by MCFD (2005) which states that “at the heart of this restructuring is the belief that individuals and families know best when it comes to what they need” (p.3). In order for the community decision model to be successful, it would need to at arms length from government and it would be critical to have family involvement at the governance level. According to Stainton (in press), since the 1970’s there has been a steadily growing focus in the disability movement on rights as the basis for supports and services. Stainton further explained that we began to see explicit protection for people with intellectual disabilities in a range of legal instruments. Examples of this included the inclusion of *mental disability* in Canadian Charter of Rights and Freedoms in 1982 and the Americans with Disabilities Act in 1990 (Stainton, 1994). The mentioned protection for people with disabilities further emphasizes the need and importance for individuals to have a right and be involved in the decision making for services they require. One of the focus group participants captured it well when they stated that “future

funding processes need to retain the community based decision making process. Involving family members in decision making is a crucial to success”.

Throughout the study findings it was clear that individuals with disabilities and their families have been positively impacted by receiving a grant. As a result, some of them have a ‘new vision’ for the individual whom they are supporting. The fund has given families hope and kept them together.

#### Scope and Limitations of the Research

Although I acknowledge the limitations of this research, they do not detract from the significance of the study. This research has provided insights into and deeper understanding of the impact of the CLRF on individuals with disabilities and their families, but I must note a few limitations regarding the methodology and the target populations.

The small sample sizes of both the questionnaire and the file review have limited generalization beyond this study’s population. Because there were 830 recipients of the CLRF grant, the random sampling of the file review was the only feasible way to obtain a sample; however, it may not have accurately reflected the population.

Because the focus group was comprised of an identified group of individuals responsible for disbursing the funds since the inception of the CLRF, there may have been some bias in the data that they provided.

In retrospect, I realize that the data that researchers obtain are driven by the questions that they ask. Some of the questions that I asked in this study did not capture the information that I sought and therefore did not optimize my potential to gather qualitative data.

Although limited by the size of the sample and the methodology that I used, the data that I gathered resulted in valuable insights into how the CLRF has benefited individuals with

disabilities and their families. It was evident throughout the study that the impact of the fund on grant recipients has been an enhanced quality of life for all concerned. These findings provide the basis for meaningful recommendations that I hope will assist future decision making on the need for similar types of funding for individuals with disabilities and their families.

## CHAPTER FIVE – RESEARCH IMPLICATIONS

### Introduction

My study is about exploring supports and services for individuals with disabilities and their families. The research question is, “How can supports and services for individuals with disabilities and their families, which had previously been provided by the Community Living Restructuring Fund, be sustained?” In the course of the research, it became clear that the question “what value the supports and services had on the individuals with disabilities and their families?” had also become key to the research. This chapter draws on findings related to both of these questions. This chapter contains three sections: (a) recommendations/options based on the study conclusions, (b) potential implications for any organization and stakeholders who continue to be part of the Community Living Movement, and (c) considerations for future research.

### Study Recommendations

In making recommendations based on the conclusions in chapter four, I have tried to focus on ways in which similar funding to the CLRF could continue to provide sustainable supports for individuals and families while keeping in mind the importance of ongoing enhancement of quality of life, increased mobility, increased independence, keeping families together, and cost reduction and efficiencies for the MCFD and CLBC in service delivery. The below options were derived from multiple sources which included key informants, literature reviews, and dialogue with families, file reviews, focus group discussions and analysis of completed questionnaires. My recommendations include the following options.

*Option 1: Flow-Through Funding*

Consider the option of flow-through funding, as Ward and Groom (2005b) suggested in the funding proposal that they submitted to Minister Hagen. Under this option MCFD and CLBC would commit to ongoing flow-through funding of \$10 million per year for the next three years to be utilized in the same manner as the CLRF had been. This fund would take into consideration the learnings from the previously expended CLRF funds and implement new policies and procedures to capture the learnings of the Trust Advisory Committee, the Victoria Foundation, and community recipients. Taking into account the new structure for CLBC, two primary field level roles have been created to carry out its work: facilitator and quality service analyst. To provide further synergy and interaction, the facilitators could include this fund in their planning with families and help them to draw up plans and budget requests. This support would further contribute to one of CLBC's (2005a) goals of "enabling individuals and families to access or develop more individually tailored supports and services" (p. 12). The facilitators could play a complementary role in ensuring that individuals and families develop well-rounded support plans and that the supports and services that they identify enhance their quality of life.

This option has the advantage of already having been tried and been successful; however, it depends on continued commitment of funding from MCFD/CLBC, and the long-term monitoring of grants that have been approved is not possible.

*Option 2: Permanent Endowment Fund*

Consider the establishment by the MCFD and CLBC of a long-term, permanent endowment fund to allow families to apply for assistance to keep their child or youth with developmental disabilities at home if they wish to do so. Ward and Groom (2005a) recommended a similar option in the funding proposal that they presented to Minister Hagen for

consideration to “establish a permanent endowment fund with a commitment to invest \$5 million per year for the next five years commencing April 2005” (p. 4). The ultimate solution to the problem of meeting the needs of individuals and families lies in creating a permanent endowment that would eventually become self-sustaining by accruing interest that would be used for grants and ensure access by all individuals in BC with developmental disabilities and their families. The scope of this permanent endowment fund could be extended for broader inclusion to cover all disabilities rather than just developmental disabilities. The fund could continue to be specifically targeted at aids, adaptations, renovations, safety issues, and transportation supports. The disadvantage of this option is that it would require a massive endowment to generate enough income to support the grant needs of individuals with various disabilities in BC. The advantage is that, once the fund reaches the required level to generate adequate funding, no further requests would need to be made to the MCFD or CLBC for grant dollars.

*Option 3: Community Living Foundation*

Explore a foundation funded by MCFD that would be independent of CLBC operations. This may be a way of securing a permanent fund to support families that would not be subject to cutbacks or overwhelmed by agency or system operations. A granting organization such as the CLRf could be set up via CLBC through its own foundation. The MCFD and CLBC could provide input on the criteria for funding, but they should have no authority over the funding process. The advantage of this option would be the savings in fees charged by outside organizations; however, the downside is that it would require developing a new organizational framework and staffing component. Another advantage would be the ability to monitor the use of funds that have been granted on a long-term basis.

*Option 4: Foundation with Government Matching Funds*

Create an independent organization or foundation similar to that discussed above that would solicit donations from the community that would be matched by the MCFD. Developing this fund outside of the government and CLBC would allow more flexibility for independent decision making, creativity, and the ability to seek funding externally. However, this recommendation may be a less desirable option because of the difficulty of obtaining donations in a competitive fundraising environment.

Finding a suitable place to 'house' the fund is essential. In the CLRF case, the Victoria Foundation as a community foundation ensured a process that was responsive to the needs of the Community Living sector. This might not be the case in all agencies, foundations or government offices. There appears to be more openness to building an endowment for Community Living in the community sector, as governments have not tended to work this way in the past, due to their year to year funding.

In terms of the scope of the fund, we need to consider what families have indicated. Agencies will always need support for infrastructure funding, upgrades, staffing and training. This level of funding has not been made available to families and most likely needs to be considered. Agencies have more access to the funding dollars, whereas; families have greater difficulty in accessing funding as sources are scarce and they are so involved in the care of their family members.

Whilst conducting the CLRF evaluation file reviews, many of the families had identified that there are no other sources of funding for housing, renovations, lifts/ramps etc. Mobility issues will always be existent. Although, there are some supports for this, families are always looking for sources of funding for wheelchairs, vans, tracking etc. Housing is a huge issue for

families as homes are not built with accessibility needs in mind. Housing and building prices are astronomical in this province and it is difficult to keep up with the rising costs.

In moving forward, the new funding focus has to be on families as is recommended in the September 23, 2005 CLRF Business Proposal, and that Service Providers in general would be excluded from the fund (p.3). A separate fund may need to be considered to support agencies.

MCFD and CLBC should use the experience gained from the CLRF as a seed to examine the importance of such a resource to families. Overall, what is important is that there be a fund available and that it be ongoing. This fund needs to provide families with the same opportunities as the CLRF provided. The fund can be part of the CLBC mandate as long as it is independently managed and is structurally separate from the operational money of CLBC.

#### Organizational Implications

According to Senge et al. (1999), “You can’t redesign your system by dividing it into parts; everyone must look at the whole together” (p. 91). To operate as whole, organizations, stakeholders, individuals with disabilities, and their families have to continue the art of dialogue.

Funding has been inadequate for many years now. In fact, in 1997 the BCACL wrote a brief to the government called “Hitting the Wall” that addressed the lengthy waitlists for 19-year-olds who needed support as they left school. Since then (2002), the adult CLS budget has been cut by 11%, which has only exacerbated the problem (L. Bryenton, personal communication, January 17, 2006).

There have been major cutbacks all around, and now the government is faced with the same situation as with Education and Health in which funding sources need to expand and move beyond government control alone. The sector needs to look at innovative ways of funding. CLRF provided a model of funding that is outside the traditional funding stream and that has proven to

be cost effective, with minimal bureaucracy. In a final CLRF report that Bearpark (2005) prepared for the Victoria Foundation, she stated that the Trust Advisory Committee has estimated the cost savings for the MCFD and CLBC from this one-time \$24 million fund at over \$10.7 million annually and that “these annual savings have been achieved through a combination of contract adjustments; the closure of Willow Clinic; and cost avoidance to the Ministry and CLBC from individuals not going into care” (p. 14).

In the same report, Bearpark (2005) wrote:

The Advisory Committee approved a total of \$24,131, 557.95 in grant funding through the CLRF. The largest percentage of grant funding was approved for individuals and their families (82%) to provide safer, accessible care for family members living with developmental disabilities. A total of \$19,730,656.26 was approved for individual and family grants. Agency grants accounted for \$4,120,608.59 or 17% of the CLRF funding and the remainder of grant funding assisted in the closure of Willow Clinic, the last residential institutional care setting in BC (1% or \$280,293.10). (p. 9)

To continue to achieve similar outcomes, there is a need to examine partnership funding with agencies, families, government, and donations from the private sectors, and, in this case, community foundations and to look toward long-term commitments.

There is a gap in ongoing monitoring and data management in Community Living. The system also needs to determine what is meant by “an acceptable standard or level of care.” There is a risk with larger group homes if professionals do not speak out, as one of the focus group participants cautioned. These ‘mini-institutions’ will be perpetuated if only cost-efficiency measures are considered. There is also a risk with young people being housed with the elderly in group homes or large institutions, which will be seen as a way to cut costs. We have moved away

from congregate care for good reasons. If economies of scale determine what happens, the quality of service provided to those who keep children and adults with developmental disabilities in their homes/group homes also needs to be monitored.

There continues to be a lack of knowledge about the numbers of people who need services and the levels of care that they require and a need for services to be monitored, and a lack of a realistic view of the costs (CLRF, 2005). The CLRF provided short-term solutions for those in need in the two-and-a-half years that it existed, and it did this at a reduced cost to government and service providers. The \$10.7 million annual savings for the MCFD and CLBC “on an investment of \$24 million . . . represents a payback period of 2.4 years” (Ward & Groom, 2005a, p. 1). It has been a cost-effective investment that has enhanced the quality of life of individual applicants, family members, and the agency staff who support them. According to the CLRF’s Business proposal (2005), the savings attributed to the closure of Willow Clinic was \$1.2 million annually: eight individuals relocated at an annual expense of approximately \$150,000 compared to \$300,000 per year at Willow.

Those who live with developmental disabilities in this province continue to face huge gaps in housing and transportation resources (CLRF, 2005). The CLRF has decreased the gap for those individuals whom it has funded; however, the fund became oversubscribed, and not all requests could be approved. The Trust Advisory Committee also moved towards approving partial contributions rather than full funding to stretch finite dollars and ensure greater access to the fund.

According to one of the members of the focus group, “There appears to be difficulty in communication between MCFD and families that are part of the Community Living sector.

Communication is at a bureaucratic level and hence often problematic.” In contrast, this fund was ‘hands on’ and supported families through direct communication at a time of real need.

Another participant in the study criticized, “Governments seem quick to want to avoid areas of potential conflict and less interested in what is working well and hearing success stories.” Nevertheless, the government should be commended for taking a proactive, preventative approach in establishing the CLRF and must be encouraged to continue. Systems of monitoring and planning are often geared to cost savings alone, and there will need to be a way of measuring and evaluating enhancements in quality of life and keeping families whole.

The CLRF has been a unique model of partnership and relationship building because it worked on building trust between individuals who live with disabilities in this province, their families, and the agencies that provide care. With innovative, community-based approaches such as the CLRF, there is great potential to continue to meet the unique community living needs in this province in a humane and cost-effective way.

#### Future Research

In conducting this research, I was confident that the qualitative approach to this inquiry was the best approach because it is suited to inquiries into areas where there is not a great deal of established information on a topic or area (Palys, 2003). When I started this research, I had the impression that there would be volumes of information on the Community Living Movement, only to discover that there was very little organized inquiry that examined the approximately 50 years of Community Living’s existence.

Future research is needed to track the number of individuals in care, the number coming into care, and the supports that are needed by age and diagnosis. CLBC may need to continue to research, to monitor and track data, and to identify ways of measuring outcomes. Cost savings

are not the only measure of success in terms of care; such areas as the impact of a diagnosis on family stability, financial hardship, and sibling outcomes also need to be considered (CLRF, 2005).

Future research could also include a government examination of why funding is available for foster family and agency support, but not for family members who wish to care for their loved ones at home. Families often extend care beyond their own limits and either injure themselves or completely burn out.

Conducting a long-term assessment of the fund would prove interesting. The results might show that it will not only have a short-term impact on the quality of life for the individuals served and their families, but also both short-term and long-term financial benefits to the individuals, their families, and the system, which is indicated in the statistics that I have cited in this study in terms of the cost savings to the MCFD and CLBC.

Although the vast majority of the CLRF grants were to individuals with developmental disabilities, as that was an eligibility criterion, it might be of value to further inquire whether the fund primarily supported those with both physical and developmental disabilities rather than those with developmental disabilities. Additionally, further inquiry as to whether the agencies need to support a broader population in the future would be useful to explore.

Future research could also include a different, broader sample group of participants, which would require fine-tuning the methodology. It would be interesting to obtain data from a more diverse group of people and perhaps to conduct quantitative research based on real dialogue with families on what the alternative would have been for them if the fund had not been available to assist them.

## CHAPTER SIX – LESSONS LEARNED

## Research Project Lessons Learned

The final chapter provides personal insights into my research experience. My journey was filled with many new discoveries and learning experiences. I realized throughout the process that I needed to address and resolve challenges, but that there were as many opportunities for personal growth. The following comments are the personal reflections that I want to share with future researchers and an outline of some of the challenges that those who will be embarking on a similar journey might face.

My learning regarding leadership in terms of this project was interesting. I became more aware that leadership is not a strategy or approach; rather, leadership is very much about how we are with ourselves and how we interact with others. O'Toole (1995) maintained:

One's creativity depends on interaction with others one trusts, others who feel trusted.

For one to be unfettered in risking creative interaction with another, that other must know the trust of openness, objectivity, and a complementary creative spirit. Trust is power.

(p. 56)

It was important for me throughout the project to create an environment in which there was trust, openness, and the opportunity to dialogue and give and receive constructive feedback. Without trust, there is no leadership of ourselves or others. Through ongoing integration of my leadership experiences, I was able to build trusting relationships and create open relationships with everyone involved.

This project was an exercise in community-based action research. Stringer (1999) described it as a process that “enables people (a) to investigate systematically their problems and

issues, (b) to formulate powerful and sophisticated accounts of their situations, and (c) to devise plans to deal with the problems at hand” (p. 17). It was evident throughout the research process that action research is an ongoing, interacting spiral of activities that involves a “look, think, act” (p. 19) process.

As with any major undertaking, reflective thinking allows consideration of the ways in which the research process could have been conducted differently. I offer some of the lessons that I learned through conducting this study:

1. Allow others to help. Asking for assistance initially was difficult; however, I learned very quickly in the early stages the importance of seeking support and the value that seeking continual feedback, sharing resources, and using ‘subject experts’ to provide background and historical context added to my project. The support and information that I received from my project sponsor, the Victoria Foundation Community trust coordinator, the CLRF Advisory Committee, pioneer members of the Community Living Coalition, and the executive director of the BCACL were extremely beneficial. Had I not approached them, I would not have done justice to my project. Additionally, continually use your faculty supervisor as a source of support. Whenever in doubt, ask questions for clarification or direction.
2. Have a support network. Initially, I felt a little lonely in my exploration of my topic. Although people were interested in our brief conversations, I did not have a solid network of individuals around me in the initial stage. Midstream, I became aware of the isolated feeling and realized the need to reach out and create the supports that I would need. Having a support network that included fellow cohorts’ members, family and friends, my project sponsor, and my faculty supervisor helped me to stay focused

- and motivated throughout the various stages of the project. In fact, this network provided a means for additional dialogue and healthy discussions in terms of where I was with my project. The support network also allowed me to validate concerns, share anxieties, and seek guidance from fellow cohort members who were also feeling similar uncertainties.
3. **Back up your data.** Regardless of how confident or busy you are, always back up your data. I intended to back up my data at some point, but the importance of doing so regularly soon became very clear to me when I accidentally deleted my draft proposal prior to starting the second residency. It took an enormous effort to compile the information again. The hard copies of each section that I have kept in my files have assisted me tremendously. Thereafter, I made it a regular practice to back up all of my data, communications, references, and pertinent information.
  4. **Complete a literature review.** During the second residency at Royal Roads, we were advised to complete our literature reviews before we left campus. However, I had completed some of it prior to starting the residency and decided to leave the rest until I returned home, and it took me a very long time to be able to concentrate on finishing the review. My advice is to take advantage of the focused time available during the second residency and complete the literature review so that when you return, you can begin working on your ethical review documents and other preparations prior to beginning your actual research.
  5. **Recognize the importance of blocked writing time.** It is important to let your family know that you will be needing blocks of time to work on your writing. If you have certain responsibilities, it is important early on to delegate or recruit support as it can

- become very easy to get caught up in other activities rather than focus on your writing. My suggestion is to schedule about three hours each day for two to three days a week to focus on the writing. It is extremely important not to have any distractions during this time.
6. Concentrate on the data-gathering process. It was very interesting to note that the data that I gathered from the questionnaires, focus group, and file review were aligned with what I had expected. However, in hindsight, I should have asked a couple of the questions differently to make them less open ended. Some of the key informants felt that because of the questions' open-endedness, they had difficulty in responding; hence, they kept their responses brief. I did not receive as extensive responses as I had hoped I would. In preparing questions or surveys, it is important to be cognizant of feedback to optimize the responses that might be gathered from the questionnaires.
  7. Be open to new learnings and challenges. In various stages of the research project I felt self-doubt in terms of my ability to complete what was required of me. I realized that only by accepting the challenges at hand would I be able to overcome them, acquire new skill sets, and gain more self-confidence in my ability to tackle new areas. For example, I had never done a spreadsheet analysis from a file review before and was extremely intimidated in terms of how to even begin. However, in reaching out and asking for support, I realized that all that was required was a genuine interest in wanting to learn a new skill. In the same manner, I realized that over time my writing skills were sharpening up as a result of the ongoing communication with and constructive feedback from my project sponsor and faculty supervisor, and I began to write the final chapters of my project more concisely and clearly. I also valued the

technical learning that provided me with additional skills that will be transferable to other projects and research on which I might embark in the future. Being able to acquire and enhance my skills in research, increase my technical learning, and improve my writing had an enormous positive impact on my self-confidence and the overall research process.

I learned a great deal about my major project topic, my fellow cohort members, my family, and myself. During the research process, the project also provided a formal, systematic evaluation of the supports and services that individuals with disabilities and their families value most.

This project dealt with a topic about which I am very passionate and genuinely wanted to learn more about. I believe that conducting the research was a journey towards continued personal and professional growth in terms of understanding the needs and challenges of those with developmental disabilities, and it is my hope that this project will further validate the ongoing need for supports for these individuals and their families.

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## APPENDIX A – CONSENT FORM

Options to Continue Supports and Services for Individuals with  
Developmental Disabilities and Their Families  
Research Project

The purpose of this action based research study is to explore options and possible ways to continue supporting individuals with developmental disabilities and their families as the Community Living Restructuring Fund has been expended. Additionally, this research will identify the supports and services which individuals and families valued the most. The participation in this study is voluntary. The methods used in the project include questionnaires, interviews, a file review, and a focus group. The findings will be used to provide options and recommendations for future supports and services for individuals and families, as well as a tool for further dialogue and advocacy.

I am conducting this study in partial fulfillment for a degree in Master of Arts in Leadership and Training from Royal Roads University. The information gathered will be summarized and reported to both the University and CLRF. The final report will be housed at Royal Roads University and will be publicly accessible.

I, \_\_\_\_\_, agree to participate in a research project exploring the options available to individuals and families. I agree to be interviewed by Shairose Jinnah under the following conditions:

1. I have the right to withdraw from any activity in this project at any time. If I choose to do so, the information I provide will be returned to me and not used in the project.
2. I agree to an initial interview of approximately 45 minutes in duration. The interview will be facilitated by Shairose Jinnah.
3. I understand that the interview will be audio recorded and may be transcribed to verify any disputed action resulting from the interview. I also understand that the information will not be shared with anyone besides the research team.
4. The digital recording will be erased following completion of the final report. Other data gathered will be retained in a secure, confidential location until one year after convocation.
5. I understand that my identity will be kept confidential and will not be revealed in the project report.
6. The researcher will endeavour to ensure that no harm will come to me through my participation in this project. No deception will be used in this study.

I agree to these conditions:

Signed \_\_\_\_\_ Date \_\_\_\_\_

Researcher

Signed \_\_\_\_\_ Date \_\_\_\_\_

For further information regarding the purpose and methods of this project, feel free to contact:

Shairose Jinnah, Researcher

Tim Stainton, PhD, Project Supervisor

## APPENDIX B – FAMILY RECIPIENTS’ QUESTIONNAIRE

“Supports and Services for Individuals With Disabilities and Their Families”

The purpose of this action based research study is to explore options and possible ways to continue supporting individuals with developmental disabilities and their families, as the Community Living Restructuring Fund (CLRF) has been expended.

The following are questions on the CLRF funds. The findings will be used to provide options and recommendations for future supports and services for individuals with disabilities and their families, as well as be a tool for further dialogue and advocacy.

- a) What did you value about the CLRF fund?
- b) What specific results did you achieve from your project, renovation or purchase?
- c) What impact did the grant have on your family and available resources?
- d) Can you describe some examples of the direct or indirect impact of the funding?
- e) What specific results did you achieve from your project, renovation or purchase?
- f) How did you find the process of applying for CLRF? Are there areas that you think could have been improved?
- g) Do you think this type of support should be available in the future? Do you have any thoughts on how it might be best delivered?
- h) Any final thoughts/comments?

APPENDIX C – MAJOR PROJECT QUESTIONNAIRE  
(KEY INFORMANT STAKEHOLDERS)

“Supports and Services for Individuals With Disabilities and Their Families”

The purpose of this action based research study is to explore options and possible ways to continue to provide the supports previously provided by Community Living Restructuring Fund (CLRF) to individuals with developmental disabilities and their families.

The following questions are on the CLRF funds. The findings will be used to provide options and recommendations for future supports and services for individuals with disabilities and their families, as well as be a tool for further dialogue and advocacy.

- a) What major outcomes were achieved through this fund?
- b) What are the risks to individuals with developmental disabilities and their families upon the depletion of this type of fund?
- c) Do you think there is a need for a service like the CLRF? If so, how best might the services and supports provided by CLRF be met now that the CLRF funds have been expended?
- d) Do you have any suggestions regarding ongoing options for those living with developmental disabilities in BC?
- e) What are some advantages and disadvantages of this type of structure/funding?
- f) Any final thoughts/comments?