

**ACCESS TO RESPITE CARE FOR PARENTS WHO HAVE
CHILDREN WITH DISABILITIES IN B.C.**

by

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Bachelor of Arts, University of British Columbia, 2006

PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF PUBLIC POLICY

In the
Faculty
of
Arts and Social Sciences

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SIMON FRASER UNIVERSITY

Spring 2009

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Abstract

This study uses quantitative and qualitative methods to examine publicly funded respite care for parents who have children with disabilities in British Columbia and the current barriers to accessing this service. A survey was distributed to parents of such children to determine their attitudes towards respite care and the barriers they encounter. This survey data is supplemented by case studies of the respite care systems in Alberta and Manitoba. Analysis of these materials reveals that parents value publicly funded respite care highly and that significant barriers exist to accessing it. The policy alternatives developed through analysis of the data are elimination of the wait list, elimination of the cost to the user, revised eligibility criteria, and improving access to respite care workers. The study assesses the combinations of policies that should be implemented to improve access to respite care effectively and feasibly.

Executive Summary

This study explores options to improve access to respite care for parents who have children with disabilities in B.C. Using a policy analysis approach, it proposes alternatives designed to reduce barriers to accessing the existing publicly funded service. Both quantitative and qualitative methods are used. Data from a survey of 118 parents throughout the province who have children with disabilities are analyzed using descriptive statistics and cross-tabulations. The data reveal that parents benefit greatly from publicly funded respite care and that a number of barriers arise in accessing this service. The main barriers include:

- Long wait lists and a lack of communication of wait list times
- A shortage of respite care workers qualified to deal with the complex needs of children with disabilities
- Eligibility criteria that exclude many who would benefit from respite care

This data as well as research literature and case studies from Alberta and Manitoba are used to identify policy alternatives that could reduce the barriers to accessing respite care. The proposed policy options are:

- Elimination of the wait lists
- Elimination of the cost to users
- Revised eligibility criteria
- Improving access to respite care workers

Revision of the eligibility criteria is found to most effectively improve access in the most efficient way. However, these alternatives are not mutually exclusive and two or more can be implemented simultaneously to most effectively reduce the barriers to accessing respite care. Although implementing all of them would be most effective, this is not realistic from a budgetary and administrative perspective. Therefore, two combinations of alternatives are proposed that would still effectively reduce many of the barriers but are more feasible. These are:

1. Elimination of the wait lists, revised eligibility criteria, and improving access to respite care workers.
2. Elimination of the wait list and revised eligibility criteria.

All of the proposed policy alternatives are costly in terms of both money and administrative resources. However, they are essential in order to reduce the barriers to accessing respite care and to ensure that children with disabilities enjoy the citizenship rights to which they are entitled. Further research should focus on how the budget should be allocated among the different regions in the province.

Dedication

To my parents

Acknowledgements

Firstly, I would like to thank Dr. Jon Kesselman for his guidance, direction, and insight throughout the capstone process. Thank you also to Dr. Nancy Olewiler for her thoughtful and challenging questions during my defense which helped me to strengthen and improve my research.

This research would not have been possible without the Family Support Institute and the BC Association for Community Living who distributed my survey as well as the many families who took the time to complete the survey. Also, thanks to the parents and advocacy group members who discussed my research with me and provided helpful suggestions.

I would also like to acknowledge all of my MPP classmates for making the last two years a wonderful experience. A special thank you to Katharine for spending many long hours at the library with me over the past year.

Lastly, thank you to my family and friends for their endless support and encouragement.

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Glossary

AHP	At-Home Program
ASD	Autism Spectrum Disorder
BCACL	British Columbia Association for Community Living
CLBC	Community Living British Columbia.
FSCD	Family Support for Children with Disabilities
FSI	Family Support Institute
ICF	The World Health Organization's International Classification of Functioning, Disability and Health
MCFD	Ministry of Children and Family Development
PALS	Participation and Activity Limitation Survey (conducted by Statistics Canada)
RCYBC	Representative for Children and Youth, British Columbia. An independent office of the B.C. Legislature whose responsibilities include advocating for vulnerable children and youth.

1: Introduction

Traditionally, children with disabilities were often hidden from view, removed from their families and communities, and housed in institutions. The past generation has seen a shift toward keeping children with disabilities at home with their parents and families in communities across Canada. This is partly due to the view of disablement shifting from a deficit model, which defines disability as a problem needing to be corrected, to one that sees people with disabilities as a vital part of the Canadian social fabric (Valentine, 2001). This approach was entrenched in the *Canadian Charter of Rights and Freedoms* in 1985 with the guarantees of equality for persons with mental and physical disabilities.

The Government of Canada made further gains in ensuring full citizenship rights for children with disabilities in 1991 when it signed the *United Nations Convention on the Rights of the Child* (Valentine, 2001). It recognizes their right to equality, special care such as family support, and services such as health care and rehabilitation (Hanvey, 2002). The Convention acknowledges the extra assistance and differential treatment required by children with disabilities compared to their non-disabled peers, and it states that they should have effective access to the supports necessary to reach their full potential. This also applies to the citizenship rights of the parents of children with disabilities (Valentine, 2001).

Along with the shift in society's view of people with disabilities, policy perspectives in Canada have moved toward making communities more inclusive for people of all abilities. The Representative for Children and Youth, British Columbia (RCYBC) noted that a measure of a strong society is the support it provides to vulnerable children and that equal opportunities should be available for children with special needs and their families (RCYBC, 2008a). While disability issues were once recognized as only matters of social security, health, welfare, and guardianship, they are increasingly being recognized as human rights issues (Degener, 2003). However, despite these advances, many children with disabilities and their families continue to experience less than full civil and social rights and do not receive the level of support required. The Canadian Coalition for the Rights of Children noted that the supports and services necessary to ensure the Convention rights of children with disabilities are often viewed as privileges, rather than the entitlements that they are. Furthermore, these supports vary depending on where in Canada the child lives, and programs are reduced during times of fiscal restraint (Hanvey, 2001). Full

citizenship exists when the rights and responsibilities outlined in the legal instruments that Canada has committed to are fully realizable; this can be helped or hindered by public policies and programs. While access to support is available, recent research indicates that it is frequently under-resourced and delivered through a complex and uneven set of service delivery frameworks (Valentine, 2001).

The shift from institutional to home care of disabled children has also put new pressures on their families. This affects the health and well-being of families and leads to stress and exhaustion. Evidence shows that parents of children with disabilities value them highly, and many describe their experiences caring for them as rewarding and satisfying. They tend to blame their stress and fatigue not on their children, but rather on lack of support. Families consistently report needing more support via respite care, which is short-term, temporary relief from caregiving. Research literature supports the importance of respite in promoting the well-being of families (Hanvey, 2002). Furthermore, evidence indicates that respite care has effects on the improvement of parental distress equivalent to other more expensive and time-consuming services (Mullins et al., 2002). However, access to respite remains difficult, particularly for children who have complex health issues or behavioural disabilities (Hanvey, 2002).

The policy problem examined in this study is that access to respite care for parents of children with disabilities in British Columbia is insufficient and as a result the children have less than full citizenship rights. In B.C., as in some other Canadian provinces, many parents are unable to access respite care due to various factors. I investigate the specific barriers to respite care and examine ways in which access can be improved. My research methods include a survey distributed among parents with disabled children to gain information on barriers to respite care and a comparison of B.C. provisions for respite care with those in other provinces.

The study is organized into eight sections. Section 2 presents a literature review on the effects of caring for a disabled child on families and the role that respite care plays in alleviating these effects, as well as background on respite care in British Columbia and elsewhere in Canada. Section 3 describes the methodology and data used for the study, while section 4 presents results and analysis of the data. Section 5 describes the proposed policy alternatives, section 6 describes the criteria used to evaluate the policy alternatives, and section 7 presents an evaluation of the alternatives based on each criterion and policy recommendations. Section 8 concludes the study.

2: Background

2.1 Children with Disabilities in Canada

2.1.1 Definition of Disability

Disability is a complex concept with no consistent, universally agreed definition. It is a multi-dimensional phenomenon that has been viewed from numerous perspectives (Human Resources Development Canada, 2003). However, in 2001 the World Health Organization launched its International Classification of Functioning, Disability and Health (ICF), which provides the following comprehensive definition:

‘Disabilities’ is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (World Health Organization, 2001, 3).

Statistics Canada uses the ICF as its framework in its 2001 post-censal disability survey and views disability as “the interrelationship between body functions, activities and social participation, while recognizing the role of the environment as providing barriers or facilitators” (Statistics Canada, 2002). These definitions take into account the social aspects of disability and do not view it simply as a medical or biological dysfunction. The following are some examples of both physical and psychological disabilities:

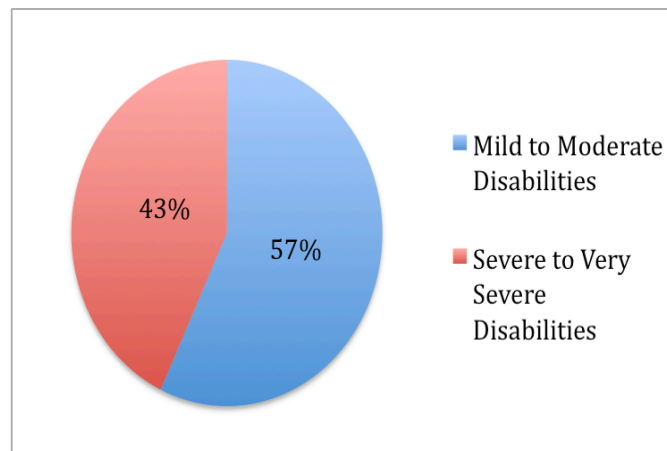
- Cerebral palsy
- Autism spectrum disorder
- Down syndrome
- Fragile X syndrome
- Fetal alcohol spectrum disorder
- Spina bifida
- Dissociative disorders

2.1.2 Characteristics of Children with Disabilities

Despite the fact that children with disabilities are increasingly having their needs addressed, little comprehensive data exists on them. Nevertheless, some data exists that helps to provide a general understanding. According to the *National Population Health Survey* (NPHS), about 565,000 children and youth aged 19 years and under have a disability or an activity

limitation; this is 7.7 percent of all children in Canada (Valentine, 2001, 15). The Roeher Institute (2000b) compiled data on children with disabilities and highlighted the diverse nature and severity of disabilities. It concluded that between 5 and 20 percent of Canadian families have children with disabilities and that of this 5 to 20 percent, around 15 percent have a moderate or severe level of disability. Other data from the Statistics Canada Participation and Activity Limitation Survey (PALS) indicates that about 155,000 children between five and 14 years old had activity limitations in 2001; this is about 4 percent of all children in this age group. Figure 1 displays the distribution of this 4 percent by severity of disability (Statistics Canada, 2001, 6). The government of B.C. has identified that about 5.65 percent of the province's children and youth, or about 52,000 individuals, have significant special needs (RCYBC, 2008c).

Figure 1: Distribution of Children with Disabilities by Severity



Source: Statistics Canada, Participation and Activity Limitation Survey, 2001

Although very little data on characteristics of children with disabilities exist, it can be deduced that they are as racially and culturally diverse as all other children. Data indicate that 7.5 percent of children speak neither French nor English as a first language and 5 percent were born in another country (Valentine, 2001, 17). The 2006 Canadian census also indicates that the population of Canada, and B.C. in particular, is becoming increasingly multicultural and diverse. Its data indicates that 27.5 percent of the B.C. population are immigrants, compared to 26 percent in the 2001 census and 19.5 percent of Canada in 2006 (Ministry of Children and Family Development, 2008, 11). This point highlights the need to design culturally appropriate and accessible services for these children with special needs (RCYBC, 2008b).

Twenty-two percent of Aboriginal youth are reported to have a disability, which is three times higher than non-Aboriginal youth (Hanvey, 2002, 6). However, the data on First Nations

children with disabilities is limited, since First Nations people consist of numerous groups with diverse values, customs, and beliefs. This has resulted in differing definitions of disability within First Nations communities, which affects data collection and interpretation (Prince, 2001). The federal government is responsible for providing services to Inuit peoples and First Nations peoples who are status Indians living on reserve, and provincial governments have responsibility for non-status Indians and Metis peoples. Thus, jurisdictional disputes arise due to whether someone is granted “status” according to federal law (Valentine, 2001). In B.C. in particular, services for children with disabilities are not accessible in many First Nations communities, and confusion arises over who has the obligation to deliver services on reserve (RCYBC, 2008c). In addition, a higher disability incidence rate, discrimination, and issues of remote geographic isolation result in a lack of access to services for First Nations people with disabilities compared to non-First Nations people (Valentine, 2001).

2.2 Effects of Caring for Children with Disabilities

2.2.1 Effects on Health and Well-Being

Evidence shows that caring for a child with a chronic disability can be extremely stressful and places an increased burden on the family. Bouma and Schweitzer (1990) conducted a study to better understand the burden associated with the care of a chronically ill child. Their sample consisted of mothers of children aged 5 to 12 years with cystic fibrosis (a primarily physical disorder with a short life expectancy), those with children with autism (a primary psychological disorder with a high life expectancy), and a control group. The authors hypothesized that each clinical group would report greater overall stress than the control group and that a chronic psychological disorder contributes more to family stress than a chronic physical illness; the results confirmed both of these hypotheses. The authors note that this does not suggest that children with psychological disorders are more entitled to help than those with physical disorders. Rather, it highlights the need for family-based intervention programs customized to suit the nature of the child’s disorder.

Hastings et al. (2005) expanded the research on the effects of children with disabilities on their parents by examining not only the child as a source of stress and other family members’ well-being as the outcome, but also the possibility that family members affect one another. Specifically, they explore the notion that parental well-being may be a function of a child with autism as well as the mental health of their spouse. The researchers found the typical gender differences in mental health with mothers reporting more problems than fathers. They also found

that while maternal stress was affected by both their child's behaviour problems and their partner's depression, paternal stress was positively predicted only by their partner's depression. They note that this finding may be due to the fact that mothers typically report increased involvement in the care of their child with autism and that fathers tend to use different coping strategies for their child's behaviour problems.

Burton et al. (2008) examined whether the health status of married and lone mothers is affected by parenting a child with a disability or chronic condition. They found that for both married and lone mothers, overall health status in 2000 was lower for mothers of a child with a disability or chronic condition. Health status for all mothers was lower in 2000 than in 1994, but the health status fell more for mothers of a child with a health problem. Furthermore, the health status of lone mothers was lower than that of married mothers. The authors conclude that from a policy perspective, these results highlight the importance of providing supports to mothers of children with disabilities in order to help them maintain quality of life. This is important not only for the mothers, but may also be essential for the children who require their care.

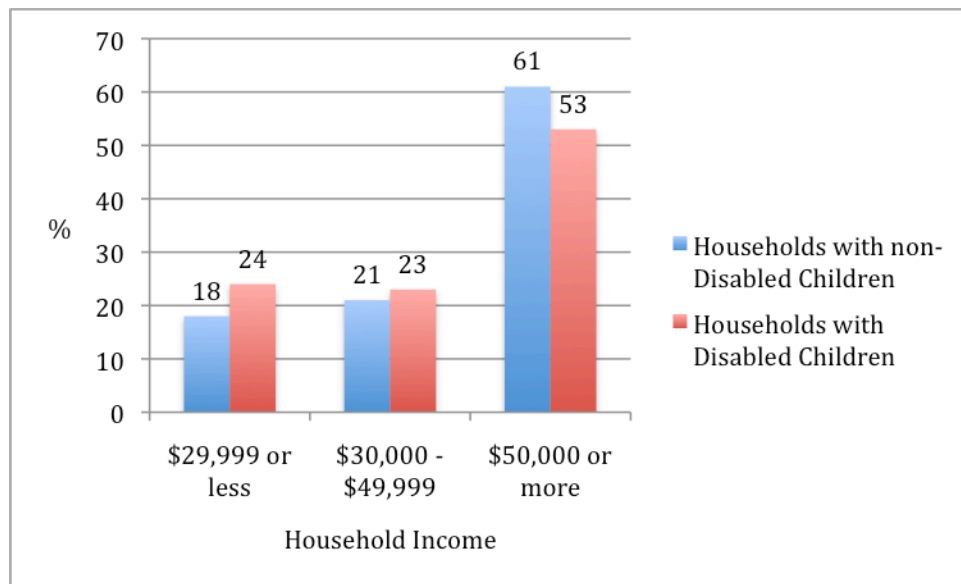
2.2.2 Effects on Income and Employment

Research has also been conducted on the effects of having a child with a disability on parental employment. Shearn and Todd (2000) examined the attitudes towards and salience of employment for mothers of children with intellectual disabilities and how support is used to combine the roles of mother and worker. They conducted qualitative interviews with mothers of children with intellectual disabilities. The researchers found that employment was highly valued for financial reasons, autonomy, adult conversation, a chance to use skills and abilities, and release from the pressures of caring for their child. Mothers of children with disabilities are greatly under-represented in the workforce compared to mothers in general; the majority of women in the study did not work, and those that did often worked for only a few hours a day in low-paid, low-skilled jobs. Work was found to be an aspiration for many, and absence from the workplace was not through choice, but an outcome of lack of support. Furthermore, the stress of caring for a child with a disability was found to derive from care-giving tasks and also from the inability to take part in other important life domains such as employment (Shearn and Todd, 2000).

Evidence also indicates that children with disabilities in Canada are more likely to be poor than other children. Twenty-nine percent of children with disabilities live in families where the total income is in the lower-middle and lowest income quintiles, in comparison to only 17 percent of children without disabilities. Also, almost 17 percent of children with disabilities live

in families who depend on government income support, in comparison with about 8 percent of non-disabled children (Roeher Institute, 2000b). Furthermore, as shown in Figure 2, the data find that households with disabled children are more likely than those with non-disabled children (24 versus 18 percent) to have an income below \$30,000. Households with disabled children are less likely than those with non-disabled children (53 and 61 percent respectively) to be earning \$50,000 or more (Statistics Canada, 2001, 11).

Figure 2: Percentage of Households with Disabled and Non-Disabled Children Across Income Groups



Source: Statistics Canada, Participation and Activity Limitation Survey, 2001

Researchers believe that poverty leads to disability and also that disability leads to poverty. People living in poverty may live in circumstances that increase the risk of injury and may have less access to health services. Disability may lead to poverty since parents of children with disabilities face barriers to labour force participation and face additional financial costs, such as special transportation, medication, and home adaptations (Hanvey, 2002).

Among children aged 6 to 11 in two-parent families, 35 percent of those with special needs had both parents working in comparison to 46 percent of those with no special needs (Hanvey, 2002, 10). Data from the PALS shows that 54 percent of parents of children with disabilities reported that their child's condition affected their family's employment situation (see Table 1). Among parents with children with severe to very severe disabilities, this percentage increased to 73 percent. Various impacts were reported, including working fewer hours, quitting

working, and turning down a promotion or better job. In 71 percent of all cases, mothers experienced an impact on employment; in 14 percent of cases, both mother and father experienced impacts; while in 11 percent of cases fathers alone experienced an impact (Statistics Canada, 2001, 9). These impacts on employment result in reduced income as well as stress and isolation (Irwin and Lero, 1997). Very little research exists on single parents of children with disabilities; however, it is expected that they experience even greater challenges with workforce participation than two-parent families (Hanvey, 2002).

Table 1: Impact of Child's Disability on Family's Employment Situation

	Total	Mild to Moderate Disability	Severe Disability
<i>Children with Disabilities (5 to 14 years)</i>	154,720 (100%)	88,690 (100%)	66,030 (100%)
Children with families whose employment situation has been affected	83,720 (54.1%)	35,800 (40.4%)	47,920 (72.6%)
<i>Impacts on Employment Situation*:</i>			
Worked fewer hours	51,940 (33.6%)	21,130 (23.8%)	30,800 (46.6%)
Changed work hours	48,840 (31.6%)	19,900 (22.4%)	28,890 (43.9%)
Not taken a job in order to care for the child	42,980 (27.8%)	15,180 (17.1%)	27,800 (42.1%)
Quit Working	29,830 (19.3%)	10,120 (11.4%)	19,710 (29.9%)
Turned down a promotion or a better job	26,380 (17.1%)	9,190 (10.4%)	17,180 (26.0%)

** Respondents could choose more than one response*

Source: Statistics Canada, Participation and Activity Limitation Survey, 2001

2.2.3 Need for Assistance

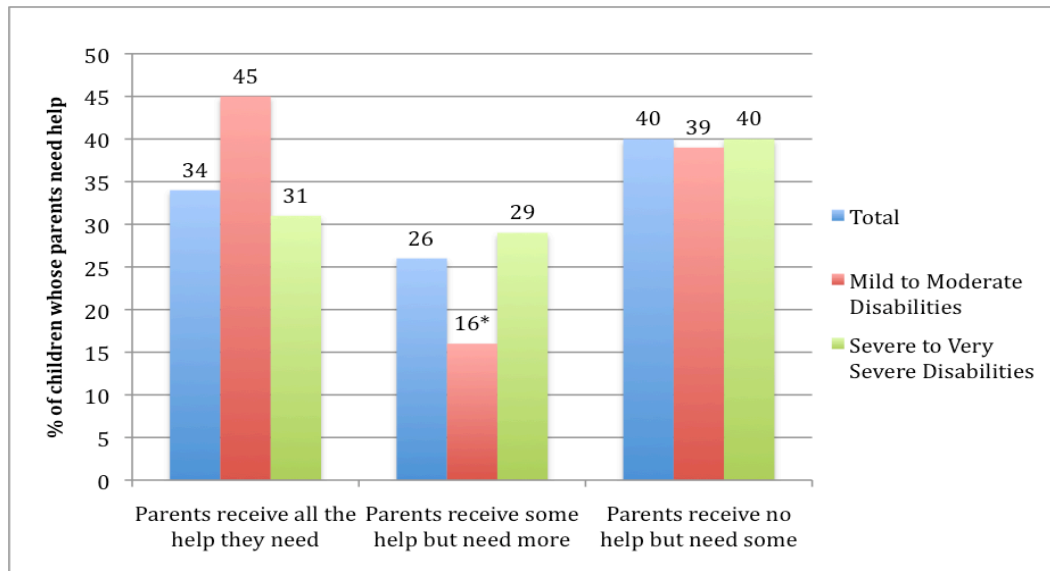
Of the 155,000 children aged five to 14 with disabilities in 2001, about 35,000 (23 percent) required help with daily activities, most of which was required for personal care as opposed to moving within the home. Sixty-two percent of children who required help with personal care received most of the help from their mother, 30 percent received it from both mother and father, and only 3 percent received help primarily from the father (Statistics Canada, 2001, 7). Parents with children with disabilities must also often play numerous roles such as nurses, case managers, advocates, and educators. As a result many of them, especially mothers, are stressed out and exhausted; this affects their health and well-being (Hanvey, 2002). One report found that parents with disabled children spend an average of 50 to 60 hours a week on

personal care, advocacy, and coordination of services for their child in addition to domestic responsibilities and paid work (Roehrer Institute, 2000a, 12). Furthermore, this rigorous caretaking usually does not lessen as the children continue into their teens and young adulthood.

In some cases, the stress of multiple roles and lack of adequate support has serious negative consequences on families. For example, some parents are forced to place their child in institutional or foster care due to insufficient support; this poses distress to the families as well as a great cost to society. One survey of parents of children with disabilities found that half of them named denial of respite and child care services as responsible for out-of-home placement (Roehrer, 2000b). Another report found that foster parents of children with disabilities tend to receive better financial support from the government than do natural families (Hanvey, 2002).

Data also highlights the importance of outside help for parents of children with disabilities. Of the 155,000 children aged five to 14 with disabilities, 52,000 had parents who required help with housework, family responsibilities, and time off for personal activities because of their child's condition, while parents of 31,000 reported receiving this help. Of these 31,000, 44 percent received help from family members not living with them, 28 percent from family members who did live with them, and 27 percent from friends or neighbours (Statistics Canada, 2001, 8). Also, about 44 percent received help from government organizations or agencies; these were more likely to be parents of children with severe to very severe disabilities. As shown in Figure 3, one third reported receiving all the help they needed, 26 percent received help but needed more, and 40 percent received no help but needed some. Of those with children with severe to very severe disabilities, only 31 percent got all the help they needed (Statistics Canada, 2001, 8).

Figure 3: Unmet Needs for Help with Housework, Family Responsibilities, and Time Off for Personal Activities



**Use with Caution*

Source: Statistics Canada, Participation and Activity Limitation Survey, 2001

Other data from PALS indicates that cost is preventing parents from getting help; of the 34,000 parents who reported unmet needs, 71 percent reported cost as a reason. Sixty-two percent said that help from family and friends was not available, 42 percent said services and special programs were not available at the local level, and 36 percent said they did not know where to look for help (Statistics Canada, 2001, 9).

A survey was also conducted among community-based agencies providing services for children and youth with special needs. The vast majority (76 percent) reported barriers that prevented this population from accessing their services. The most common barriers identified were lack of availability of trained staff and financial barriers (including the families' inability to pay for services and the inadequacy of funding available to the agencies). A large percentage (43 percent) also indicated that their unmet needs had increased in the five years prior to the survey (Hanvey, 2001, 46).

These findings suggest that both children with disabilities and their parents often require access to various services in order for them to enjoy full citizenship rights. Differential support is needed due to the high incidence of stress, negative impacts on income and employment, and necessity for assistance in a variety of daily activities. The following section provides evidence for how respite care can help to alleviate these effects.

2.3 Benefits of Respite Care

Research finds that respite care can significantly reduce the stress placed on families with disabled children. Sherman (1995) conducted a study to assess the effectiveness of home-based respite in terms of its impact on families. Families with disabled children ranging in age from infancy to 19 years completed interviews prior to the receipt of respite services and again after six months of participation in the program. The results showed that families had significantly higher levels of stress at intake than they did after six months of participation; the majority of respondents reported that this was because they had the opportunity to spend time in activities other than caregiving. Many reported that their children also benefited from the socialization experience with people outside the family which instilled trust in others.

Cowen and Reed (2002) conducted a study to determine if utilization of a respite care intervention program impacted parenting stress, foster care placement, and child maltreatment among at-risk families. Participants included parents taking part in a respite intervention program. Among the participants of the study, there were many cases of child maltreatment or foster care placement, and many fell below the poverty line. The majority of parents had a high stress score, signifying a risk for development of dysfunctional parenting behaviours. Although both the pre-test and the post-test means were above the high stress range, stress levels decreased significantly following the respite care interventions.

Other research indicates that the benefits of respite care are maintained over time. Mullins et al. (2002) conducted a longitudinal study to examine the psychological benefit of respite services on parents, whether the beneficial effects of respite care are maintained over a 6-month period, and the effect of respite services on child functional abilities. Using a quasi-experimental design, the researchers examined families who had applied for services at a treatment centre serving children with developmental disabilities. Children were admitted to one of two types of available services which differed in length of stay and receipt of services. Respite care consisted of a 3- to 7-day admission to the centre; no formal therapy services were initiated as the goal was to provide reprieve for the parents. Short-term inpatient treatment typically consisted of a 30-day admission and treatment. As predicted, the researchers found that psychological distress was significantly lower at discharge for the respite group, and these improvements were maintained over a 6-month period. Also noteworthy is the finding that both the reduction in psychological distress and the improvement in functional ability of the children were equal to that of the comparison group, whose admission to the centre was substantially

longer and involved intense treatment. These results add to the empirical support for the long-term effectiveness of respite care for families of children with developmental disabilities.

Results from the literature thus provide substantive evidence for the advantages of respite care. A number of studies have shown that it helps to alleviate the stress of parents of children with disabilities and that this is maintained over time. Although relief for the caregiver is the primary purpose of respite care, it indirectly provides other benefits as well. For example, it is beneficial for the children as they are able to develop trust in others. Furthermore, it has the same effect on parents' well-being as other more intensive and expensive supports, indicating that it is a cost-effective measure for assisting parents.

2.4 Policies for Children with Disabilities

2.4.1 Government of Canada

Although provincial governments are primarily responsible for the provision of supports and services to children with disabilities and their families, overlap exists with the federal government. Through their policies and programs, provincial governments help to realize federal mandates for strengthening citizenship and equality. Although no federal department is specifically responsible for these issues, most of them are directed to Human Resources and Social Development Canada, which has an Office for Disability Issues. The federal government also plays a significant role through the Canada Health and Social Transfer (CHST), which replaced the Canada Assistance Plan (CAP) in 1996 and was divided into separate Health and Social Transfers in the 2007 budget. The Canada Social Transfer consists of cash and tax transfers to the provinces, which are used for post-secondary education, social assistance, and social services. Provinces can spend this block transfer in areas of their choosing. Consequently, policies for children with disabilities and their families are often low priorities compared to other areas such as education (Valentine, 2001).

During the 1990s, the Canadian government's focus was on fiscal restraint and labour market attachment; consequently, little attention was devoted to the needs of children with disabilities and their families. A number of initiatives attempted to ameliorate the situation. For example, the *Social Union Framework Agreement* placed a priority on policies affecting both children and disability, and the Federal-Provincial-Territorial Council on Social Policy Renewal began to work on these issues in 1996. During the same year, Human Resources Development Canada, the Department of Finance, Revenue Canada, and the Department of Justice Canada established the Federal Task Force on Disability Issues. Its role was to examine the future role of

the federal government in regard to the Canadian disability community (Valentine, 2001). In 1999, the federal government released a strategy document titled *Future Direction to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship*.

Initiatives such as these indicate that the federal government recognizes the importance of assisting Canadians with disabilities in reaching their full potential. However, children with disabilities and their parents were rarely mentioned in these frameworks for actions, and their issues and concerns were not specifically addressed. A number of national disability organizations issued *A National Strategy for Persons with Disabilities: The Community Definition* in November 1999 in response to this lack of acknowledgement. Their primary complaint was that official reports dealt primarily with issues affecting persons with disabilities of working age and omitted children with disabilities and their families (Valentine, 2001).

Despite initiatives and advocacy attempting to put children with disabilities and their families on the policy agenda, barriers remain in this area. The limited text on disability issues in the 2005 budget continued to portray the old view of disability as a tragedy and biomedical problem and implied that people with disabilities were a burden to their caregivers. Although the current social model of disability, with its focus on equality rights and full citizenship, had been apparent in previous budget speeches, it was absent in the 2005 budget (Prince, 2006).

2.4.2 Government of British Columbia

British Columbia is one of a number of provinces that have improved their policy frameworks in recent years to make them more inclusive to children with disabilities and their parents, partly due to the document *A National Children's Agenda – Developing a Shared Vision* and advocacy from disability organizations such as the Canadian Association for Community Living. The Gove Inquiry into Child Protection also affected British Columbia's policy framework in 1995 (Valentine, 2001). In response to the report, B.C. created the Ministry of Children and Families in September 1996, which was solely responsible for legislative frameworks, policy development, administration, and service delivery for children and their families. It consisted of policies and programs taken from the ministries of Social Services, Health, Education, Women's Equality, and the Attorney General. A main goal of the ministry was to combine the fragmented policies and guidelines from the separate ministries into a policy framework; the result was the *Policy Framework for Services for Children and Youth with Special Needs* in January 2001 (Valentine, 2001).

When the BC Liberal Party was elected in 2001, the government changed the Ministry for Children and Families to the Ministry of Children and Family Development (MCFD).

Adoption, child protection, community living for adults, and major boards and commissions are the four primary responsibilities of the ministry (Valentine, 2001). Shortly after the creation of the MCFD, the government reviewed its programs and services and assessed the ability to meet economic, fiscal, and social objectives. Interested parties were invited to provide submissions on the future direction of the ministry. Most of the respondents felt the systems to care for people with disabilities were rigid, overly bureaucratic, and unsustainable in the long term (Community Living British Columbia, n.d.). The Minister at the time, Gordon Hogg, appointed a 25-person Community Living Transition Steering Committee, which consisted of advocates and family members of people with disabilities. Its role was to help define the transition from government to community-based governance for community living services. In 2002, they released a report recommending that a province-wide governance authority called Community Living British Columbia (CLBC) be created to provide services to adults with disabilities and children with special needs. CLBC became a legal entity and designated a Crown agency on July 1, 2005, when it assumed responsibility for services from MCFD. CLBC is also classified as a “Service Delivery Corporation,” which requires following strict reporting and financial regulations and accountability to the provincial legislature. Its responsibilities include developing policy, directing operations, enforcing standards, and managing funds and services, while the Ministry’s responsibilities include funding, setting provincial standards, and monitoring CLBC’s performance (CLBC, n.d.).

As of March 31, 2007, CLBC provided supports and services for 8,943 children and youth with special needs and their families. The demand for children’s services is increasing due to factors such as increased survival rates, improved diagnosis, and increased public awareness. In particular, children with autism spectrum disorder (ASD) have contributed to the increase in demand in recent years, and about 5,400 to 6,000 children have ASD. Furthermore, ASD diagnoses are occurring earlier, which means that supports are required for a longer period of time, and research shows that a developmental disability accompanies ASD 50-60 percent of the time. As new diagnostic and assessment tools are becoming more widespread, the number of children and their families served is expected to continue to grow in the next few years; CLBC anticipates that in 2008-2009 alone it will grow by 5.5 percent. It is estimated that a 1 percent increase in the supported population will lead to an increase of \$400,000 in annual resources requirements by MCFD to CLBC (Community Living British Columbia, 2008a, 25).

2.5 Respite Care in British Columbia

CLBC provides services for children who have an Autism Spectrum diagnosis, are eligible for the At Home Program (AHP), or have a developmental disability. In order to be considered as having a developmental disability, a child must receive a formal diagnosis from a registered psychologist before age 18, must have an IQ score or cognitive skills score that is significantly sub-average, and must have accompanying deficits in adaptive behaviour. In order to qualify for AHP benefits, a child must be age 18 or younger, a resident of B.C., and living at home with a parent or guardian. An assessment is not required for children who have a palliative condition; they qualify for full AHP benefits. Children with Indian Status who are eligible may receive AHP benefits not overlapping benefits from First Nation and Inuit Health, Government of Canada, or the Band or Aboriginal Agency. Eligibility for all services is reassessed yearly to determine the suitability in meeting the families' needs (CLBC, n.d.).

Respite services are designed to provide rest or relief for families with children who have special needs to help families maintain their independence and quality of life (CLBC, n.d.). In general, the AHP provides respite and other services for children with complex physical and medical disabilities, while children with autism and developmental disabilities have access to other types of respite programs (CLBC, personal communication, October 2, 2008). CLBC staff work with a child's family to develop an individual support plan with a focus on a child-centred experience. Services are provided through a direct funding option, contracts with community service providers, or approved resources. Respite can be provided in the child's home, the respite worker's home, or in a staffed setting (CLBC, n.d.). The respite workers who are hired to provide care through the community facilities are assessed and assigned a level of 1, 2, or 3 based on their skills and abilities to care for children with special needs. In contrast, for the direct funding option families are paid directly and hire their own respite worker, and they sign a contract agreeing that CLBC will not be involved in the process in any way (CLBC, personal communication, January 20, 2009).

Through the AHP, eligible children receive respite care either in their home or at another location, depending on which best suits the needs of the children and their families. Parents make a written agreement with CLBC and can choose to receive benefits through a monthly payment or through reimbursement of respite expenses. Any person providing respite services who is a dependent of the family and lives in the same household, or who is a parent of the child, is not covered under the program. Exceptions to this rule may be made in certain situations, such as if no appropriate caregiver is available to provide for the unique needs of the child. This may be because of the nature and degree of care required, rural or remote location causing accessibility

issues, cultural considerations that affect care needs, and communication barriers. It is the parents' responsibility to arrange for respite care, pay the caregivers, manage their respite budget, and maintain a record of respite expenditures (CLBC, n.d.).

To receive AHP benefits, families submit an application form to the AHP Regional Contact at their local CLBC regional office. The application form is reviewed and an arrangement is made for an assessment by a qualified assessor. The assessor comes to the family home to assess the child's abilities in the four areas of daily living (washing, toileting, feeding, and dressing); he or she may also contact the child's physician or other health care professional to discuss the child's needs and abilities. A regional eligibility committee then makes an eligibility decision based on the application and assessment. Children who are dependent in three out of the four areas of daily living are eligible for respite benefits. They are considered to be dependent when they need much more assistance with tasks than other children of the same age. Parents then receive a letter notifying them of the eligibility decision, and if their child is not eligible they may be referred to other supports and services (CLBC, n.d.).

Depending on family income, respite benefit rates are typically \$2,400 to \$2,800 or about 28 days per year, but greater amounts can be granted if needed. Income levels for determining benefit levels vary depending on the number of people in the family. For instance, for two-person families the income cut off is \$1,082 per month, and for six person families it is \$1,704 per month. Families earning more than the cut-off pay a portion of the respite costs. If the child is younger than 12, the family contributes \$422 per year, and if the child is older than 12 they pay \$533 per year (CLBC, personal communication, October 2, 2008).

Newly approved families are typically placed on a waitlist, as respite funding is usually not provided immediately. Waitlists for respite care and other CLBC services are maintained by each regional office and vary by regions. For example in Vancouver, which has a high, dense population and many young families, service needs are higher (CLBC, personal communication, October 2, 2008). Individuals are placed on the waitlist in order of priority based on length of time waiting followed by specific individual requirements. If individuals move to a different community, their status on a waitlist does not change. Certain emergency situations are managed outside the wait-listing process; these include risk of serious physical harm to self or others, abuse or neglect, and death or illness of the sole caregiver. Representatives from each region meet every six months to review waitlists and to share relevant information (CLBC, n.d.). Once a family is approved for services, they do not have to rejoin the waitlist and continue to receive services (CLBC, personal communication, January 20, 2009).

RCYBC notes that very limited reporting exists on services provided by CLBC. Its data

cannot be compiled to provide a picture of how many children are being served, at what cost, and with what outcomes, and its reporting framework is based on the quantity of activities rather than the effect on recipients. CLBC is aware of the problem and is currently working on a client management system and a contract management system. Monitoring and reporting standards from CLBC to MCFD are also lacking. CLBC notes that MCFD has developed provincial standards only for services related to children in care and residential services (RCYBC, 2008c).

On June 23, 2008, the B.C. government announced a transfer of services for children with disabilities, including respite care, from CLBC to MCFD (RCYBC, 2008a). This shift resulted from complaints over the past few years from families who found access to services confusing and not responsive to their needs. Both CLBC and MCFD have stated that they are currently working to ensure an efficient transition process. A series of public consultation meetings, during which families and care providers had the opportunity to make suggestions, took place from October 30th to December 8th, 2008. Some issues that were discussed are having a single point of contact for services, integrating cross-ministry service delivery with the ministries of health and education, and providing services in rural and remote areas. MCFD already provides numerous services to children with special needs, so CLBC services will be integrated with them. Responsibility for CLBC will be transferred to the new Ministry of Housing and Social Development (MHSD), and they will continue to provide services for adults with disabilities. MCFD and MHSD will work to assist transitioning youth with special needs to adult supports when they turn 19 years old (Ministry of Children and Family Development, n.d.). The government is taking a phased approach to the transition process and anticipates that it will be finalized by October 2009. During the transition process, services are remaining at the status quo to minimize impacts (RCYBC, 2008a).

RCYBC is concerned that the transition will not improve service responsiveness and effectiveness. It notes that the transfer has the potential to improve services by reducing fragmentation of services, but the framework for the transfer was not in place at the time of the announcement, and an external evaluation of CLBC's effectiveness has not been conducted. Furthermore, RCYBC notes that although there has been no evident disruption in service, the uncertainty is causing anxiety and confusion among families of children with disabilities (RCYBC, 2008a).

2.6 Barriers to Respite Care

Despite the large body of evidence that shows the importance of respite care in maintaining the well-being of families, it remains in short supply throughout the country (Hanvey, 2002). In one study, 90 percent of families said that respite care was among the main things they required to support their children, but the need was not being met. This is particularly true for children who have complex health issues or behavioural disabilities (Roehrer Institute, 2000a). Another problematic issue in Canada is that parents are forced to constantly portray their child in a negative manner and must repeatedly justify their need for support. They also feel that they are penalized for their child's progress with a reduction of supports (Douglas, 2001).

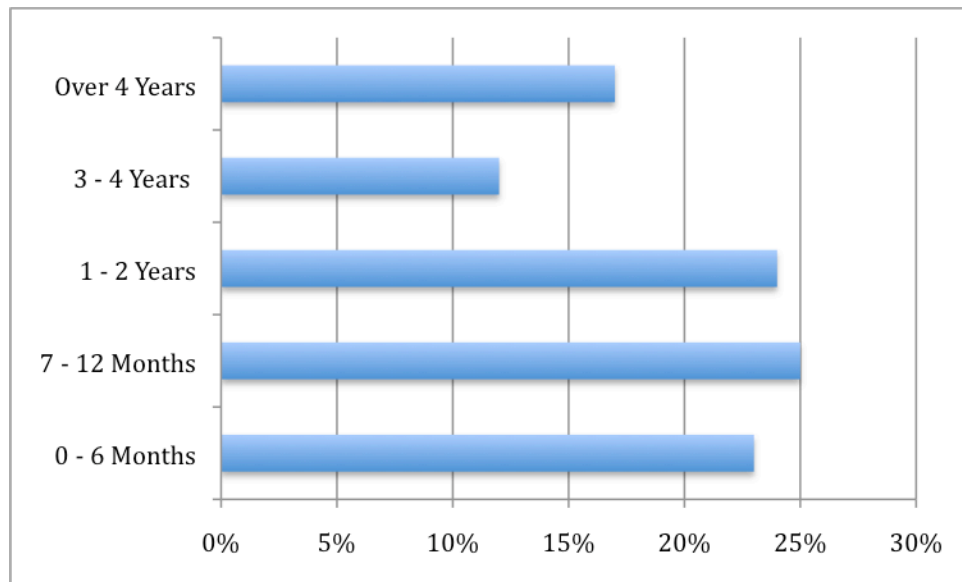
One barrier in B.C. is that income is used to determine access to fully funded respite care. The income cut-off level for fully funded public respite care in British Columbia, which varies by the number of people in the family, is very low. For example, for a two-person family it is only \$1,082 per month, and those earning more than that must pay a contribution to the respite cost. Therefore, only very low-income families are receiving fully subsidized public respite. Many families who earn more than the cut off but are still relatively low income may not be able to afford to pay the contribution to care. The required contribution is approximately \$500 per year; this is unlikely to be a burden to middle- and high-income families, but may be significant for families whose incomes are still very low. This problem is compounded by the fact that children with disabilities often require expensive equipment and other supports and that the employment of their parents is often affected by their complex care needs.

The eligibility criteria determined by the province may also constrain access to respite care in B.C. For the AHP, eligibility requires that children be dependent in three out of the four areas of daily living, a criterion that appears to be rigid and mechanistic. Criteria for other respite services are broader; they include those eligible for the AHP, those with developmental disabilities, and those with ASD. While this encompasses a wide range of children with disabilities, it is a diagnostically driven approach rather than a more inclusive functional approach. The government is currently engaged in a Cross-Ministry Children and Youth with Special Needs Framework for Action process with the ministries of Health and Education. One of the primary principles of the Framework is the provision of services based on function rather than diagnosis, and MCFD is conducting research on other jurisdictions and best practices regarding functional needs assessment. This is still at a very preliminary stage, and a timeline for implementation has not yet been established. RCYBC maintains that many children with comparable needs do not meet the diagnostic requirements and urges MCFD to proceed quickly in this area to ensure that a child focus is brought to service responsiveness (RCYBC, 2008c).

Another significant barrier to access to respite care is a shortage of qualified workers. Even when families have access to public funding, they face difficulties in finding someone to manage their child’s complex needs. The shortage of respite workers is due in part to the fact that they are self-employed contractors who earn very low wages. Also, while their incomes were previously non-taxable, they are now taxable (Community Options BC, personal communication, February 9, 2009). Furthermore, if families choose not to receive their respite through an authorized facility, they are responsible for the hiring and payroll of their care worker, which places a burden on their already stressful lives.

A final important barrier to respite care is the waiting list. In June 2008, CLBC published results from a service satisfaction survey that included 957 questionnaires from families of children, families of adults, and self-advocates across B.C. Seventeen percent of respondents in total and 19 percent of parents of a child reported to be waiting for requested paid supports or services which had not yet been provided (CLBC, 2008b). Figure 4 shows distribution of wait list times from the CLBC survey; just over half of respondents on wait lists reported their waiting times in excess of one year.

Figure 4: Waiting Times for Those Waiting for Supports and Services



Source: CLBC Service Satisfaction Survey: Provincial Overview, 2008

The waiting lists also vary considerably across regions in the province, with Vancouver Coastal reporting the highest percentage of people waiting for services (26 percent) and the Northern Interior and Upper Fraser regions reporting the lowest percentage (11 percent) (CLBC, 2008b, 7). Respite services and waitlists in British Columbia are determined separately in each of the regions (Vancouver Coastal, Vancouver Island, Fraser, North, and Interior). This creates equity issues across the province since access to care varies depending on where families live, and it can be detrimental for both urban and rural dwellers. Although urban areas may have more services, they also have very high demand due to their high-density populations. Those living in rural and remote areas can also be at a disadvantage because of a lack of services in these areas. Table 2 displays the percentage of respondents from each region waiting for services.

Table 2: Waitlist Variations Between Regions in British Columbia

Region	Number of Respondents	Percentage Waiting for Services
Vancouver Coastal	95	26
Surrey, Delta, Richmond	120	18
Southern Vancouver Island	113	14
North	43	12
Northern Interior	105	11
Southern Interior	62	19
Upper Fraser	74	11
Central-Upper Vancouver Island	267	14
Simon Fraser	78	17

Source: CLBC Service Satisfaction Survey: Provincial Overview, 2008

Many believe that waitlists for respite care and other essential services for young children result in higher costs for the government in the long term since missing out on these services in their early years puts children farther behind. They argue that having access to these services at an early age provides them with an advantage for later in life (Thomson, 2009). A lack of communication and accountability also exists with regards to wait lists. While CLBC has waitlist data, it cannot be collected to provide a comprehensive depiction of wait times. The waitlist data itself is not necessarily an accurate portrayal of wait times because of inconsistent practices and the lack of available data. The data are managed by the regions, and no rigorous data collection standard exists. Information on wait times is important because it can influence a family's choice of service. For instance, if a child is eligible for either respite or medical benefits, medical benefits may be chosen because of long waitlists for respite care. Thus, the choice is influenced

by wait times and not by which services best suit the child or the family. RCYBC has identified this lack of data regarding wait times, and MCFD has noted that policies and tools to support wait-list management will be implemented as part of the transfer of services from CLBC to MCFD (RCYBC, 2008a). CLBC is in the process of implementing a provincial wait list for children and youth services, and MCFD is developing consensus about waitlist definitions (RCYBC, 2008c).

The barriers described above are exacerbated by the fact that the system for respite care and other services for children with disabilities is very bureaucratic and difficult to navigate, which became clear while attempting to obtain information for this research. Specific information and numbers regarding wait list times, budget allocation among regions, and amount of funding provided to families either did not exist or were inaccessible. Also, while some services are provided by MCFD, others are provided by CLBC, and little cohesion exists between the two groups. Services provided by CLBC, including respite care, are in the process of being transferred to MCFD; as noted above in the Government of British Columbia section, many such transfers and changes to the system have occurred in the past number of years. While these changes are made with the intention of simplifying and improving the system, they inevitably cause confusion and frustration among parents. Furthermore, while the government maintains that no disruptions to services will occur during the current transfer, it acknowledges that no necessary improvements will be made until the transfer is complete (RCYBC, 2008a).

3: Methodology

To gain information on the adequacy and shortcomings of respite care in B.C., I use both qualitative and quantitative research methods. First, I have undertaken a survey of parents with children with disabilities, which I analyze both quantitatively and qualitatively. Second, I compare respite care in B.C. to that in other provinces in Canada using a case study approach.

3.1 Survey

My survey is designed to gain information on parents' experiences with accessing respite care and the barriers that they perceive. Respondents were recruited from a number of parent advocacy groups and other organizations for people with disabilities throughout B.C. Organizations that distributed the survey to their clients are the Family Support Institute (FSI), the British Columbia Association for Community Living (BCACL), and Pony Pals Therapeutic Riding Association. FSI is a province-wide organization that provides information, training, and networking to assist families who have a member with a disability (Family Support Institute, n.d.). BCACL is a provincial association that promotes the participation of people with developmental disabilities in all aspects of community life (British Columbia Association for Community Living, n.d.). Pony Pals is a facility in Delta that offers a therapeutic horseback riding program for people with disabilities (Pony Pals Stables, n.d.). The survey was distributed in two formats—web and hard copy—depending on the needs of particular organizations. In general, the advocacy groups that do not necessarily have parents attend their facilities in person, FSI and BCACL, emailed the link to the survey to their members. Pony Pals Therapeutic Riding Association, which is attended by families on a regular basis, distributed the survey in a hard-copy format. The questions on the two formats of the survey are identical.

The survey includes demographic questions, such as age, household income, number of children in the family, and whether the family is a single-parent or two-parent home (see the Appendix for the full survey instrument). It then asks parents to describe the nature of their children's disability and the extent of special care that they require. Further questions relate to the families' experiences with accessing respite care; those who currently have access are asked about their satisfaction with the amount of publicly funded care they receive and the effect that it has had on the well-being of their family. Those who do not have access to public subsidies for care are asked if they have tried to access it and if they have made use of other alternatives.

I analyzed the results to determine whether the respondents have had experiences similar to many parents of children with disabilities, such as if their employment has been affected by the extra care needs of their child. Other variables of interest in relation to access to public respite are household income, extent of the children's disabilities, and whether the household is single- or two-parent. The amount of respite care received publicly and its effect on the well-being of the family are among the other relationships examined. I examined the open-ended questions qualitatively and used cross-tabulations to determine whether there is a significant difference between certain variables and those who do and do not have access to public respite care.

One major limitation of my research is the size and scope of the sample size due to time and budget constraints. The sample size is relatively small, and although the survey was distributed throughout the province, it does not ask respondents to indicate their region. Difficulty accessing respite care is even more pronounced among particular groups, such as Aboriginal peoples and people living in rural and remote areas. In retrospect, I would have added questions asking where the families live and if they identify themselves as Aboriginal in order to examine whether that has an effect on their access to respite care. Further research should examine how to improve the barriers for these and other specific groups.

3.2 Case Studies

The second segment of the study consists of comparisons to other jurisdictions in Canada. Respite care in Canada is provided by the provincial governments with much variation across the country. One key difference is that some jurisdictions impose no direct cost to the user for in-home respite, while other jurisdictions, including B.C., determine eligibility by income or income plus assets. In these provinces, therefore, publicly funded plans are provided in full only to those with very low incomes while those with modest or high incomes are required to hire their own services on the private market independently or contribute a portion of the costs (Dunbrack, 2003). This discrepancy has important implications for equity across Canada. Also, those with incomes not low enough to qualify for fully subsidized public respite care may not necessarily be able to afford the high costs of private care.

The respite care programs of Manitoba and Alberta were examined in more detail to determine if they have practices that B.C. can implement to improve its provision of respite care. Specifically, aspects examined include program description, eligibility criteria, and cost to users. Manitoba was of particular interest since it has no cost to the user and because a number of survey respondents replied that they moved from there to B.C. They noted that in Manitoba they had access to public respite care and were very satisfied with the service, while in B.C. their child

has not met the eligibility criteria or they have been placed on a long waiting list. In 2004, Alberta became the first province to introduce legislation especially for children with disabilities and their families. It was thus chosen to examine whether that legislation had an effect on the provision of services for this population.

4: Results

4.1 Survey Results

4.1.1 Descriptive Statistics

The total number of surveys submitted was 129. However, eleven of these were discarded since the respondents' children were 19 years or older (19 is the age at which persons with disabilities are transitioned to adult services in B.C.). Thus, the final analysis included a sample of 118 surveys. Females represented the vast majority of the respondents, at 93 percent (N = 110) of the sample. This is consistent with research by Burton (2008), who notes that mothers typically respond to surveys, particularly those involving child health. Tables 3 through 5 display frequencies for family type, age of respondent, and age of spouse. They indicate that the majority identified their families as being two-parent homes and that most respondents and their spouses are 40 years or older.

Table 3: Family Type

Family Type	Frequency	Percent
Two-Parent	97	82.2
Single-Parent	18	15.3
Other	3	2.5

Table 4: Age of Respondents

Age of Respondent	Frequency	Percent
34 or younger	17	14.5
35-39	21	17.9
40-44	35	29.9
45-49	29	24.8
50 or older	15	12.8

Table 5: Age of Respondents' Spouses

Age of Spouse	Frequency	Percent
34 or younger	5	5.1
35-39	18	18.2
40-44	32	32.3
45-49	20	20.2
50 or older	24	24.2

Table 6 displays the frequencies and percentages for total number of children and number of children with disabilities in the household. Most respondents reported having between one and three children in their household, with two children being both the most common response and the average number of children. The majority had one child with a disability. The ages of the children with disabilities ranged from two years to 18 years, with a relatively equally distribution among the different ages and an average age of 10 years.

Table 6: Number of Children in the Household

Number of Children		Frequency	Percentage
Total	1	35	29.7
	2	52	44.1
	3	27	22.9
	4 or more	4	3.3
With a Disability	1	98	83.1
	2	18	15.3
	3	2	1.7

Respondents were asked to describe their children's disabilities, and a wide range of physical and psychological disabilities were identified, including Down Syndrome, ASD, Rett Syndrome, cerebral palsy, epilepsy, Fragile X Syndrome, and Fetal Alcohol Syndrome. Many children were also identified as having multiple disabilities. Respondents were also asked to describe the nature and extent of extra care, supervision, medication or other regular special care services the child routinely requires. Responses to this question were also very diverse and

included services such as behavioural therapy, speech therapy, physiotherapy, and occupational therapy, as well as a variety of medications. Many respondents also indicated that their children require constant, 24-hour care and supervision due to various reasons such as safety issues, frequent seizures, and inability to perform tasks such as eating and toileting.

Fourteen percent of respondents (N = 17) indicated that disability restricts their child from attending regular school. However, these results may not be entirely accurate because of a lack of clarity of the definition of 'regular school.' For instance, several respondents who responded that their child cannot attend regular school indicated that their child attends a special school or a special class in a regular school. Those who responded that their children do attend regular school made similar comments, and many noted that accommodations had to be made in order for them to attend regular school. Only a few respondents indicated that their children cannot attend school at all and are home-schooled.

Table 7 demonstrates the number of hours worked by the respondents and their spouses. Of the 109 respondents who indicated the average number of hours per week they spend in paid employment, 30 percent do not work at all. The highest number reported was 76 hours of paid employment per week, and the average was 20 hours per week. In contrast, of the 91 respondents who indicated the amount that their spouse spends per week in paid employment, only 7 percent do not work at all and 8 percent work 30 hours or less per week. The highest number reported for spouses was 80 hours of paid employment per week, and the average was 40 hours.

Table 7: Weekly Hours Spent in Paid Employment by Respondents and Their Spouses

Weekly Hours in Employment		Frequency	Percent
Respondent	0	33	30.3
	1-10	11	10.1
	11-20	10	9.2
	21-30	22	20.2
	31-40	28	25.7
	More than 40	5	4.6
Spouse	0	6	6.6
	1-10	1	1.1
	11-20	5	5.5
	21-30	1	1.1
	31-40	48	52.7
	More than 40	30	33.0

An overwhelming majority of respondents (86 percent, N = 101) indicated that either their or their spouse’s employment situation has been affected by the special needs of their child. Respondents’ reasons included reducing work hours, declining promotions, working part-time, not returning to work at all, and changing careers. One respondent noted a “complete loss of a professional career,” and another wrote that she has not worked since her child’s diagnosis due to “the emotional adjustment to having a special needs child.” These statistics are consistent with Hastings’ (2005) finding that mothers typically indicate increased involvement with the care of their child with a disability and with Shearn and Todd’s (2000) finding that mothers of children with disabilities are vastly under-represented in the workforce compared to mothers in general.

Table 8 displays household income and indicates that it is fairly evenly distributed throughout the income ranges, with slightly more falling in the lower end. Of the 114 respondents who indicated their income, 40 percent have household incomes of less than \$60,000 per year, 33 percent have household incomes of between \$60,000 and \$99,999, and 27 percent have household incomes of more than \$100,000 per year. The most common income range chosen was ‘\$40,000-\$59,999.’

Table 8: Household Income

Household Income	Frequency	Percent
\$0 – 19,999	8	7.0
\$20,000 – 39,999	12	10.5
\$40,000 – 59,999	25	21.9
\$60,000 – 79,999	20	17.5
\$80,000 – 99,999	18	15.8
\$100,000 - \$119,999	17	14.9
\$120,000 or more	14	12.3

Sixty-one percent (N = 72) of respondents reported that they do not receive unpaid respite care from others such as relatives, friends, and neighbours. Of the remainder who do receive unpaid respite care, 32 indicated the number of hours per month that they receive this service. The number of hours per month varied greatly from two to 120, although the majority receive less than 12 hours per month (63 percent, N = 20). The average number of unpaid respite care hours per month was 17.

The sample was nearly evenly split between those who currently have access to publicly funded respite care and those who do not. Fifty-three percent (N = 62) have access to public respite care, while 47 percent (N = 56) do not. Following the question asking respondents to indicate if they have access to public respite, they were asked to complete one section of the survey if they have access and a different section if they do not.

Those who do not have access to public respite were first asked if they have attempted to access it, and 65 percent (N = 36) reported that they have. Of the 30 respondents who indicated the length of time that they have been attempting, answers ranged from four months to eight years. About half (53 percent, N = 16) have been attempting for two years or less while the rest have been attempting to access public funding for respite for more than two years. The average time attempting was 2.7 years. They were also asked if they are currently on a waiting list for it, and nearly half (45 percent, N = 25) reported that they are.

Respondents who do not have access to public respite were then asked if they have ever been denied respite care because their child did not meet the eligibility criteria set by the province. Of the 54 subjects who answered this question, 22 percent (N = 12) reported that they have been denied. When asked if they paid for private respite care from their own pockets, almost half (46 percent, N = 26) indicated that they do. Finally, they were asked to indicate on a scale of 1 to 5 the extent to which they think having access to publicly funded respite care would

improve the well-being of their family. A large majority (84 percent, N = 47) chose either ‘4’ or ‘5’, indicating that they believe it would improve their well-being significantly. Only 4 percent (N = 2) replied ‘1’ or ‘2’, indicating that it would improve their well-being not at all or very little.

Those who do currently have access to public respite care were asked how long they have been receiving it, and Table 9 displays the responses. Exactly half of the 60 respondents who answered this question have been receiving public respite care for four years or less, while the other half have been receiving it for more than four years. The average amount of time was 5.7 years and the majority were placed on a waiting list prior to receiving access. Length of time on the wait list ranged from two months to seven years, and more than half of the 43 respondents who indicated the length of time had waited for two years or more, with an average wait time of 2.2 years.

Table 9: Length of Time Receiving Public Respite Care for Those Who Have Access

Length of Time	Frequency	Percent
1 year or less	10	16.7
1.5 – 4 years	20	33.3
4.5 – 8 years	13	21.7
More than 8 years	17	28.3

Participants were asked to indicate the location of the public respite care they receive, and a variety of locations and combinations thereof were provided (see Table 10). The most common response was receipt of respite only at the family’s home, while only one respondent reported receiving it only at an authorized facility. Many respondents reported receiving respite care at a variety of combinations of places.

Table 10: Locations of Public Respite Care

Location	Frequency	Percent
Family Home	26	42.6
Respite Worker’s Home	14	22.9
Authorized Facility	1	1.6
Other	4	6.6
Combination	16	26.2

When asked to indicate the amount of respite they receive publicly, respondents were given the option of replying in either dollars or time. Although they could answer in dollars per month or year or hours or days per week, month, or year, answers were converted to dollars per month and days per month in order to provide a consistent measure for analysis. Of the 33 who replied in dollars, the amounts ranged from \$92.58 to \$950 per month, with an average of \$328.70. Nearly half (48 percent, N = 16) receive more than \$233.33 per month. This is equivalent to \$2,800 per year, the maximum amount generally provided through AHP (although more may be provided if required). Of the 27 who replied in amount of time, the amounts ranged from one day per month to nine days per month, with an average of 3.7 days per month. Participants were also asked if they pay for any respite privately, beyond what is provided to them publicly. Of the 59 who replied, more than half (58 percent, N = 34) responded that they do. Twenty-nine provided the dollar amount per month that they pay from their own pockets, and answers varied greatly from \$25 per month to \$1,408 per month and averaged \$277.37 per month.

Three questions were asked to assess the effects of public respite care on families and their satisfaction with it; each was scored on a 1 to 5 scale. First, participants were asked to indicate the extent to which they think having access to publicly funded respite care has improved the well-being of their families. Of the 61 who replied, most (82 percent, N = 50) responded either '4' or '5' indicating that public respite has significantly improved the well-being of their families, while only 5 percent answered '1' or '2' indicating that it has improved their well-being not at all or very little.

Responses also showed that the participants are satisfied with the quality of respite care they receive publicly. Sixty-two percent (N = 38) replied either '4' or '5' and only 13 percent (N = 8) replied either '1' or '2'. For their overall satisfaction with the amount of respite care they receive publicly, responses showed much more variation. The most frequent response was '3' (33 percent, N = 21), indicating being neither satisfied or dissatisfied with the amount. Nearly equal numbers of respondents are unsatisfied (with answers '1' or '2') and fairly satisfied (with answers '3' or '4'), at 30 percent (N = 19) and 37 percent (N = 22) respectively.

Finally, respondents were asked to add any other comments about their experiences with accessing public funding for respite care, including barriers that they feel could be improved. Again, a wide variety of responses were provided, and the barriers to respite care identified were consistent with those found in the literature. The most common complaint concerned a lack of respite workers; many respondents wrote that even though they have public funding, they are not able to access workers qualified to deal with the complex needs of their child. Another frequent response in this area was that respite workers are paid too little and thus stay in their position only

temporarily. This is detrimental for children with special needs, many of whom thrive in a stable and consistent environment and do not like change. Furthermore, the respite workers are contract workers so parents are required to handle the hiring and training themselves. As one parent stated, “The funding given to me directly means hiring, interviewing and doing payroll for staff which is an added burden on the family and a lot of work.” In contrast, one respondent who receives respite care through an authorized facility reported being very happy with the service and not having to deal with money.

Another very common response was that the wait lists are too long. Many respondents also reported a lack of communication regarding the wait lists; they have had difficulty receiving information on where they are on the list and when they are expected to reach the top. Others reported that the system is too complicated and that they have had difficulty navigating it, as one participant stated, “I find that the system is too complicated and frustrating. I have always had to fight to access funding and think that is ridiculous considering the considerable amount of stress already in our lives simply being the parent of a special needs child.” Another respondent also noted that they have to repeat their story every time they speak to someone about their case and suggested that families be assigned to a case worker who deals with them consistently.

One respondent reported living in a remote area lacking all respite services. Several also objected to the eligibility criteria set by the province; for instance, they do not like labelling their children or have children with disabilities that do not have a certain label and therefore do not qualify for respite care. Many who have access to public respite funding noted that although they appreciate the help they get, they feel that it is not enough and that they would benefit greatly from more funding. “\$200.00 per month does not go very far if you have to pay a large hourly wage for properly trained individuals to ensure the safety and well being of your child. A few hours of regular respite for some families can be the difference between keeping a family intact and together and far worse scenarios.”

Other comments provided useful insight into respite care in general. One parent wrote, “The term ‘respite’ needs to be normalized and not looked at as a parental ‘shortcoming’ or flaw, especially when coping with the everyday challenges that parenting a child with a disability can bring.” Another responded, “This is the single most important support we have received for our child. Without it I cannot imagine how we would be functioning ... this is a must have for all families facing such a situation.”

In sum, the survey results confirm the main findings from the literature. Respite care is a service that parents value highly and that has a positive effect on their well-being. However, a number of significant barriers prevent families from receiving it from the government, including

insufficient eligibility criteria, long waiting lists, and a lack of adequate respite care workers to manage the complex needs of children with disabilities.

4.1.2 Cross-Tabulations

The demographic characteristics thought to affect access to public respite care are the main variables examined through cross-tabulations of the survey results. Table 11 summarizes the hypotheses for these variables.

Table 11: Hypotheses

Variable	Hypothesis: Characteristic more likely to access public respite care
Family Type	Single-parent families
Age of Respondent	Older respondents
Age of Respondent's Spouse/Partner	Older spouses
Number of Children in the Family	Families with more children
Number of Children with a Disability in the Family	Families with more children with a disability
Income	Families with lower household incomes
Age of Child with Disability	Families with older children with disabilities

Tables 12 through 15 show relationship tests for information on which survey participants receive public respite care as well as information on hours of work, amount of public respite care provided, and amount of unpaid respite care received. The first column shows the variables that were predicted to have an effect on access to public respite care. The 'N' column shows the total number of surveys collected for this variable. Each variable is coded into two categories, and the two 'category' columns indicate the name of each category. The number of responses to each category (n), the number who have access to public respite care, and the percentage of those who have access are compared to produce the (+/-) column. This last column displays the differences in percentage of respondents who have access to public respite in each category. An asterisk denotes statistical significance at the 0.05 level as tested by the Pearson Chi-Square test.

Table 12: Access to Public Respite Care

Variable	N	Category 1	n	Access to Respite	%	Category 2	n	Access to Respite	%	+/-
Family Type	118	Single-parent family or other	21	13	62	Two-parent family	97	49	51	+11
Age of Respondent	117	40 or older	79	47	60	Younger than 40	38	15	40	+20*
Age of Spouse	99	40 or older	76	39	51	Younger than 40	23	12	52	-1
Number of Children	118	More than 2	31	14	45	2 or less	87	48	55	-10
Number of Children with a Disability	118	More than 1	20	11	55	1	98	51	52	+3
Income	114	Less than \$60,000	45	26	58	\$60,000 or more	69	33	48	+10
Age of Child with Disability	114	10 years or older	60	37	62	Less than 10	54	22	41	+21*

Key: N = population; n = sample size; Access to Respite = access to public respite care; (%) = Access to Respite/n; (+/-) = Difference in Access to Respite (%) between Categories 1 and 2
 Pearson Chi-Square scores: *significance level < 0.05

Table 12 demonstrates the relationship tests for which respondents have access to public respite care. Based on results from the literature and examination of B.C.'s respite care system, it was hypothesized that single-parent families, respondents 40 years or older, spouses 40 years or older, more than two children in the family, more than one children with a disability, household incomes of \$60,000 or less, and children with disabilities aged 10 years or older would be more likely to receive public respite care. The only two variables that are significant at the 0.05 level are the age of the respondent and the age of the child with a disability. As predicted, respondents aged 40 years and older and children with disabilities aged 10 years and older are more likely to have access to public respite. This can possibly be attributed to wait lists; due to the long wait times to receive public respite care, it is logical that older children and parents are receiving it.

Other possible reasons may be that some disabilities are not diagnosed until the child is older or that parents feel a greater need for respite care as they get older and as their child gets older.

Table 12 shows the statistics for an income cut-off of \$60,000; this was chosen because it is the amount closest to the mean. Significance was also tested for cut-offs of \$40,000 and \$80,000, and both of these levels also yielded statistically insignificant results. One explanation for this may be that income is used to determine access to respite care based on the number of members in the family, and this was not accounted for with the household incomes of the survey respondents. Another explanation is that income is not used to determine whether families have access to public respite, but rather how much they have to contribute to the cost.

Table 13: Effect of Family Type on Hours of Work

Variable	N	Category 1	n	More than 20 hours of work/week	%	Category 2	n	More than 20 hours of work/week	%	+/-
Family Type	109	Single-parent family or other	20	14	70	Two-parent family	89	41	46	+24*

Key: N = population; n = sample size; (%) = More than 20 hours of work/week/n; (+/-) = Difference between Categories 1 and 2
 Pearson Chi-Square scores: *significance level < 0.05

Table 13 displays the relationship test for family type and number of hours spent in paid employment weekly. It was hypothesized that respondents who work more than 20 hours per week will be less likely to be from two-parent families than single-parent or other types of families. When tested at the 0.05 level with the Pearson Chi-Square test, a statistically significant difference exists between the respondents who are in two-parent families and those who are in single-parent or other types of families. That is, respondents who work more than 20 hours per week are less likely to be in two-parent families. One explanation for this is that since their partner likely has an income, they are not required to work as much in order to handle the special needs of their child. In contrast, those respondents who are single parents or in other family situations may need to work more in order to earn a sufficient household income. This finding is also consistent with the finding that the overwhelming majority of respondents have had either their or their partner's employment situation affected by the special needs of their child. For

instance, many noted that they work fewer hours than they normally would as a consequence on their child's disability.

Table 14: Factors Affecting Provision of More than \$233.33 per Month in Public Respite Care

Variable	N	Category 1	n	More than \$233.33 in public respite/month	%	Category 2	n	More than \$233.33 in public respite/month	%	+/-
Income	33	Less than \$60,000	18	9	50	\$60,000 or more	15	7	47	+3
Number of Children	33	More than 2	6	3	50	2 or less	27	13	48	+2
Number of Children with a Disability	33	More than 1	8	4	50	1	25	12	48	+2

Key: N = population; n = sample size; more than \$233.33 in public respite/month = amount publicly provided; (%) = More than \$233.33 in public respite/month/n; (+/-) = Difference between Categories 1 and 2

Pearson Chi-Square scores: *significance level < 0.05

Table 14 shows the relationship tests for variables predicted to have an effect on respondents who receive more than \$233.33 per month in public funding for respite care. This amount is equivalent to \$2800 per year, which is generally the maximum amount provided (CLBC, n.d.) A relationship was expected for income, number of children, and number of children with a disability in the household; none of these variables was found to be statistically significant. Similarly to Table 12, \$60,000 was chosen as the income cut off because it is closest to the mean, but the relationship was also tested for cut offs of \$40,000 and \$80,000 without any findings of significance. Also, as noted above, only total household income was considered, while income and number of family members is considered when determining the amount of public respite provided. Another limitation with this relationship test is the small sample size compared to the other cross-tabulations conducted. Since only those who receive public respite

care and indicated the amount they receive in dollars were included in the analysis, the sample was only 33.

Table 15: Effect of Public Respite on Unpaid Respite Received From Friends and Family

Variable	N	Category 1	n	More than 10 unpaid respite hours/month	%	Category 2	n	More than 10 unpaid respite hours/month	%	+/-
Access to Public Respite	104	No	48	7	15	Yes	56	6	11	+4

Key: N = population; n = sample size; (%) = more than 10 unpaid respite hours/month/n; (+/-) = Difference between Categories 1 and 2
 Pearson Chi-Square scores: *significance level < 0.05

Table 15 displays the relationship test for the effect that having access to public respite has on the amount of unpaid respite care provided by friends, neighbours, or family members. It was hypothesized that those who do not have access to public respite care will receive more unpaid respite care. Ten hours per month was chosen as the cut-off because it is close to the mean (16.8 hours per month). No statistical significance was found, indicating that access to public respite care does not affect the amount of unpaid respite that families receive from others.

4.2 Case Studies

4.2.1 Manitoba

In Manitoba, respite services are provided by the Department of Family Services and Housing through the Services for Persons with Disabilities Division under Children’s Special Services. Staff in six regional offices throughout the province and six community areas in Winnipeg provide services tailored to the unique needs and circumstances of eligible children and their families. The purpose of the services and supports provided by Children’s Special Services is to reduce families’ stress in order to prevent or delay costly out-of-home placement. In addition to respite care, services provided by the program include counselling, therapy services, home modifications, and transportation. Children’s Special Services also provides consultation

and funding to non-government agencies that provide respite services (Manitoba Family Services and Housing, n.d.).

Children's Special Services are available to natural, extended, or adoptive families who have a child 17 years or under. In order to qualify, the child must have a mental or physical disability, a developmental delay, a risk of developmental delay, a pervasive development disorder, or lifelong extreme complex medical needs which result in a dependency on medical technology (Manitoba Family Services and Housing, n.d.). An assessment is made with each family to determine if they qualify and how much respite care is required to meet the needs of the family (Government of Manitoba, personal communication, January 14, 2009).

A wait list currently exists in Manitoba, but only to receive respite care from workers provided directly by the government. While on the wait list, respite care is outsourced and families can receive care from other programs and agencies that provide respite; funding for this is provided by the government. Respite workers are not required to have any specific training, but preferably they have some experience working with people who have special needs. Their rate of pay is based on the needs of the client and is categorized as Level 2, 3, or 4 (Level 1 was eliminated due to lack of need). Children whose care needs are relatively straightforward are assigned a Level 2 worker, those with more complex needs a Level 3 worker, and those with the highest needs a Level 4 worker. The rates of pay increase accordingly for each level. The respite workers are hired and paid directly by the government (Government of Manitoba, personal communication, January 14, 2009).

4.2.2 Alberta

On August 1, 2004 Alberta's *Family Support for Children with Disabilities (FSCD) Act* came into effect; it was the first of its kind in Canada to provide separate legislation for children with disabilities and their families. The Act replaced a section of the *Child Welfare Act*, which many felt did not sufficiently meet the unique needs of children with disabilities and their families. Alberta's Department of Children and Youth Services developed the Act after consultation and participation with a wide range of stakeholders, including parents of children with disabilities, advocates, health care professionals, aboriginal representatives, and service providers. As a result, the Act promotes a family-centred approach focusing on the child's developmental needs and recognizes the importance of proactive supports and services for children with disabilities and their families. The family-centred approach views the child and family as a unit, respects the values and cultural background of each family, and provides families alternatives and choices based on their own strengths and needs (Alberta Ministry of

Children and Youth Services, 2004).

Respite care is one of the services covered by the FSCD Act along with health-related supports, disability-related clothing and footwear, and out-of-home living arrangements. They are provided based on the individual needs of the child and the family and vary depending on the child's disability and the family's circumstances. The services are delivered through the province's ten Child and Family Services Authorities (CFSAs) and eighteen Delegated First Nation Agencies (DFNAs) (Alberta Ministry of Children and Youth Services, 2004). Since the implementation of the FSCD Act, services such as respite care have been steadily increasing (Government of Alberta, personal communication, January 12, 2009).

In order to be eligible for the FSCD program, the child must be under 18 years old, a Canadian citizen or permanent resident, the parent or guardian must maintain full guardianship of the child, and the child and parent or guardian must reside in Alberta. The child must have a disability as defined in the FSCD Act: "a chronic, development, physical, sensory, mental, neurological condition or impairment that does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal daily living" (FSCD, Section 4-4). A health professional must provide documentation that identifies the child's disability and how it impacts the child's daily activities (Alberta Ministry of Children and Youth Services, 2004).

Respite is defined by the FSCD as "temporarily relieving parents from the full care and supervision demands of their child with a disability ... by temporarily relieving parents of the full care demands for their child, respite support provides families with an opportunity to address other needs such as completing errands, attending to housework, spending time with their other children or taking some time for self care" (FSCD Act, Section 9-27). Respite supports are intended to help strengthen the family's ability to care for their child in the family home and should build on the family's natural supports (Alberta Ministry of Children and Youth Services, 2004).

The type, amount, and duration of respite provided are determined by an assessment of the care and supervision demands of the child and the abilities and needs of the family. Respite may be provided in the family home, in the respite worker's home, or in the community by a private person, a community agency, or in unique circumstances an adult relative. Such unique circumstances include the child reacting negatively to people he or she is not familiar with, no other consistent care provider available, or communication limitations due to language or cultural needs of the family (Alberta Ministry of Children and Youth Services, 2004).

Respite services are provided as short-term hourly care for the child under the Family Support section of the Act. In- or out-of-home respite is generally up to 240 hours annually, based on but not limited to 20 hours per month. When the assessed need for respite exceeds the maximum 240 hours available under Family Support Respite, additional hours may be provided as long as the child meets the criteria of being significantly limited in activities of daily living. Under the Child Focused section of the Act, up to 30 24-hour days of care annually, either in-home or out-of-home, may be provided. In addition, extended respite services are available if required. These extended respite days are intended to maintain a child's primary residence in the family home while addressing the need for a significant amount of out-of-home respite. If public transport is the only possible means of travel, the cost of the child and one adult to accompany the child from the home to the place where respite services are provided is covered as well (Alberta Ministry of Children and Youth Services, 2004).

No wait list for funding currently exists for respite care in Alberta. However, respite workers are in short supply, as in B.C., so families may have trouble finding suitable people to care for their child. But if someone is available, there is no barrier to accessing the funding for respite care as there is in B.C. Community standards for rates of pay are set; these vary as respite workers generally charge more in remote areas where there are less services available. Funding is allocated based on these community standards, and families are required to pay above and beyond what is provided to them publicly only if the services they use cost more than the community standard in their area. Families are generally able to find adequate workers at the community standard rate of pay (Government of Alberta, personal communication, January 12, 2009).

4.2.3 Case Study Summary

Table 16 displays the key findings from the case studies relative to the findings from the analysis of B.C.'s respite care system. The main ways in which B.C. differs from the other provinces are the wait lists and the eligibility criteria. Both Alberta and Manitoba essentially have no wait lists and provide respite care funding to all families who require it. This implies that their provincial government values families with children with disabilities and makes providing services to them a high priority. Furthermore, both provinces' eligibility criteria are much more inclusive than B.C.'s due to their functionally driven approach rather than a diagnostically driven approach. The deficiencies in B.C.'s system may be partially attributed to the various changes in the ministries and departments in the past several years.

Table 16: Summary of Case Study Findings

	British Columbia	Alberta	Manitoba
Wait Lists	Long wait lists and lack of communication	No wait lists	Wait list to receive respite worker directly from government. Funding is provided in the meantime to obtain respite care elsewhere.
Eligibility Criteria	Diagnostically driven	Functionally driven	Functionally driven
Availability of Respite Care Workers	Shortage of workers	Shortage of workers	Shortage of workers

5: Policy Alternatives

This section describes four policy alternatives that could improve access to respite care in B.C. They were developed through analysis of the survey results and best practices used in other provinces as described in the case studies. The survey results indicated that parents view respite care as a very valuable service that positively affects their families; however, a high level of dissatisfaction with the current system in B.C. was revealed. The following alternatives address the respondents' concerns and could help to ensure that not only more families receive this valuable service, but also that it is delivered more effectively. The alternatives further draw from my analyses of systems in other provinces with methods that could improve B.C.'s system.

5.1 Status Quo

The status quo is included in the policy analysis as a comparison against which to evaluate the other alternatives and to demonstrate how access to respite care would remain without changes to existing policies. The status quo includes the current eligibility criteria, the cost to the user based on income and family size, the wait list structure, and the shortage of respite workers. Since MCFD intends to increase funding for services for children with disabilities and their families in the next few years, this will be considered when evaluating the status quo. With the status quo option, it is important to consider not only the current demand for respite care but also the increasing demand for services for children with disabilities and their families as anticipated by CLBC. Furthermore, CLBC is forecasting that a tight labour market may lead to staff shortages and that the resulting cost escalation may exceed the funded level. It is currently experiencing difficulty in hiring qualified staff and predicts that if this situation continues to worsen, some Service Plan components may not be accomplished (CLBC, 2008a). These challenges will also be considered when evaluating the status quo. While MCFD is in the process of developing new eligibility criteria and improving reporting of waitlist data and number of families served, a framework and timeline for implementation has not yet been announced. Therefore, these changes will not be considered when evaluating the status quo.

5.2 Policy Alternative #1: Elimination of Wait List

This alternative involves providing respite funding to all eligible families in need of it, resulting in the elimination of the wait lists. The long wait lists and lack of communication about their length were among the most common complaints by survey respondents, indicating that it is a notable barrier to accessing respite care. Manitoba and Alberta do not have wait lists for respite care as found in the case study analysis. Although they both have other significant barriers, including a shortage of suitable respite workers, funding is provided to all those in need. In Manitoba, although a wait list exists to receive respite care directly from the province, funding is provided in the meantime for respite services through programs and facilities elsewhere.

In order to eliminate the wait list, a comprehensive and accurate picture of the province must be provided by CLBC. This would involve developing a clear definition of a wait list, a rigorous reporting standard for the regions, and a procedure to compile detailed waitlist data from each region. Once that has been established, the amount of funding required to eliminate the wait list could be determined. This alternative will undoubtedly involve a significant increase in funding from MCFD to CLBC, particularly in areas with a high population density in which the demand for respite services is higher. It is also anticipated that the funding would need to increase in the future as demand for services rises due to population growth.

5.3 Policy Alternative #2: Elimination of Cost to User

This alternative would eliminate the additional cost that families must pay as a function of their income and family size. As mentioned previously, only very low-income families have their respite care fully funded by the government and the income cut-off is very low. Although the out-of-pocket money required may be minimal for middle- to high-income families, it could be a significant burden for families whose incomes are still very low. This situation is compounded by the fact that children with disabilities often impose additional costs and that their parents very often have to change their employment situations, resulting in a decreased income.

Of the case studies examined, other provinces have considerably lower costs to the user than B.C. Manitoba has no cost to the user, regardless of income or other assets. Families in Alberta only have to pay out-of-pocket if they choose to pay a respite worker more than the community standard wage set by their area, which is the amount provided to them by the

government. Thus, in essence both provinces do not require their clients to pay any additional costs over and above what is provided to them publicly. Similar to Policy Alternative #1, this option will require a significant increase in funding in order to provide the same amount of care to each family that currently pays out-of-pocket for their care and to meet the increasing demand.

5.4 Policy Alternative #3: Revised Eligibility Criteria

Although the current eligibility criteria for respite care funding in B.C. are fairly inclusive, they could be altered to be even more inclusive. For example, the criteria for the AHP state that a child must be dependent in three out of the four areas of daily living (eating, dressing, washing, and toileting). The criteria for other respite services are less mechanistic; children who are diagnosed with Autism or a developmental disability qualify. However, this diagnostically driven criterion may continue to exclude some children whose families would benefit from respite care. For example, all children diagnosed with ASD qualify for respite care. Thus, a very high functioning child with autism could be given priority over a child who requires it more, but whose disability does not fit in within the labels provided (D. Steele, personal communication, February 11, 2009). A few survey respondents indicated that they feel that they have to label their child negatively in order to qualify for respite care services. Also, of those who do not have access to public respite care, a number of respondents indicated that they have been denied respite because their child did not meet the eligibility criteria set by the province. One respondent even noted moving from Manitoba, where the child qualified for respite care, to B.C. where the child did not meet the eligibility criteria.

Although guidelines for access to provincial services need to be specific and unambiguous, B.C.'s criteria could be revised for greater inclusiveness. Both Alberta and Manitoba provide examples of how this could be implemented. Alberta's FSCD Act defines disability as "a chronic, development, physical, sensory, mental, neurological condition or impairment that does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal daily living" (Alberta Children and Youth Services, 2004). In order to qualify for respite services in Manitoba, a child must have a mental or physical disability, a developmental delay, a risk of developmental delay, a pervasive development disorder, or lifelong extreme complex medical needs which result in a dependency on medical technology (Manitoba Family Services and Housing, n.d.) Both of these provinces' criteria are broader and more inclusive than those of B.C. but remain clearly defined and unambiguous.

5.5 Policy Alternative #4: Improved Access to Respite Care Workers

The most common complaint among the survey respondents was the lack of qualified workers to provide respite care. Some respondents noted that even when they had reached the top of the wait list and received public funding for respite care, they had to give up their funding because they could not find someone suitable to care for their child. Another common related complaint was that the respite workers are paid a low wage and view the job as only temporary. As a result, children do not have a constant worker for a long period, which can be detrimental as many children with special needs thrive on stability and have idiosyncrasies that take time to learn to manage effectively. Furthermore, other respondents did not like having to deal with the hiring and payroll themselves, which placed an additional burden on their already stressful lives, and noted that a lack of accountability exists in terms of the care providers. For instance, there are no standards for care providers, and their progress with the children is not monitored.

Best practices from Manitoba and Alberta can help to address some of these concerns. Although both provinces also report a significant shortage of qualified and suitable respite care workers, they provide some examples of how B.C. could improve its situation. For instance, both provinces have clearly defined rates of pay for respite workers. In Alberta, these are based on community standards, and Manitoba has specific levels depending on the needs of the child. B.C. could set similar standards with pay rates higher than those currently paid respite workers. Experts would determine the qualifications and standards necessary for each level, and workers would be assessed based on them. Training programs with specific standards would also be made available to those workers who wish to achieve a higher level and corresponding pay scale. Although this would not necessarily eliminate the shortage of respite workers, it could help to increase the supply and also help to ensure that the workers remain in their jobs for longer periods, which would be beneficial for those children who require a stable long-term worker. The increased pay rates for respite workers would require increased funding to respite services.

Another way to improve access to respite care in B.C. is by having the government directly hire and pay the respite workers. These workers would also be held accountable to the government. This should be optional, as some families may already have someone they trust who works well with the child, can properly manage his or her idiosyncrasies and complex needs and can remain a constant presence in his or her life. However, it would be beneficial for those parents who view hiring and paying their respite worker as an increased burden. This option would require an increase in administrative resources, as additional workers would be needed to hire the workers, deal with their payrolls, and hold them accountable. Available respite workers

could then be incorporated into a comprehensive database and organized into categories such as regions and specific qualifications (Mainstream Association for Proactive Community Living, personal communication, February 5, 2009).

6: Criteria

Each policy option will be evaluated based on four criteria to determine how well it achieves the goal of improved access to respite care in B.C. The four criteria are budgetary cost to the provincial government, effectiveness, equity, and administrative feasibility, as described below. Each criterion is given a measure and assessed on a scale of high (3), medium (2), or low (1). The effectiveness criterion is divided into three subcomponents and each one is ranked on the same scale. For the qualitative criteria, a score of 3 means that the alternative ranks well against the criterion and a score of 1 means that the alternative ranks poorly against the criterion. For the quantitative criteria, specific indices are assigned to each score. The scores for each alternative will help support their analysis and will be used to determine policy recommendations. Table 17 displays the criteria and measures used for the policy analysis.

Table 17: Criteria and Measures

Criterion		Definition	Measure	Evaluation Index
Budgetary Cost		Amount of funding required	Amount of additional funding required from the provincial government	High = 3 (<\$1 million) Medium = 2 (\$1 – 3 million) Low = 1 (>\$3 million)
Effectiveness	Number of families receiving care	Extent to which alternative improves access to respite care	Number of families receiving care; amount of funding they receive; quality of care	High = 3 Medium = 2 Low = 1 (Separate ranking for each subcomponent)
	Amount of funding they receive			
	Quality of care			
Equity		Ability to create equal treatment among a specific group	Which families are receiving public respite care - amount of funding they receive with respect to income (vertical equity) and need for respite care due to severity of disability	High = 3 (Improves all equity barriers) Medium = 2 (Improves one barrier) Low = 1 (Does not improve equity)
Administrative Feasibility		Factors such as authority to implement the policy, institutional commitment, financial and staff capability, and organizational support	Ease of implementation for the provincial government and its personnel; staffing resources required	High = 3 Medium = 2 Low = 1

6.1 Budgetary Cost

Budgetary cost in public policy analysis refers to the amount of funding necessary to implement the alternative. In this study, alternatives will be measured based on the amount of provincial government funding they would require. Cost is a particularly important consideration since public respite care depends entirely on government finances, and limited funding appears to be one of the primary barriers to access. It affects the need for waiting lists, the restrictive criteria for eligibility, and the required contribution from participating families above the lowest incomes.

6.2 Effectiveness

Effectiveness refers to the extent to which a proposed policy option addresses the policy problem. In this study, the evaluation of effectiveness will measure the extent to which each alternative improves access to respite care. Subcomponents will include the number of families receiving publicly funded respite care, the amount that they receive, and the quality of care. Each subcomponent will be assigned a separate ranking. Therefore, a greater weight will be placed on effectiveness compared to the other criteria in the final analysis; this is because of the need to improve the respite care system in B.C. despite the costs and efforts required.

6.3 Equity

The equity criterion measures the ability of a policy to create equal treatment among a specific group. Equity in this study will be evaluated by the equality of treatment between parents of children with disabilities within B.C. It will be measured by which families are receiving respite care and how much they are receiving with respect to variables such as income and the need for respite care due to the severity of the child's disability.

6.4 Administrative Feasibility

Administrative feasibility consists of a number of factors, including the authority to implement the policy, the institutional commitment, financial and staff capability, and organizational support. In this study, the primary stakeholder for this criterion will again be the provincial government. This criterion will be measured by the ease of implementation for each alternative and the staffing resources required in the long term. Ease of implementation will be measured by the planning and staffing resources required initially.

7: Evaluation of Policy Alternatives

This section provides an assessment of each of the proposed policy alternatives against the criteria outlined in the previous section. Information received from the survey results and best practices from the case studies is used to evaluate the alternatives. The results of the policy analysis are summarized below in a matrix as Table 18.

Table 18: Policy Matrix

Criteria	Status Quo	Elimination of Wait List	Elimination of Cost to User	Revised Eligibility Criteria	Improved Access to Respite Workers
Budgetary Cost	<i>High (3)</i> Requires \$0	<i>Medium (2)</i> Requires \$2.52 million	<i>Medium (2)</i> Requires \$2.82 million	<i>Medium (2)</i> Requires \$1.68 million	<i>Low (1)</i> Requires \$8 million
Effectiveness	<p>Number of Families: <i>Low (1)</i></p> <p>Amount of Funding: <i>Low (1)</i></p> <p>Quality of Care: <i>Low (1)</i></p>	<p>Number of Families: <i>High (3)</i></p> <p>Amount of Funding: <i>Low (1)</i></p> <p>Quality of Care: <i>Low (1)</i></p>	<p>Number of Families: <i>Low (1)</i></p> <p>Amount of Funding: <i>Medium (2)</i></p> <p>Quality of Care: <i>Medium (2)</i></p>	<p>Number of Families: <i>High (3)</i></p> <p>Amount of Funding: <i>Low (1)</i></p> <p>Quality of Care: <i>Low (1)</i></p>	<p>Number of Families: <i>Low (1)</i></p> <p>Amount of Funding: <i>High (3)</i></p> <p>Quality of Care: <i>High (3)</i></p>
Equity	<i>Low (1)</i> Does not improve inequities in access to respite care	<i>Medium (2)</i> Improves equity since all eligible families receive respite care	<i>Low (1)</i> Only improves access slightly since low-income families now receive full access	<i>High (3)</i> Solves the equity issue of access based on diagnosis rather than function	<i>Medium (2)</i> Allows families who currently cannot find a respite worker to do so
Administrative Feasibility	<i>Medium (2)</i> No implementation required, but a staffing shortage exists	<i>Medium (2)</i> Would eliminate some administrative requirements but would introduce new ones	<i>High (3)</i> Little required in terms of implementation and long term staffing resources.	<i>Low (1)</i> Somewhat difficult to implement, additional staffing resources required	<i>Low (1)</i> Significant administrative and staffing resources required for both implementation and long term
Total Score	9/18	11/18	11/18	11/18	11/18

7.1 Evaluation of the Status Quo

Budgetary Cost: High

The status quo ranks as high on budgetary cost since it requires minimal additional funds from the provincial government. Although the ministry is planning to increase funding for services for children with disabilities in the upcoming years, CLBC predicts that this increase is not sufficient to meet the anticipated increase in demand. It anticipates a growth in demand of 5.5% in 2008-09, and estimates that a 1% increase in population served translates to \$400,000 in additional funds (CLBC, 2008a). This results in a required increase of \$2.2 million for 2008-09 alone, which has been incorporated into CLBC's service plan. However, this cost will not be incorporated into the policy analysis; since all the policy alternatives face the same increase in cost due to demand, the benchmark budgetary cost will be zero.

Effectiveness: Low

- **Number of Families Receiving Care: Low**
- **Amount of Funding Received: Low**
- **Quality of Care: Low**

The status quo ranks low on all of the subcomponents of effectiveness because it does little to improve access to respite care. Although the increase in MCFD funding in the upcoming years may result in more families receiving respite care or families receiving more funding, it unlikely will be sufficient to meet the increasing demand. The quality of care received will also likely be unaffected.

Equity: Low

The status quo also ranks low on equity since no changes are made to which families have access to care or to the provision of respite care as a function of income or the extent of children's disabilities. Only very low income families will continue to receive fully funded respite care, while other families will be required to pay a portion of the costs. While equity as a function of income may not be an issue for middle and higher income families for whom the modest extra cost is not significant, it could be a burden for families whose incomes do not fall below the cut-off but still have low incomes. The existing wait lists, which vary depending on the region in which the family lives, and the current eligibility criteria mean that equity issues in accessing respite care will remain.

Administrative Feasibility: Medium

The status quo is given a medium ranking for administrative feasibility. Since no major changes are made to the existing policy, no authority is needed to implement it, and no changes are made to the organizational structure. Therefore, the ease of implementation appears high. However, a medium ranking is assigned because CLBC is currently having difficulty attracting staff to the area of services for children with disabilities and their families, so the current structure would rank low in terms of staffing resources.

7.2 Evaluation of Policy Alternative #1: Elimination of Wait Lis

Budgetary Cost: Medium

This alternative is assigned a medium ranking for budgetary cost because of the moderate provincial government funds required to implement it. In order to provide respite care funding for every family that requires it, the government would need to significantly increase funds in this area. This is especially true given the expected increase in families with children with disabilities requiring government services such as respite care. According to the CLBC Service Satisfaction Survey, 19 percent of parents from a random sample of families with members with disabilities are waiting for respite and other publicly funded services. In order to provide funding for all those waiting, considerable funds would be required. An estimated approximately 900 families are on the wait list for respite care in the province. Based on the general maximum of \$2,800 per year provided, it would cost about \$2.52 million to eliminate the wait list. In order to continue providing the funding in subsequent years and to accommodate the increasing demand, this additional funding would need to be maintained over time.

Effectiveness: Medium

- **Number of Families Receiving Care: High**
- **Amount of Funding Received: Low**
- **Quality of Care: Low**

The elimination of the wait list allows many more families to access public respite care and eliminate the associated equity issue. However, it does not address some other important barriers. For instance, many survey respondents noted that even when they have access to respite care funding, they are not able to find a suitable respite worker to care for their child. Thus, the subcomponent of effectiveness improved by this option is the number of families receiving respite care; it would increase by about 900 families, the approximate length of the wait list. The

amount of funding received by each family and the quality of care would be unaffected. If implemented on its own, this alternative would only moderately improve access to respite care. If implemented in conjunction with the other alternatives, it could significantly improve access.

Equity: Medium

This alternative is also ranked as medium because, similarly to effectiveness, it would help to ensure that more families in need of respite care receive it, but it does not address some other important barriers. Although it would help to make the system more equitable since all families requiring care would receive it, if the current eligibility criteria and cost to users were still in place, inequities would still exist. Therefore, as in the case of the effectiveness criterion, this alternative would significantly improve equity only if implemented simultaneously with other policy alternatives.

Administrative Feasibility: Medium

The elimination of the wait listed is assigned a medium ranking because it would eliminate some administrative requirements but would introduce some new ones. Fewer staffing resources would be required to administer the wait lists. However, more staff resources would be required to manage the greater number of families receiving respite care services, and additional administrative resources would be needed to implement the change.

7.3 Evaluation of Policy Alternative #2: Elimination of Cost to Users

Budgetary Cost: Medium

The elimination of the cost to users would require a moderate amount of government funds and is thus assigned a medium budgetary cost ranking. In order to cover the costs of the families who are currently paying a portion of their respite costs, additional funds would be required. For example, two-person families earning more than \$1,082 monthly with children under 12 would need to be covered for the \$422 they pay annually, and those with children over 12 would need to be covered for the \$533 they pay annually. The vast majority of families have incomes above the income cut-off and must pay about \$470 (the rough average of \$422 and \$533). When considering that approximately 6,000 families receive respite care, the provision of this \$470 would cost the government \$2.82 million (approximately a 20 percent increase).

Effectiveness: Medium

- **Number of Families Receiving Care: Low**
- **Amount of Funding Received: Medium**
- **Quality of Care: Medium**

This alternative is assigned a medium ranking on effectiveness because although it may not help to improve all of the subcomponents for this criterion, it could significantly improve at least one of them. Eliminating the cost to user would not necessarily increase the number of families receiving respite care. However, the amount of respite care provided publicly would increase by about 20 percent for those who already do have access. This would affect most families who currently receive public funding since only very low-income families receive the full funding at no extra cost. The quality of care received may also be indirectly improved by this alternative since families may be able to afford respite workers with higher qualifications better suited to the complex needs of their child.

Equity: Low

This alternative is ranked as low because it would help to only slightly improve one aspect of the inequity issue at hand, but when implemented in isolation does not address another important barrier. Eliminating the cost to user would help to improve equity slightly since low-income families who currently have to pay a portion of the cost would have fully subsidized access to public respite care. However, since it does not specifically address the wait list, and therefore the amount of families receiving the funds, inequity would still exist. The measure of equity in terms of the need for respite care due to the extent of the child's disability is also not addressed by this alternative.

Administrative Feasibility: High

Eliminating the cost to users ranks high on administrative feasibility since it would not result in any significant changes in administration. It would be easy to implement since all beneficiaries would receive the full amount, and no effort would also be required in the long term. Little would also need to be altered in terms of staffing resources. Fewer resources may even be required since the cost to user would not need to be determined for each family.

7.4 Evaluation of Policy Alternative #3: Revised Eligibility Criteria

Budgetary Cost: Medium

Revised eligibility criteria is assigned a medium budgetary cost ranking because more families would be eligible for public respite care and would therefore require provincial funding. The survey results indicated that a number of families have been denied respite care due to the current eligibility criteria, which reveals that broadening the criteria would result in a greater number of families receiving this service. The most recent CLBC service plan notes that changes in eligibility criteria could lead to a significant increase in costs (CLBC, 2008a). With an estimated 10 percent increase, this results in an additional 600 families. If they all received \$2800 annually, this would require approximately \$1.68 million in government funds.

Effectiveness: Medium

- **Number of Families Receiving Care: High**
- **Amount of Funding Received: Low**
- **Quality of Care: Low**

This alternative is assigned a medium ranking because it would expand access to respite care by about 600 additional families. Families with children whose disabilities do not currently meet the province's eligibility criteria would be able to apply for and receive funding under this alternative. CLBC predicts that a change in eligibility criteria would lead to a significant increase in the population served (CLBC, 2008a). Other measures of effectiveness, the amount of funding received by families and the quality of care, are not addressed specifically by this alternative.

Equity: High

'Revised eligibility criteria' is scored as high on the equity criterion because it would help to ensure that a greater number of families who would benefit from respite care have access to it. The current eligibility criteria based on diagnosis rather than function creates major inequities, and this alternative directly address this. Consequently, the amount of respite funding would be affected since families not eligible for this service prior to the change will potentially receive public funding equal to their counterparts who had access to it prior to the change. Thus, in terms of the measures for this criterion, equity would improve with respect to the extent of the child's disability and the amount of funding received by families. The amount of funding provided with respect to income would be unaffected.

Administrative Feasibility: Low

This alternative is assigned a low ranking because it would be relatively difficult to implement and would require some additional staffing resources. In order to be implemented, the specific eligibility criteria to be adopted would need to be carefully considered and refined by a variety of government officials and other stakeholders such as health professionals. Additional staffing resources would also be required, both initially and in the long term, as more families would apply and be eligible for the service.

7.5 Evaluation of Policy Alternative #4: Improved Access to Respite Care Workers

Budgetary Cost: Low

Improving access to respite care in the form of setting a standard rate of pay and introducing the option of having the government hire the workers would require a large amount of additional government funding. An increase in pay would translate into more funding for each family in order for them to receive the same amount of respite care hours. The current respite workers' pay increase would comprise a portion of this additional funding. Currently, families receive about \$2800 or 28 days per year; based on a 10-hour day, this results in a \$10 hourly wage for the respite workers. An increase to \$13.50 per hour is proposed; this is comparable to wages received by Early Childhood Educators in B.C. (ECEBC, n.d.). This would result in an increase of about \$1,000 of additional funding per family. For the 6,000 families currently receiving respite care, this results in a total funding increase of \$6 million. Government resources would also be required to hire the workers, create and maintain the provincial database of workers, and provide benefits; this would cost an estimated \$2 million. Thus, this alternative would cost an estimated \$8 million.

Effectiveness: High

- **Number of Families Receiving Care: Low**
- **Amount of Funding Received: High**
- **Quality of Care: High**

This alternative would help to improve access to respite care, particularly the 'quality of care' subcomponent. This measure is directly addressed by the alternative since a higher standard rate of pay and more rigorous standards would likely elicit more qualified and consistent respite care providers. Although it does not directly increase the number of families receiving respite care, this may be improved indirectly since families who have access to funding but cannot find a

suitable care provider will be more likely to find quality care with this alternative. The amount of funding provided to each family would also increase by an estimated \$1,000 annually as they would be required to pay the respite workers more.

Equity: Medium

Improving access to respite care workers is assigned a medium ranking because the increased availability of respite workers would improve equity across families. Currently, some families are able to find adequate workers while others are not, which creates inequity. Improving access to workers would improve equity in that sense. However, access as a function of income and the child's disability would remain unchanged, so some equity issues would remain.

Administrative Feasibility: Low

This alternative ranks low on administrative feasibility because considerable resources would be required in terms of both implementation and staffing in the long term. For implementation, standard rates of pay would need to be set, and specific requirements would need to be determined in consultation with a variety of stakeholders. Considerable staffing resources would also be required, both initially and in the long term, to hire the respite workers, train them, manage their payrolls, and maintain the provincial database of workers.

7.6 Evaluation of Criteria

The policy alternatives presented here are not mutually exclusive. They should be examined not only in terms of how they would affect access to respite care individually, but also how they would operate if implemented concurrently. When evaluated solely in terms of the total score received, none of the alternatives rank much higher than the status quo; they all receive scores of 11 compared to the status quo score of 9. This highlights the importance of evaluating how the alternatives rank when implemented simultaneously and demonstrates that no single alternative will significantly improve access to respite care in B.C. In theory, adopting all four policy alternatives would greatly improve on the existing policy problem. However, this is likely unrealistic from both a budgetary and an administrative perspective. Therefore, this section provides an analysis of which combinations of alternatives would most improve respite care in terms of each criterion; this assumes that each criterion taken alone is the sole policy objective. The status quo is not included in this analysis since it does not address any of the barriers to respite care.

Budgetary Cost

Of the four proposed policy alternatives, three rank medium on budgetary cost since they require moderate additional provincial government funds to be implemented (between \$1 million and \$3 million). Improved access to respite care workers, is assigned a low ranking at \$8 million. The additional funds required are compounded by the increase in demand for services in the upcoming years predicted by CLBC. This demonstrates that regardless of the combination of policy alternatives chosen, the government will need to increase funding in this area significantly.

Effectiveness

Effectiveness received a greater weight than the other criteria due to the importance of improving access to respite care, which is directly addressed by this criterion. ‘Improving access to respite care workers’ received the highest total score on effectiveness because it improves two of the subcomponents significantly. If all four policy alternatives were implemented, effectiveness would improve greatly since all of its measures would be improved significantly. That is, the number of families receiving respite care, the amount of funding they receive, and the quality of care would all be improved. However, a more feasible combination of alternatives that would address all the measures is ‘revision of the eligibility criteria’ and ‘improving access to respite care workers.’

Equity

Revising the eligibility criteria receives the highest ranking on equity because it eliminates the inequities of basing eligibility on diagnosis rather than function. Eliminating the wait list addresses equity in terms of the number of families receiving the funding; if implemented, all eligible families would receive access. Therefore, implementing ‘elimination of the wait list’ concurrently with ‘revised eligibility criteria’ would best address the equity issues.

Administrative Feasibility

All of the alternatives require administrative resources, either for implementation or in the longer term. ‘Elimination of the cost to user’ is the most feasible option in terms of ease of implementation and staffing resources while the other three alternatives require more resources.

7.7 Policy Recommendations

This section describes three combinations of policy alternatives that would best improve access to respite care. The first proposed combination is all four alternatives. The alternatives are very different as each addresses all measures of various criteria, and no single alternative addresses all the barriers to respite care. Therefore, they could all be implemented concurrently to effectively improve the policy problem; this would ensure that each measure of each criterion would be improved, and access to respite care would be improved considerably. However, since none of the alternatives ranks high in terms of budgetary cost, introducing all of them may be unrealistic. This could be a long-term goal for implementation over a number of years. Some other combinations that also help to improve respite care to a lesser extent but that are less costly and easier to implement in the short term are thus also proposed.

If only one alternative were to be implemented, it should be ‘revised eligibility criteria.’ It is the least expensive alternative in terms of budgetary cost, eliminates an important inequity issue, and significantly improves effectiveness in terms of the number of families able to access public respite care. Furthermore, although it would be somewhat difficult to implement, once the new criteria were in place no significant additional administration would be required in the long term (other than those required for the greater number of families receiving care).

The first proposed combination is ‘elimination of the wait list,’ ‘revised eligibility criteria,’ and ‘improving access to respite care workers.’ With these three options, nearly all the main barriers to accessing respite care and the measures for each criterion are improved. ‘Elimination of the cost to user’ is not included because even without it effectiveness and equity are both improved on every measure. It also ranks medium on budgetary cost and requires some administrative resources. Therefore, excluding it would be less costly than implementing all four alternatives yet would still improve access to respite care considerably.

The second proposed combination is ‘elimination of the wait list’ and ‘revised eligibility criteria.’ Although these two alternatives do not remove all barriers to accessing respite care and do not improve all the measure of all the criteria, they do address very important equity and effectiveness issues. If implemented, the number of families receiving care would increase substantially. They both rank medium on budgetary cost and are feasible administratively. Therefore, these two alternatives most effectively address the policy problem in the most cost-efficient manner.

8: Conclusion

My study proposes policy alternatives to improve access to respite care for parents who have children with disabilities in B.C. These alternatives are evaluated based on insights derived from a review of the literature, analysis of survey data, and best practices used in other provinces in Canada. Research shows that caring for a child with a disability is very stressful, that respite care can help to relieve this stress, and that a number of significant barriers currently exist in accessing this service in B.C. Survey data confirm that parents value publicly funded respite care highly and that many are having problems accessing this valuable service. Review of respite care systems in Alberta and Manitoba reveals a number of practices that could potentially be adopted in B.C. to improve the system.

The policy alternatives proposed through the analysis are elimination of the wait list, elimination of the cost to the user, revised eligibility criteria, and improving access to respite care workers. These alternatives are not mutually exclusive, and this is highlighted by the fact that they all received identical scores and not high above the status quo when evaluated against the criteria of budgetary cost, effectiveness, equity, and administrative feasibility. This demonstrates that a combination of alternatives should be implemented to improve access to respite care. Although implementing all four of them would be the most effective, this is likely unrealistic in terms of budgetary and administrative resources, at least in the short term. Therefore, the study also proposes combinations of alternatives that would be more feasible but would still be effective in addressing the policy problems and reducing the existing barriers to respite care.

This evaluation also reveals that all the policy alternatives require significant budgetary and administrative resources. Although adopting policies that will effectively improve access to respite care for parents who have children with disabilities in B.C. may seem costly and difficult to implement, they are necessary in order for these children to enjoy their full citizenship rights.

Further research is required to more effectively improve access to public respite care. More research should be conducted to determine how access could be improved specifically in the different regions across the province. B.C.'s regions vary greatly in terms of population density, and this affects access to services considerably. For example, areas with large populations, such as Vancouver, have much greater demand but also have relatively better access to respite workers than other areas. In contrast, Northern regions likely have less demand but less access to qualified workers. These differences have significant consequences on how the budget should be allocated and how the various policy alternatives should be implemented differently in the various regions. The provincial government must also improve its measurement and

recording systems as well as coordination between the regions. It currently lacks concrete numbers and accountability regarding how many families have access to respite care and the length of the wait lists. Access cannot be significantly improved in an efficient way until the precise extent of the problem is known.

Appendix

Survey Instrument

PART A

1. Are you:

- Female Male

2. Is your family a:

- Single-parent home Two-parent home
 Other (please specify) _____

3. Your age:

- 25 or younger
 26-29
 30-34
 35-39
 40-44
 45-49
 50 or older

Your spouse's age (if applicable):

- 25 or younger
 26-29
 30-34
 35-39
 40-44
 45-49
 50 or older

4. How many children (under 18 years) currently live in your household? _____

5. How many children in your household have a disability? _____

6. What age is/are your child(ren) with disability/ies? _____

7. Briefly describe your child(ren)'s disability/ies.

8. Briefly describe the nature and extent of extra care, supervision, medication, or other regular special care services the child routinely requires.

9. Does your child's disability restrict him/her from attending regular school?

- No Yes

If yes, what other accommodations have been made?

PART B

10. On average, how many hours per week do you spend in paid employment?

11. On average, how many hours per week does your spouse/partner spend in paid employment (if applicable)? _____

12. Has either your or your spouse/partner's employment situation been affected by the special needs of your child? (Such as turning down a promotion or better job, working fewer hours, or changing hours of work).

No Yes (please specify)

Self _____

Spouse _____

13. What is your annual household income?

- \$0 - \$19,999 \$20,000 - \$39,999 \$40,000-\$59,999
 \$60,000 - \$79,999 \$80,000 - \$99,999 \$100,000-\$119,999
 \$120,000 or more

14. Do you receive unpaid respite care from others such as relatives, friends, and neighbours?

No Yes

If yes, how many hours per month? _____

15. Do you currently have access to publicly-funded respite care?

No Yes

If no, proceed to Part C. If yes, proceed to part D.

PART C

16. Have you attempted to access public funding for respite care? No Yes

17. If yes, for how long have you been attempting? _____

18. If no, why have you not attempted?

19. Are you currently on a waiting list for respite care? No Yes

20. Have you ever been denied respite care because your child did not meet the eligibility criteria set by the province? No Yes

21. Do you pay for respite care privately? No Yes

22. Please indicate, on a scale of 1 to 5, the extent to which you think having access to publicly funded respite care would improve the well-being of your family.

Not at all 1 2 3 4 5 Significantly

Please add any other comments you have about your experiences with accessing public funding for respite care, including barriers to access that you feel could be improved.

END OF SURVEY

PART D

23. For how long have you been receiving respite care? _____

24. Before receiving care, were you placed on a waiting list? _____

25. If yes, for how long? _____

26. Do you receive care:

- a) At your home _____ b) At the respite worker's home _____
c) At an authorized facility _____ d) Other (please specify) _____

27. How much respite care is publicly provided to you? (Please answer in either dollar amount or number of days)

\$ _____ per month / year (circle one)
_____ hours per week / month / year (circle one)

28. Do you pay for any other respite care privately, beyond what is provided to you publicly (including user fees at facilities)? No Yes

If yes, approximately how much per month? \$ _____

29. Please indicate, on a scale of 1 to 5, the extent to which you think having access to publicly funded respite care has improved the well-being of your family.

Not at all 1 2 3 4 5 Significantly

30. Please indicate, on a scale of 1 to 5, your overall satisfaction with the amount of respite you receive publicly.

Not at all satisfied 1 2 3 4 5 Extremely satisfied

31. Please indicate, on a scale of 1 to 5, your overall satisfaction with the quality of respite care you receive publicly.

Not at all satisfied 1 2 3 4 5 Extremely satisfied

Please add any other comments you have about your experiences with accessing public funding for respite care, including barriers to access that you feel could be improved.

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