

**Failing Families:
The Case for Increasing Supports for Families
Impacted by Autism Spectrum Disorder**

by

Allison Kathleen Rounding

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Approval

Name: Allison Rounding
Degree: Master of Public Policy
Title: *Failing Families: The Case for Increasing Supports for Families Impacted by Autism Spectrum Disorder*

Examining Committee: **Chair:** Nancy Olewiler
Professor, School of Public Policy, SFU

Olena Hankivsky
Senior Supervisor
Professor

Kora DeBeck
Supervisor
Assistant Professor

Michael Orsini
External Examiner
Professor

Date Defended/Approved: March 16, 2016

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Abstract

The prevalence of autism spectrum disorder (ASD) is rising, and supporting individuals with ASD and their families is of increasing importance. Caregiving responsibilities associated with ASD are known to negatively affect employment and income. Yet in BC, government funding only partially covers the costs of autism treatments, leaving parents with significant out-of-pocket costs. An online survey of parents of children with ASD was used to gauge the actual impact of caring for a child with ASD on parental employment and income, and to identify policies that would better support their families. The results demonstrate that households impacted by ASD face high levels of financial stress, experience significant negative effects on parental employment, and need a range of more supportive government programs. Along with the status quo, this project assesses four policy options - increasing funding under the existing Ministry of Children and Family Development (MCFD) program, adding coverage for autism treatment within the healthcare system, integrating ABA into the public school system, and offering leave for parents to care for their child. The report recommends increasing funding under the MCFD model, along with other supportive policies.

Keywords: Autism spectrum disorder; ASD, caregiving; online survey; British Columbia; financial stress; parental income; employment effects; Ministry of Children and Family Development; children with special needs

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List of Acronyms

ABA	Applied Behavioural Analysis
AFU	Autism Funding Unit
ASD	Autism Spectrum Disorder
ASBC	Autism Society of BC
BCAAN	British Columbia Autism Assessment Network
BI	Behavioural Interventionist
CASDA	Canadian Autism Spectrum Disorders Alliance
CIHR	Canadian Institutes of Health Research
DSM	Diagnostic and Statistical Manual of Mental Disorders
IEP	Individualized Education Program
MCFD	Ministry of Children and Family Development
MSDSI	Ministry of Social Development and Social Innovation
NEDSAC	National Epidemiological Database for the Study of Autism
RESP	Registered Education Savings Plan
RDSP	Registered Disability Savings Plan

Glossary

Autism Spectrum Disorder (ASD)	A neurological disorder that is characterized by difficulties in social interaction, communication abilities, and repetitive behaviours. The abilities of an individual with ASD vary widely across the spectrum, but many people with ASD require assistance with daily living activities. ASD is a lifelong condition, but Applied Behavioural Analysis (ABA) and other specialized services can improve the functioning of individuals with ASD.
Neurotypical	A person without a developmental disability such as autism.
Neurodiversity	The concept that neurological differences, like ASD, are a normal and natural result of variation in the human genome.

Executive Summary

The prevalence of autism spectrum disorder (ASD) is increasing, and now affects 1 in every 68 children (Centre for Disease Control [CDC], 2014). ASD is a lifelong condition that impacts communication and social skills, but with support and help of early intervention services, like Applied Behavioural Analysis (ABA) based programs, children with ASD can reach their best outcomes. ASD also impacts a child's family – the demands of caring for a child with ASD impact parents' careers and reduces their income, at the same time that they are faced with new out-of-pocket expenses related to their child's condition. Coverage for ASD therapies and interventions is not covered by the Canadian healthcare system. In the public school system children with ASD may or may not receive support tailored to their needs, which leads to families paying for at-home programs and/or home-schooling. Provinces, such as BC, provide some coverage for ASD interventions through social services, but families impacted by ASD regularly pay for their child's support services out-of-pocket, frequently to the tune of thousands of dollars per year. The public policy issue is that the direct and indirect costs of caregiving for a child with ASD places an excessive burden on families, and places their child's functioning and the household's financial future in jeopardy.

An online survey of 197 parents of children with ASD in BC was used to investigate the extent of the employment effects and out-of-pocket costs of caregiving, and to determine which policies and supports are most needed by parents. The results indicated high levels of financial stress and concern for the future of their child. Respondents reported serious employment effects – three quarters experienced a career or paid work interruption related to their child's diagnosis, over a third voluntarily left the labour force, and a third reduced their work hours to part-time, therefore decreasing their income. There was a wide range of out-of-pocket costs, but the average was \$6,745 annually per child with ASD and the median was \$4,000 annually. The bulk of these expenses were for items partially covered by MCFD: behavioural therapy, respite care, and services from paraprofessionals (e.g. speech therapy, occupational therapy, physical therapy).

These survey results were used to inform a policy analysis and make a policy recommendation for the province. Along with the status quo, four policy options were

considered: increasing and targeting funding under the existing Ministry of Children and Family Development program, adding coverage for autism treatment within the healthcare system, integrating ABA into the public school system, and offering leave for parents to care for their child. These options were evaluated using five criteria: equity, stakeholder acceptability, efficacy, cost to government, and implementation complexity. This report recommends that the province of BC immediately increase and target funding for children with ASD using the current MCFD program. The success of this policy would also require complementary measures to increase access to services in rural areas, respite care, and childcare. In the long term, this report recommends integrating ABA into the public school system.

Chapter 1. Introduction

On April 3, 2014, Angie and Robert Robinson were found dead in their Prince Rupert home. Angie, overwhelmed by the stress caregiving for Robert, her 16-year-old son with ASD, gave him a fatal overdose of his anxiety drugs. She then killed herself. Robert was a large, non-verbal young man who was severely impacted by his ASD and intellectual disability. Robert's aggression worsened as he went through puberty, and Angie was no longer able to handle his physical aggression. He would punch holes in the walls, and smash through car windshields. The RCMP had been called on two occasions to subdue him (Ministry of Justice, 2015b, p. 6). Angie was overwhelmed by the financial, emotional and physical stress of caring for Robert. The \$6,000 in annual funding she received from the Ministry of Children and Family Development (MCFD) did not cover the costs of his one-to-one worker (Ministry of Justice, 2015b, p. 3). Robert also received special education and life skill classes his local high school. Angie and Robert were eligible for respite care from MCFD, but it was not available in Prince Rupert. Angie took the bus with Robert to Terrace, over 150 kilometers away, for respite care. The travel required to access respite care meant that Angie was unable to use her full allotment of respite care (Ministry of Justice, 2015b, p. 4). In the days before their deaths, Angie contacted MCFD and explained that she could no longer care for Robert. They were unable to provide her with immediate help, so Angie made a permanent, desperate, and tragic decision to end their lives.

The responsibility for their deaths goes beyond issues of ASD related public policy – Angie was in an abusive relationship, she struggled with mental illness and had previously attempted suicide – but the lack of support available for families impacted by ASD certainly played a role in their deaths. The jury in the coroner's inquest issued recommendations to this effect, recommending that transportation issues be addressed separately from MCFD autism and respite care funding (Ministry of Justice, 2015a, p. 9),

the availability of ABA training in rural areas be increased, and the \$6,000 annual cap on funding for youth with severe ASD be re-evaluated (Ministry of Justice, 2015b, p. 10).

The story of Angie and Robert Robinson is an extreme example of what can happen when adequate support services are not available, but many other families in BC are struggling. The policy problem is that the indirect and direct costs of caregiving places an undue burden on families impacted by ASD, and places their child's functioning and the household's financial future in jeopardy. ABA treatment is not covered by the Canadian healthcare system. While some provinces provide funding and support services through their social service ministries, there are long wait times and no province fully covers the cost of ASD treatment, leaving families with large out-of-pocket bills related to their child's condition. These out of pocket costs are compounded by the caregiving responsibilities related to ASD and their impact on parental employment. Nationwide just 15% of families with ASD say that they can easily afford to pay for ASD related services (Weiss et al., 2014, p. 32). The Canadian Senate acknowledged this problem in a 2007 report, stating that "the financial burden on these families and caregivers is excessive and a solution must be found" (Canada, Parliament, Senate, 2007, p. 14). This problem is expected to grow, as autism is the fastest growing developmental disability in North America (Baker, 2007, p. 688). As of 2014, one in every 68 children¹ has ASD (CDC, 2014). The vulnerability of families affected by ASD raises serious concerns about equity, and poses a significant public policy problem as the prevalence of ASD increases.

This policy problem is a classic problem involving the distribution of services. As Stone has argued elsewhere, "there wouldn't be a policy conflict if there were not some advantage to protect or loss to prevent" (Stone, 1998, p. 40). The lack of government support for ASD services is a hot button issue for parent activist groups, but government services for children with ASD are often meagre. Research done in the United States, Sweden and the UK (Järbrink et al., 2003; Järbrink, 2007) demonstrates the burden of ASD related costs on families, but there is a lack of data on the impact of ASD caregiving

¹ This figure comes from American research, as no comparable prevalence estimates are available for Canada. There is some concern over the methodology of the CDC estimates (Mandell & Lecavalier, 2014) but this is the best prevalence estimate currently available. The prevalence in BC is very close to this figure, with 1 in 69 children receiving autism funding according to Autism Community Training (CBC News, 2015 Dec 8).

upon income and employment in Canada. By conducting an online survey of parents of children with ASD in BC, this project addresses this knowledge gap.

This project focuses on provincial public policy related to ASD due to provincial jurisdiction in this area. BC was chosen because this province has been site of important legal cases related to ASD policy, and has a politically active community of parents of children with ASD. Additionally, the BC government provides more generous ASD support than many other Canadian provinces, but parents still report struggling to pay for their child's treatment while also engaging in paid work. The survey attempts to quantify these employment effects and out-of-pocket costs. The survey asks primary caregivers of children with ASD questions related to five key areas: parent and child demographics, parental employment status and trajectories, income, spending on ASD related out-of-pocket expenses, and planning for the financial future of the child(ren) with ASD and their parents.

The data from this original survey, as well as information gathered from the academic literature, is used to evaluate policy options for ASD funding and supports in BC. Along with the status quo, four policy options are considered: increasing funding under the existing Ministry of Children and Family Development program, adding coverage for autism treatment within the healthcare system, integrating ABA into the public school system, and offering leave for parents to care for their child. These options are evaluated using five criteria: equity, stakeholder acceptability, efficacy, cost to government, and implementation complexity.

In the short term, this report recommends that the BC government increase and target funding for children with ASD under their existing MCFD program, while also implementing complementary supportive policies. In the long term, this report also recommends that ABA based methods be used in the BC public school system. The knowledge gained from this project will be shared with the Autism Society of BC and the online parent groups who distributed the survey within BC. Given the rising prevalence of ASD, and the lack of adequate support services throughout most of Canada, it is hoped that other jurisdictions can take away lessons from this research. Even though BC is relatively generous compared to other provinces, families impacted by ASD are struggling

to balance their careers with caregiving, afford effective levels of early intervention programs, respite care, and childcare, and plan for their financial future.

Chapter 2. Background

This section provides the background to autism and autism related policy. It includes information about ASD symptoms and prevalence, and explains ABA. Next, international ASD policies are examined, and provincial and federal involvement in Canadian autism policy is explained, as are the legal challenges that shaped those policies.

2.1. Autism Spectrum Disorder (ASD) and Applied Behavioural Analysis (ABA)

ASD is a neurological disorder that causes difficulties in communication and social interaction. The cause of ASD is unknown, although it may be related to genetics (Waterhouse, 2008, p. 280). Typically, children begin showing signs of ASD by age 3, and it affects more boys than girls (Baker & Drapela, 2010, p. 582). There is no simple medical test, like a blood test or a brain imaging scan, that can detect ASD – professionals diagnose ASD through the presence of ASD behaviours and symptoms (Krahn, 2012, p. 297). Individuals with ASD² typically demonstrate restricted and repetitive patterns of behaviour, or intense interest in particular activities or topics. People with ASD may be especially sensitive to sensory information. Many comorbid conditions are associated with ASD – epilepsy, sleep problems, speech and language difficulties, intellectual disabilities, gross and fine motor impairments, digestive issues, and anxiety, among others (Treating Autism, 2013). ASD describes a wide spectrum. While some people with ASD can be non-verbal and require assistance with daily living activities for the rest of their lives, others are

² The language used to discuss ASD is controversial within the autism community. Some individuals prefer the term autistic person since they see themselves as inseparable from their autism (Orsini, 2012, p. 823). This is the position typically held by neurodiversity advocates, including the Autistic Self Advocacy Network (ASAN). ASAN states that “what we are saying when we say “person with autism” is that the person would be better off if not Autistic, and that it would have been better if he or she had been born typical...we are saying that autism is something inherently bad like a disease” (ASAN, 2011). Others, particularly parents, prefer “person-first” language and use the term individual with autism. Like Baker (2007, p. 696), I will be using person-first language throughout this project since I will be discussing children who may be non-verbal, unaware of their ASD, or too young to choose their preferred terminology. The politics and theory behind the language used to describe autism is an important topic worthy of debate. However, it falls outside the scope of this public policy capstone.

able to live independently in much the same way that a neurotypical person can.

The prevalence of ASD is rising. In the 1940s, autism was thought to affect 1 in 10,000 people, the vast majority of whom did not live independently (Baker & Drapela, 2010, p. 582). ASD now affects 1 in 68 children (CDC, 2014). However, the reason for this increase is unclear. Although the theory that childhood vaccines cause autism was widely discussed in the media, the scientific community has discredited these claims (Waterhouse, 2008, p. 274). The increase in ASD prevalence may be due to increased awareness of autism and better diagnosis of ASD (Oullette-Kuntz, 2014, p. 131), changing diagnostic criteria and screening practices (Waterhouse, 2008, p. 276), or changes in genetic susceptibility or non-genetic influences (Oullette-Kuntz, 2013, p. 130). Furthermore, the prevalence of ASD varies widely in different places, and that there are geographic, racial, ethnic and cultural differences in the prevalence and diagnosis of ASD. For instance, the CDC found that 1 in 45 children in New Jersey had ASD, while only 1 in 175 children in Alabama had ASD (Mandell & Lecavalier, 2014, p. 483). In Canada, the prevalence of ASD is higher in southwestern Ontario than it is in Prince Edward Island or New Brunswick (Oullette-Kuntz, 2013, p. 130). Autism exists worldwide, but cultures perceive it differently. For instance, in Korea ASD is believed to result from bad parenting, and parents prefer to have their child diagnosed with reactive attachment disorder to avoid stigma (Kim, 2012, p. 538). In contrast, Kim found that in Nicaragua ASD was not well understood, but the community accepted people's quirks and disabilities (2012, p. 544). There are also cultural differences relating to ASD in Canada. For example, Lindblom suggests that ASD may be under-diagnosed in Aboriginal communities due to a lack of medical services, an ethnic bias on behalf of medical professionals, and cultural factors (2014, p. 1254-1257).

There is no cure for autism, although there are various treatments. Applied Behavioural Analysis (ABA) is widely thought to be one of the most effective treatments

for ASD³. Studies indicate that ABA based programs improve children's IQs and adaptive behaviours when compared to other interventions (Velazquez & Nye, 2011, p. 71). Children who receive ABA based interventions have higher levels of educational functioning and are more likely to be in mainstream classrooms (Warren et al., 2011, p. 1307). ABA may be particularly helpful for children who are severely impacted by ASD, and current data demonstrates that ABA is generally more effective than other forms of intervention (Reed & Osborne, 2012, p. 134). Individuals with ASD can also benefit from job coaching, social skills training, specialized recreational programs and other interventions (Baker, 2007, p. 690). An ABA program for ASD typically involves intensive therapeutic program involving one on one work (Baker, 2007, p. 690), and one form of ABA is Lovaas treatment. An ABA program can involve up to 40 hours per week of therapeutic work, and this can cost over \$50,000 CAD per year (Manfredi & Maioni, 2005, p. 120). ABA is a difficult program to manage and service providers can be hard to find, particularly in rural areas (Hodgetts et al., 2013, p. 142). Parents with a child in an ABA program often find themselves taking on new roles as advocates, therapists, coaches, organizers, and case managers for their child's home program (Hodgetts et al., 2013, p. 143). Taking on these multiple roles often causes parents to place their own needs aside, leading to marital breakdown, physical and mental health problems, and interruptions in paid work (Hoogsteen & Woodgate, 2013, p. 137).

2.2. International ASD Policy

Canada's healthcare system does not cover ABA treatment, but neither do other universal healthcare systems. For example, the UK's National Health System (NHS) does not cover any aspect of ABA, though other forms of early intervention services are available for children with special needs. Australia's Medicare system also does not

³ ABA is not without controversy. Some autistic individuals and caregivers feel that ABA is not effective, and that it attempts to erase a child's natural personality (Baker, 2007, p. 690). They object to the idea of trying to "cure" ASD. The Autistic Self Advocacy Network (ASAN) has expressed concern that some ABA practices may be unethical and harmful. In contrast, parents with ASD are more likely to frame early intervention and ABA as medically necessary treatments and therapies (Waddell & Shepherd, 2015, p. 3558). This can be a strategic choice, so that individuals with ASD can better access the redistributive policies of a welfare state (Orsini & Smith, 2010, p. 53)

directly cover the full cost of ABA, although families can be eligible for rebates if their out-of-pocket expenses on applicable services exceed the Medicare Safety Net. Additionally, Australian children with autism can receive up to \$12,000 in funding before their sixth birthday (Autism Spectrum Australia, n.d.). This \$12,000 funding is a lifetime limit for their needs from diagnosis to age six; it is not a yearly payment as it is in BC.

In contrast to these countries with a universal healthcare system, the United States has been praised for its progressive approach towards ASD policy. Despite having a healthcare system plagued with inequities, autism treatment is covered by health insurance in 43 of the 50 states, and the country contributes billions of federal dollars towards ASD research. An important development in the country was the passage of the bipartisan bill - The Combatting Autism Act in 2006 and authorized by President George W. Bush. This law authorized the National Institute of Health to develop and implement a strategic plan for autism research, created education programs for healthcare professionals and the general public, granted money to the states for screening and intervention programs, and to undertake prevalence data tracking. The law was reauthorized in 2011 and 2014 by President Obama, and renamed the Autism Collaboration, Research, Education and Support (CARES) Act (Autism Speaks, 2014). Mandates requiring that insurance providers cover aspects of autism treatment have been passed at the state level. The nature of the mandate varies by state – some states, including California, have no dollar limit for coverage, while other states impose an annual cap on autism related insurance coverage (National Assembly of State Legislatures, 2015). Some states have age limits or lifetime dollar caps to reduce the cost to insurance companies.

With the exception then of the United States, internationally there is little ASD related policy even though The United Nations' Convention on the Rights of the Child stipulates that "children who have any kind of disability have the right to special care and support...so that they can live full and independent lives" (United Nations, 1989). Many countries then, including Canada, are not fulfilling these rights, especially when it comes to children with ASD. Although parent group and activists have responded with outrage, governments around the world have largely been complacent and not made significant progress in supporting people with ASD.

2.3. Federal ASD Policy

Despite the fact that the federal government is not involved in directly providing ASD services, they do offer tax breaks to people with disabilities, and fund ASD research through the Canadian Institutes of Health Research (CIHR). Over 90% of funding for autism research in Canada comes from CIHR (Krahn, 2012, p. 298). Most of this funding is for research related to the biomedical and clinical aspects of ASD, with a focus on the etiology and pathogenesis of the condition. This focus on the potential causes of ASD may be overemphasizing the impairment of individuals at the expense of investigating other aspects of ASD (Krahn, 2012, p. 298). As a result, there are a number of areas of ASD that require more research, including the transition from adolescence to adulthood, brain development across the lifespan, and the need for changing treatment and support services over the lifespan. Notably, Krahn suggests that more research is needed into “what families say they need, what the system provides, and the barriers and facilitators for what families receive” (2012, p. 302). Currently only 5% of CHIR ASD funding goes towards projects aiming to better understand the ways in which cultural, social, environmental and economic factors determine health status (Krahn, 2012, p. 301).

At the federal level there are a number of tax breaks and benefits available to people with disabilities, but eligibility requirements vary. There are no tax breaks or benefits specific to ASD. Families of a child with a disability can claim attendant care expenses, the family caregiver amount, additional child care expenses, and the Disability Tax Credit. Although, as a non-refundable tax credit, the Disability Tax Credit only benefits households who pay income tax, and caregivers who greatly reduce their work hours or leave the workforce entirely will not benefit from this policy. Caregivers of children with ASD under 18 are also eligible to receive up \$2,695 per year from the Child Disability Benefit (Canada Revenue Agency, 2015). Caregivers of children with ASD can open a Registered Disability Savings Plan (RDSP) to provide for their financial future, and the government will match funds up to a certain amount dependent on income. However, given the immediate day to day costs of ASD treatment and care, caregivers may not have money available to contribute to an RDSP. The tax breaks and benefits from both the provincial and federal governments are not enough to balance out the costs of ASD treatment and caregiving.

In the wake of the passage of the Combatting Autism Act in the United States, the Canadian Senate recommended that the federal government work with the provinces and territories to develop a comprehensive National ASD Strategy. The Standing Senate Committee on Social Affairs, Science and Technology issued a report, “Pay Now or Pay Later: Autism Families in Crises,” that called for increased federal involvement in ASD policy. The Standing Committee advocated for provincial and federal collaboration, but ultimately said that it is a provincial responsibility to design and provide services. However, the report urged immediate action to support families, including better funding of ABA and respite care. They also recommended creating a public awareness campaign, a National Autism Strategy, and a Knowledge Centre where best practices would be developed, and then provinces could base their policy off of this knowledge. They also requested a report on tax code measures and how they impact ASD families (Canada, Parliament, Senate, 2007, p. 17-18). As of 2015, these recommendations have largely not been taken up by the provinces or the federal government. Canada does not have a National Autism Strategy. In fact, in 2012 the federal government actually lessened their involvement in autism policy by ending their funding of the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC).

In the lead up to the 2015 federal election, the Conservative government appointed a new Autism Spectrum Disorder Working Group with a \$2 million budget to develop a plan for a Canadian Autism Partnership to address autism research, information sharing, early detection, diagnosis and treatment. This plan was criticized as lip service and a stalling tactic that did not actually help families. The majority of the money will go towards facilitating “stakeholder participation,” while none went to services for families (Canada Economic Action Plan, 2015).

There continues to be a lack of federal legislation related to ASD, despite repeated attempts to change the situation. Bill C-211, introduced by NDP MP Peter Stoffer, proposed adding coverage for autism therapy under the *Canada Health Act* (Canada, Parliament, Senate, 2007, p. 2). Bill C-304, introduced by Liberal MP Shawn Murphy, proposed adding autism therapy to the Canada Health Act as well as creating a National Autism Strategy. Both bills failed (Canada, Parliament, Senate, 2007, p. 2). Bill C-218, another private members bill with a similar goal, failed in 2011. Under the new Liberal

government there does not appear to be any plans for adding autism coverage under the *Canada Health Act*. Since it is unlikely that the federal government will follow the Senate report recommendations anytime soon, the provinces have the most power to create policies that support people with ASD.

2.4. Provincial Autism Policy

Autism funding and supports primarily fall under provincial jurisdiction. Each province funds autism treatment differently through social services, but no province covers all of the out-of-pocket costs that parents face. Most Canadian children with ASD receive some form of intervention services within six months of diagnosis, but it varies by region, raising concerns about inter-provincial equity (Volden et al., 2015, p. e46). BC's ASD funding policies are far from perfect, but nonetheless BC is seen as one of the better provinces for ASD funding and programs. Alberta is seen as the best province in Canada for ASD funding. Through the Family Support for Children with Disabilities program, Albertan children with developmental disabilities, including ASD, receive nearly complete coverage for treatment, respite care, specialized support workers, and other services (Shepherd & Waddell, 2015, p. 3551). Children receive services tailored to their individual needs, and the wait times are minimal (Gordon, April 17 2015).

In contrast, parents view Saskatchewan and Ontario as some of the worst places in Canada to raise a child with ASD. In Saskatchewan ASD services are provided through regional health authorities. The wait lists are long, and services are meagre – children receive one to two hours of government funded therapy per week, despite expert recommendations that children with ASD receive a minimum of 25 hours per week (Wills, April 22 2014). The wait lists in Ontario for diagnosis and services are several years long. Currently there are more children in Ontario waiting for ASD services than there are receiving them, despite a 2013 Attorney General review that highlighted the negative impacts that a service shortage and long waitlists has on children with ASD and their families (Gordon, April 15 2015). Many children in Ontario do not begin receiving services until age 7, several years after early intervention is most effective. A quarter of children were rejected for funding for not having severe enough ASD, and even children deemed to qualify were receiving fewer therapy hours than is recommended (Gordon, April 17

2015; Gordon, Dec 10 2013). Desperate to receive services and help their children, families are moving to other provinces, and even the United States, for better services and funding. Activists call these families “autism refugees” and “Medicare’s orphans”, and argue that the provinces are failing to protect some of their most vulnerable citizens.

In British Columbia (BC), children suspected of having ASD are referred to the BC Autism Assessment Network (BCAAN) for an assessment by a pediatrician, psychiatrist, and/or a psychologist. This assessment is free, however, it is not uncommon to wait for a year to receive a diagnosis. Children under age 6 diagnosed with ASD receive up to \$22,000 annually from the Autism Funds Unit (AFU) of the Ministry of Children and Family Development (MCFD). MCFD gives the funding directly to parents and they can choose whichever provider and therapist they wish, as long as the provider is on the Registered Autism Service Provider (RASP) list. This funding can go towards ABA Behavioural Interventionists and Behavioral Consultants, speech therapy, physiotherapy, occupational therapy and other covered costs. Up to 20% of the MCFD funds may be used for travel to service providers (Ministry of Children and Family Development, 2012). MCFD funds may be used once ever three years to purchase an iPad or other assistive technology or device, but requests for these types of purchases are frequently denied. At age 6, the MCFD direct funding drops precipitously to \$6,000 (Ministry of Children and Family Development, 2012). Given that an ABA program can cost up to \$60,000 per year (Canada, Parliament, Senate, 2007, p. 7), this is a sizeable funding shortfall that caregivers must cover. Children whose families cannot afford to pay for the shortfall are receiving less treatment and will not have optimal outcomes, affecting their functioning for the rest of their lives. This issue raises serious equity concerns – children’s success and access to early intervention services should not be dependent on income, or where they live.

The MCFD funding structure makes no allowance for an individual child’s needs – a child who is mildly impacted by ASD and may be able to attend post-secondary programs receives the same level of MCFD funding as a child who is severely impacted, engages in self-injurious behaviour, and will require constant supervision and care for the rest of their life. Even with this funding, families often find it difficult to find service providers and therapists, especially in rural areas. Travel costs, even if covered by MCFD, come out of their therapy budget and reduce therapy hours for that child. Additionally, this funding is

not means tested. A child of two parents with professional careers will received the same funding as a child of a single mother working for minimum wage. The MCFD ASD funding is not indexed to inflation, and has increased only once since the program was introduced in 2001 (Ministry of Children and Family Development, 2009). If the funding had been indexed to inflation since the program's creation in 2001, the funding would currently be \$26,334 for each child under 6, not \$22,000⁴.

In BC children with ASD may also be eligible for the Infant Development Program and the Supported Child Development Program, which provides support to children so that they can fully participate in pre-school or childcare programs. However, the program is not available in all locations to older children whose require help in daycare or after-school care settings. Many daycares, after-school programs and summer camps will not accept children with autism, leaving parents without reliable childcare. When childcare spaces that accommodate children with special needs are available, they are often expensive. The MCFD offers childcare subsidies to low income families, and the subsidy is higher for children with special needs. Many families above the low income cut off still struggle with finding and affording suitable childcare for their child with ASD. Moreover, although respite care is technically covered by MCFD, families can be on the waitlist for years before receiving any help. This situation is not ideal, since the number of hours of respite care is related to stress and marital quality for couples with a child diagnosed with ASD - even a few hours a month of respite care can make a difference (Harper et al., 2013, p. 2615).

At age 18 the dedicated ASD funding from the BC MCFD ends. There is little disability assistance available for adults with ASD, particularly for those who are able to live semi-independently. Some adults are eligible for disability supports from the Ministry of Social Development and Social Innovation (MSDDI), including provincial Persons with Disabilities Assistance and housing support from Community Living BC (Community Living BC, n.d.). Some adults with ASD are seen as too high functioning to qualify for these supports, yet are unable to live fully independently. Many adults with ASD rely on their families for support. Income from an RDSP is valuable and helps many people with ASD,

⁴ This figure was found using the Bank of Canada's online inflation calculator.

but not all families have the means to contribute large amounts for their child's financial future. There are few skills and job training programs designed for youth and adults with ASD, leaving parents worried about their child's future, and wasting the potential of many adults with ASD. There is little known about adults with ASD in Canada, and no public policies aimed at this population.

In addition to the social services funding provided to families impacted by ASD, the provinces provide special education services as a part of the public school system. British Columbia promises to deliver "an inclusive education system in which students with special needs are fully participating members of a community of learners" (BC Ministry of Education, 2013, p. 2). Students diagnosed with ASD, and whose ASD impacts their educational performance, are eligible for special education services. These students have an Individualized Education Program (IEP) which takes into account their individual skills, and address social behaviours, motor skills, communicative competence and academic performance (BC Ministry of Education, 2013, p. 88). Specialist staff working with students with ASD should "have or acquire skills and training in behaviour management and skill development in social interaction, verbal and non-verbal communication, and social skills" (BC Ministry of Education, 2013, p. 89), although they are not required to be Behavioural Interventionists trained in ABA methods.

ABA is not offered through the Canadian public school system, except in District #36 in Surrey, BC. As a result, families are left to coordinate ABA therapy on their own time and partially at their own expense. There is often a lack of coordination between a child's home team and their school teacher and SEA (special education assistant). The Surrey ABA policy, which began in 2001, is designed to address this issue. There are now 170 ABA Support Workers in the district. They receive 1000 hours of home team based training and training through Surrey College, and are child specific (Autism Support Network, 2015). Families impacted by ASD praise this program, and some have even moved to Surrey to access it, yet school districts have not implemented it. As a result of these issues within the public school system, some parents of children with ASD opt to homeschool, which typically precludes them from working outside the home.

Although BC is relatively generous compared to most other Canadian provinces,

the MCFD program leaves parents covering out-of-pocket costs, and it is not individualized or targeted at the most impacted children. ASD related public policy in BC has many shortcomings, and the province can do a lot to improve their policies.

2.5. Legal Challenges to Autism Policy

The *Charter of Rights and Freedoms* guarantees the right of people with disabilities to live without discrimination, but this has not always resulted in fair and equitable treatment of people with ASD. Funding and supports for ASD in Canada has been a contentious policy area and ultimately culminated in a Supreme Court challenge.

Autism treatment, including ABA, has never been covered under Canada's Medicare system. It is not included as "medically necessary" service under the *Canada Health Act*. Activist parents of children with ASD frame ABA as a healthcare issue and pushed for litigation – their explicit goal was to have the courts mandate healthcare coverage for ABA. One of the key groups behind this push for a court challenge was Families for Early/Effective Autism Treatment (FEAT), an organization with chapters in the US and Canada (Manfredi & Maioni, 2005, p. 120). In 1998 FEAT issued a press release condemning the BC government for failing to fund the one effective treatment for ASD. The deputy ministers of Education and Children and Families responded by saying they were not "in a resource position" to fund ABA (Manfredi & Maioni, 2005, p. 121). Angry at this lack of action, Michelle Auton and her son Connor, along with Sabrina Freeman and her daughter Michelle, launched their lawsuit against the BC government. They argued that the lack of coverage for ABA violated their section 7 rights (the right life, liberty and security of the person) and section 15 (equality) rights under the *Charter*. They asked that the government compensate them for the past and future costs of their children's treatment (Manfredi & Maioni, 2005, p. 121). In 2000 the case went before the Supreme Court of BC, where a principal issue of contention was whether or not ABA is effective. Using evidence from the Office of Health Technology Assessment Services and Policy Research at the University of British Columbia, the BC government argued that the Lovaas studies of ABA were methodologically flawed, and that ABA was an experimental treatment (Manfredi & Maioni, 2005, p. 123). The judge, Justice Allan, was unimpressed with this argument, and criticized the methodology of the government's report. She

determined that “early intensive behavioural treatment” should be covered as a “medically necessary services” under provincial and federal legislation, and found that the children’s equality rights had been violated.

The BC government appealed this decision and the case went before the Supreme Court of Canada in 2004. The Court unanimously ruled that the provinces had not violated section 15 equality rights by declining to fund ABA. Justice McLachlin found that the Canada Health Act and provincial legislation only guarantees a right to core services. Medicare is not truly universal and therefore does not need to cover ABA. This ruling meant that ABA does not need to be funded by the medical system or the provinces, but they can choose to fund it if they wish. Although this legal challenge did not go the way FEAT had hoped, it caused BC to change their policy and provide partial coverage for ABA through the MCFD. However, the rush to fund ASD in the wake of the BC Supreme Court ruling meant that policy was not as well thought out as it could have been (Shepherd & Waddell, 2015, p. 3553). In an interview with Shepherd and Waddell, a policy maker stated “I have significant problems with the autism service delivery system, the way it’s structured right now, it’s something I inherited, and if we were to start from square one, I wouldn’t even begin to approach it that way” (2015, p. 3557).

Another significant legal challenge to ASD policy was the 2006 Hewko case, where a family sued the Abbotsford school district over their failure to accommodate and educate their young son with ASD. They successfully argued that the aide and teacher, selected by the school, were not properly trained in ABA methods and were not able to adequately handle or educate the student with ASD. This ruling affirmed the rights of parents to be consulted before an aide is assigned to work with their child, to participate in designing their IEP, and to review their child’s files. The aide must have “instructional control” over the child. The judge found that there is a lack of ABA training among school staff, and it may be necessary for the school to hire a member of a child’s home team (FEAT, n.d.). However, thus far this case has not lead school districts to adopt ABA programs in classrooms.

The Auton and Hewko cases have lead to important progress in ASD related policies. They are also important to understand when designing ASD related policies

because they establish the fact that changes must come from government, not the courts. Legislation, not litigation, will likely be the future of ASD related policy change in BC and Canada.

Chapter 3. Literature Review

The existing academic literature on ASD caregiving explores several key themes – parental stress related to caregiving responsibilities, direct costs related to ASD, the opportunity costs of caregiving and the effect on paid employment and income, and the social costs of ASD.

3.1. Parental Stress

Raising a child with special needs can be incredibly stressful. A meta-analysis by Hayes & Watson found that parenting stress was higher for parents of children with ASD than parents of children with Down's syndrome and other disabilities (2012, p. 638). Certain symptoms of ASD – impairments in social communication and repetitive behaviours – can be particularly stressful for caregivers to handle (Hayes & Watson, 2012, p. 630). Parents spend their waking hours managing and understanding their child's behaviours. Autism often becomes a “focal point of the family” and it impacts every choice that families make (Hoogsteen & Woodgate, 2013, p. 136).

There is a gendered aspect of this caregiving stress. Mothers of children with ASD report higher stress levels than fathers, and are more likely to report physical health problems as a result of this stress (Johnson, 2011, p. 245). Research by Taylor and Warren found that nearly 80% of mothers were at risk for clinical depression after their child received an ASD diagnosis (2011, p. 1414). Notably, a lower level of depressive symptoms was associated with having fewer financial barriers to accessing early intervention services (Taylor & Warren, 2011, p. 1414). The implications of this stress are incredibly important, because families dealing with depression and financial stress “may have substantial difficulties accessing and providing elements of intervention that may powerfully advance core social and communication learning processes for their children” (Taylor & Warren, 2011, p. 1415). This stress has important consequences for the parents as well as the children – children with ASD whose parents were highly stressed benefited less from early intervention (Osborne et al., 2008, p. 1098). In a qualitative study of Canadian parents of children with ASD, parents reported that finding a balance between

their needs and the needs of their child was essential to their sanity and health (Hoogsteen & Woodgate, 2013, p. 138). Receiving support, especially respite care services, was seen as important to achieving this balance (Hoogsteen & Woodgate, 2013, p. 138), but these services are not accessible in all areas, can come with years long waiting lists, or are prohibitively expensive. Parenting a child with ASD also impacts their social lives, with parents finding it hard to find the time to go out, while also dealing with stigma from other people, even friends and family (Fletcher et al., 2012, p. 61).

3.2. Direct ASD-Related Costs

There are many out-of-pocket costs related to ASD - ABA programs, medication, equipment, specialized camps and activities, and respite care, among other expenses. Since early intervention is key to the efficacy of ASD treatment, and waitlists for government services can be long, parents feel intense pressure to pay out-of-pocket for intervention services as soon they receive a diagnosis (Shepherd & Waddell, 2015, p. 3554). Parents feel they cannot wait to treat their child – the longer they wait, the less hope they have that their child will be able to live an independent life (Shepherd & Waddell, 2015, p. 3555).

Government policy influences financial burden and out-of-pocket costs – if a government offers more generous supports, families should face fewer financial problems. Studies have demonstrated a link between government policy and financial difficulties among households impacted by ASD in the US. Parish et al. found that low-income families of children with special needs who lived in US states with higher than average income inequality experienced more financial difficulties (2012a, p. 404), and families in states with lower levels of Medicaid spending on children with disabilities had higher out-of-pocket spending on ASD related expenses (Parish et al., 2012b, p. 445). Out-of-pocket healthcare expenses for children with ASD are higher than health care expenses for an average American child, and higher than expenses for children diagnosed solely with mental retardation (Liptak et al., 2006, p. 874). Out-of-pocket costs are higher for families whose child has an intellectual disability comorbid to ASD. 34.1% of American parents of children with ASD and an intellectual disability report paying over \$1,000 in annual out-of-pocket costs (Saunders et al., 2015, p. 39), and more than half of all parents of children

with ASD and an intellectual disability report experiencing financial difficulties (Saunders et al., 2015, p. 40) Among American parents of children with ASD, the annual mean out-of-pocket spending is \$729, and the median is \$219 (Parish et al., 2015, p. 168). Sharpe and Baker used data from 333 parents of children with ASD in the Midwestern United States to identify factors associated with financial difficulties in families impacted by ASD (Sharpe & Baker, 2007, p. 253-4). Families with an annual income of less than \$40,000 were more likely to experience financial problems (Sharpe & Baker, 2007, p. 257). Families who reported that autism limited their daily activities were also more likely to report financial problems. Unsurprisingly, having bills for medical appointments and therapy that were not reimbursed by insurance contributed to financial difficulties (Sharpe & Baker, 2007, p. 257). The out-of-pocket costs of ASD treatment and the impact of caregiving upon careers and income can cause serious financial difficulties for families. Sharpe and Baker stress the need for financial planners to reach out and guide families impacted by autism. They suggest that financial planners charge reduced fees or offer their services pro bono to families impacted by disabilities (Sharpe & Baker, 2007, p. 262-3).

It is important to note that in the US most states require insurance companies to cover autism treatment (National Association of State Legislatures, 2015). In Canada, where autism treatment is not covered by the healthcare system, provincial social service ministries provide varying supports. Due to the lack of coverage under the Canada Health Act, the out-of-pocket costs faced by Canadian households impacted by ASD are likely far higher than the American averages. There is a lack of data on the out-of-pocket costs for Canadian families impacted by ASD, but this project attempts to contribute to addressing this knowledge gap.

3.3. Opportunity Costs of ASD-Related Caregiving and Impact on Employment and Income

Parents of children with ASD find themselves taking on new roles – they are scheduling medical and therapy appointments, shuttling their child to and from those appointments, dealing with government bureaucracy and the school system, advocating for their child, and managing and paying for their child's care team. All of these tasks are

incredibly time consuming. After their child is diagnosed and begins early intervention, parents “suddenly discover that they have become employers and are essentially operating a clinic” (Canada, Parliament, Senate, 2007, p. 9). For this reason, parents of children with ASD may need to leave the labour force, reduce their work hours, or switch to a position with greater flexibility. These changes in paid work can reduce income, increase employment precarity, and impact a caregiver’s career trajectory. All parents, particularly mothers, pay a price in terms of income and career advancement when they take time off to raise a child, but the additional caregiving responsibilities and out of pocket costs associated with ASD can augment this effect and jeopardize the financial security of families impacted by ASD. The caregiving responsibilities associated with ASD create opportunity costs in terms of paid work, and this can reduce household income.

After controlling for parental education attainment, family structure, race, parental age, and rural/urban residence, American families with a child with ASD earned 14% (\$6,206.70) less than families with a neurotypical child (Montes & Halterman, 2008, p. 824). In a secondary data analysis of households in Wisconsin, Parish et al. found that parents of children with disabilities earned \$12,000 less than the annual average (2004, p. 419), and had 27% fewer savings (2004, p. 420). In a survey of parents of children with autism in Washington and Oregon, nearly 60% of families had experienced financial problems over the past year (Baker & Drapela, 2010, p. 587).

Montes and Halterman propose that lower incomes among families with a child with ASD may be due to poorer than expected labour market outcomes, lower labour market participation, and/or lower levels of savings and investments (Montes & Halterman, 2008, p. 824). The time required to care for a child with ASD often replaces time once spent on paid employment. In a UK pilot study, parents of children with ASD estimated that due to their caregiving responsibilities they lost 17 hours of leisure, and 22 hours that parents could have spent on paid work (Järbrink et al., 2003, p. 398). Kogan et al. found that more than half of parents of children with ASD and special healthcare needs had to reduce their work hours or stop working entirely to care for their child (2008, p. 1153). Baker and Drapela found that 20% of parents had changed jobs, and over half reported working fewer hours due to their child’s autism (2010, p. 587). One quarter reported that they had taken a leave of absence to care for their child (Baker & Drapela, 2010, p. 587).

A flexible work environment buffers some of the negative effects of caregiving responsibilities, but often workers are not in such flexible environments (Baker & Drapela, 2010, p. 589). Furthermore, employment effects are impacted by a child's functional abilities and behaviours. In a survey of unmet needs of families with a school-aged child with ASD, 37% of parents whose child had a low level of functional independence reported changing their employment status. For children with moderate functioning, 47% changed their employment situation, and 16% altered their employment for their child with a high level of functional independence (Brown et al., 2011, p. 1296).

The opportunity costs of caregiving for mothers of children with disabilities are particularly large (Parish et al., 2004, p. 414). Mothers have traditionally been expected to provide the bulk of caregiving, and often become the default primary caregivers of children with autism. Despite the fact that mothers of children with autism express the desire to work outside the home as other mothers (Baker & Drapela, 2010, p. 579), Parish et al. found that mothers of children with disabilities were particularly impacted by their caregiving responsibilities - they were less likely to work full time, less likely to hold a job for more than 5 years, and more likely to delay their re-entry into the workforce after having children (Parish 2004, p. 422). Cidav, Marcus & Mandell found that mothers of children with ASD are 6% less likely to work outside the home, and worked 7 fewer hours per week, than mothers of children without special needs (2012, p. 620-621). As a result, mothers of children with ASD in this study earned \$7,189 (35%) less than mothers of children with other limitations, and \$14,555 (56%) less than mothers of children without any special needs (Cidav, Marcus & Mandell, 2012, p. 621). These employment effects cause emotional stress - in qualitative interviews with parents of children with disabilities, Scott found that women with career aspirations "experienced emotions ranging from deep regret to despair in response to their lost career trajectories" (2010, p. 684). In qualitative interviews conducted by Fletcher, Markoulakis, and Bryden, they found that "in no way did mothers "blame" the child for their situations.... [but] these effects cascaded into other aspects of their lives (lack of vacations, lack of ability to plan for other children's educational futures, etc.)" (2012, p. 56).

The opportunity costs of ASD caregiving cause long term consequences. The lower savings and employment rates among families impacted by disability can cause

increasingly negative effects as parents age and are unable to fund their own retirement and eldercare (Parish et al., 2004, p. 423). Although there is little research into the opportunity costs of ASD caregiving and the effect on employment in the Canadian context, it can be expected that the employment impacts on Canadians parents of children with ASD would be similarly adverse.

3.4. The Social Costs of ASD

A number of studies have tried to quantify the total social costs⁵ of ASD, and all have come up with varying cost estimates. A pilot study of British parents of children with ASD estimated the social cost of ASD at £855 per week, per child. More than 50% of this total social cost fell onto the parents (Järbrink et al., 2003, p. 399), and the bulk of the costs were due to early intervention therapy, education, and lost income due to caregiving (Järbrink et al., 2003, p. 400). However, the sample size of this study was small (n=13) and as a result the standard deviations for the cost and time estimates are very large (Järbrink et al., 2003, p. 398).

Cidav et al. found that the discounted lifetime cost of ASD for an individual without an intellectual disability was £0.92 million (US \$1.36 million) in the UK and \$1.43 million in the US (2014, p. 725). For an individual with ASD and an intellectual disability, the costs were higher - £1.5 million (US \$2.20 million) in the UK and \$2.44 million in the US (Cidav et al., 2014, p. 725). The bulk of these costs is for services and lost employment productivity for the individual with ASD. The time costs for caregivers was estimated at just 2% of the total cost of ASD in the UK, and 9% in the US (Cidav et al., 2014, p. 725).

Knapp et al. estimated the total social costs of ASD in the UK to be even higher, at £3.1 million for individuals without an intellectual disability, and £4.6 million for individuals with ASD and an intellectual disability (2009, p. 326). Their total estimate for all ASD related costs in the UK is £28 billion (Knapp et al., 2009, p. 333). Ganz estimates

⁵ Each of these studies defines and calculates social costs in slightly different ways. But generally speaking, social costs are the private costs plus the external costs to society. For ASD, this typically includes the direct costs of healthcare, autism therapies, and special education, as well as the lost productivity by individuals with ASD and their caregivers.

the lifetime costs of ASD in the US to be \$3.2 million over the lifetime of an individual, with the majority of this total coming from adult care and non-medical costs (2007, p. 347).

Using the costs of healthcare, community support programs, education, time spent on informal caregiving, and relative's expenses, Järbrink calculated the total social costs of ASD in Sweden. He found that the societal costs were €51,877 annually per child, and €66 million annually for the country (2007, p. 461). However, the sample size of the survey that asked parents about their costs and time spent caregiving was small (n=33), and parents may have underestimated the hours spent on caregiving (Järbrink, 2007, p. 458-460). The true social costs of ASD in Sweden may be even higher.

Thus far, only one report has tried to quantify the social costs of ASD in Canada. The School of Public Policy at the University of Calgary examined the societal costs of care and support for individuals for ASD in Canada. This report focused only on the costs of ASD for from the ages of 14 – 64 and identified the value of caregiving for three hypothetical individuals on the spectrum who each required differing levels of support. For a severely impacted, non-verbal adult with ASD the value of caregiving time alone was estimated to be \$158,359 per year, or \$5.5 million over their lifetime (Dudley & Emery, 2014, p. 17). For a moderately impacted adult with ASD who is capable of most daily living activities but needs some assistance, the value of caregiving time is estimated at \$82,769 annually (Dudley & Emery, 2014, p. 16). The annual value of caregiving assistance for a mildly impacted adult with Asperger's syndrome is estimated to be \$30,711 (Dudley & Emery, 2014, p. 17). These value estimates are for caregiving time only, and do not include costs for housing, education, respite care, therapy, etc. Dudley and Emery did not include out-of-pocket costs for family caregivers. Lack of data on costs to families, and a lack of transparency from provincial ministries in terms of their exact funding amounts, makes calculating the social costs of ASD in Canada difficult.

Furthermore, the social costs of ASD do not need to be so high. The opportunity costs of caregiving can be reduced through public policies that support working parents of children with ASD, and through early intervention for children with ASD. Policies that support children in childcare environments, and help parents achieve flexible scheduling and balance paid work with caregiving, reduce the indirect costs of caregiving. ABA based

early intervention programs are known to reduce the social costs of ASD – Jacobsen, Mulick, and Green estimate that the near normal functioning achieved by 40-50% of children who receive the Lovaas method saves between \$274,709 to \$282,689 until age 22, and \$2.4 to \$2.8 million until age 55 (1998, p. 213). The true cost savings may be even higher, since that research did not include parental employment and income efforts, and the time cost of caregiving, but with supportive policies these could also be reduced.

Chapter 4. Methodology

An online survey of BC parents of children with ASD was conducted, and the quantitative results were analyzed using Excel. The qualitative responses were analyzed through thematic analysis. The results of this research are used in subsequent chapters to analyze policy options using criteria and measures.

4.1. Survey Design and Analysis

An online survey was conducted to document and analyze the out-of-pocket expenditures incurred by families of children with ASD, and the impacts of caregiving on income, employment, and household finances. The “Hidden Costs of Autism” survey was conducted in partnership with Dr. Sherri Brown, an SFU lecturer. As co-principal investigators, we have a memorandum of understanding so that we may each use the data independently. The survey was programmed using the SFU Web Survey Tool. The survey received ethics approval from the SFU Office of Research Ethics. It was distributed through a network of ASD parent and family groups throughout British Columbia, and in particular through groups under the auspices of the Autism Society of British Columbia (ASBC). The ASBC is a parent based and directed society that has been working to provide support to individuals and their families affected by autism since 1974. The ASBC kindly offered to support parent recruitment efforts by advertising and disseminating the study’s survey hyperlink through its monthly online newsletter. The study was also disseminated through existing online ASD parent groups on Facebook. The survey was open to respondents between December 2015 and early January 2016.

The survey asked respondents questions related to five key areas: parent and child demographics, parent employment and sources of income, parent employment trajectories and income, spending on ASD related expenses, and planning for the financial future of the child(ren) and parents (to view the complete survey questionnaire, please see Appendix A). The goal of the survey was to determine to what extent families impacted by ASD in BC are struggling financially, and to uncover what factors impact their financial vulnerability. This survey addresses the lack of data on the out-of-pocket costs related to

ASD, and the impact of ASD related caregiving on employment and income. A 2014 survey conducted by the Canadian Autism Spectrum Disorders Alliance (CASDA) asked respondents what barriers they had experienced when accessing services, but did not ask caregivers about their employment status or their out-of-pocket costs. Sixty percent of ASD caregivers reported receiving some form of financial support from the government, but only 27% indicated that this support was sufficient (Weiss et al., 2014, p. 31). These results from the CASDA survey demonstrate the financial pressures facing Canadian households impacted by ASD, but do not provide a detailed picture of their financial situation. This survey contributes to a more detailed and nuanced understanding of the problem in BC.

Survey respondents were asked about the age of their child(ren), if they had multiple children with ASD, and if their child(ren) had any comorbid conditions associated with ASD. Closed answer questions asked respondents about their individual and household income, education level, current employment status, and the ways in which their child(ren)'s ASD had impacted their career. Respondents were also asked about their out-of-pocket ASD related expenses, their retirement savings, their child's RESP and RDSP, if applicable, and their concerns for the financial future of themselves and their child. Respondents were also asked open ended questions, and were given the chance to explain their current employment situation. They were asked to reflect on their career path, and think about what types of policies or other supports would help them to achieve their desired employment situation (e.g. better daycare options, more government funding for therapy, more therapy hours, more respite care, workplace accommodations).

To avoid duplicate responses, the researchers requested that only one adult primary caregiver per household completed the survey. Due to the provincial nature of ASD policy, the survey was open to BC residents only. In total there were 197 respondents. The study limited eligible participants to primary caregivers (parents, grandparents, foster parents, and any other caregiver who assumes primary and majority responsibility for the safety, housing, and daily caregiving needs of a dependent child) of children under the age of 18 with ASD. The primary caregiver was defined as an adult over age 18. This was a convenient sample, not a random sample of parents of children with ASD in BC. Participants were members of ASBC or ASD parent groups on Facebook.

Parents that choose to become active within the ASD parent community may have different opinions and demographics than the true population of parents of children with ASD in BC. This survey did not include the voices of children or youth with ASD, only the voices of their caregivers. Moreover, since this was an online survey, it excluded families without internet access.

The quantitative data from the survey was analyzed using the 2016 Excel data analysis tools to generate descriptive and inferential statistics. Thematic analysis was used to analyze the responses to the open-ended questions. This analysis followed the six steps laid out by Braun and Clarke: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006, p. 87).

Chapter 5. Survey Results

The 197 responses to the Hidden Costs of Autism Survey by primary caregivers of children with autism in BC demonstrate the intense impact that caregiving responsibilities have on their employment situation and income. Survey respondents reported high levels of emotional and financial stress, and expressed serious concerns for the financial security of themselves and their child(ren). The results indicate that families impacted by ASD are dealing with a “double whammy” – they are working less and earning less, while also facing new expenses not covered by government policies. Respondents reported that they need more supportive and flexible workplace policies for themselves and their partners. Many shared that they could not juggle caregiving and paid work, and had withdrawn from the labour market. Participants consistently called for supportive environments in public schools and daycares, and more availability and funding for respite care. The majority of parents of children with ASD reported wanting increased government funding for more hours of treatment.

5.1. Respondent and Child Demographics

All but one of the respondents was a parent of a child with ASD, either by birth or through adoption (one grandparent participated in the survey). Most respondents were between the ages of 35-44, a life stage where people tend to focus on career development while also balancing family responsibilities. The majority of respondents (80%) lived in two-parent households. A notable minority (16%) were sole parents, and 6% were single parents who shared custody. The majority of respondents had only one child diagnosed with ASD, although a significant minority (16%) had two children diagnosed with ASD, and 2% of respondents had three or more children with ASD. The average age of children with ASD represented in the survey was 8.2 years and the median was 7 years.

The survey called for responses from primary caregivers of children with ASD, and overwhelmingly the respondents were women. This result demonstrates the deeply gendered nature of caregiving for a child with ASD. Among mothers of children with ASD there is a clear intersection between their caregiving and socioeconomic status. This data

provides insight into the lives of mothers caring for children with ASD in BC, but due to the small numbers of fathers who identified as primary caregivers and participated in the survey, insights into the impact on fathers are less certain. Future research could examine the impact ASD has on the career trajectories of fathers of children with ASD.

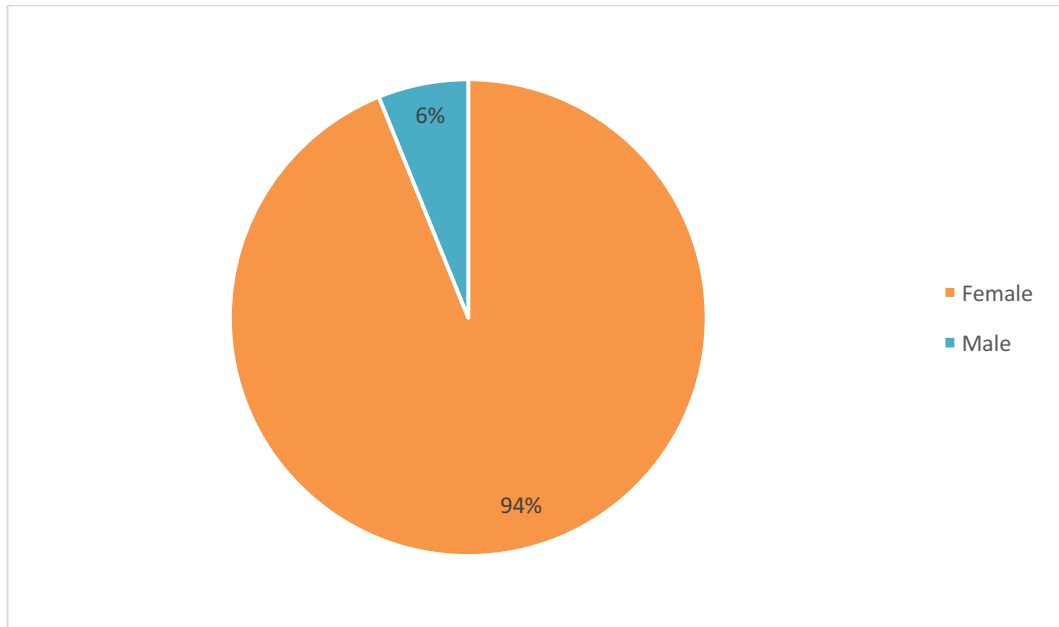


Figure 5-1 Gender of Survey Respondents

Respondents were asked detailed questions about their child's diagnosis, including the severity of their child's condition. A majority of respondents reported that their child(ren) with ASD is moderately or severely impacted in terms of aggressive and self-injurious behaviours, communication abilities, and cognitive/intellectual functioning. The majority of children had at least one condition that was comorbid to ASD. Over a third of children had an anxiety disorder, and over a quarter had sensory processing disorder or attention deficit disorder.

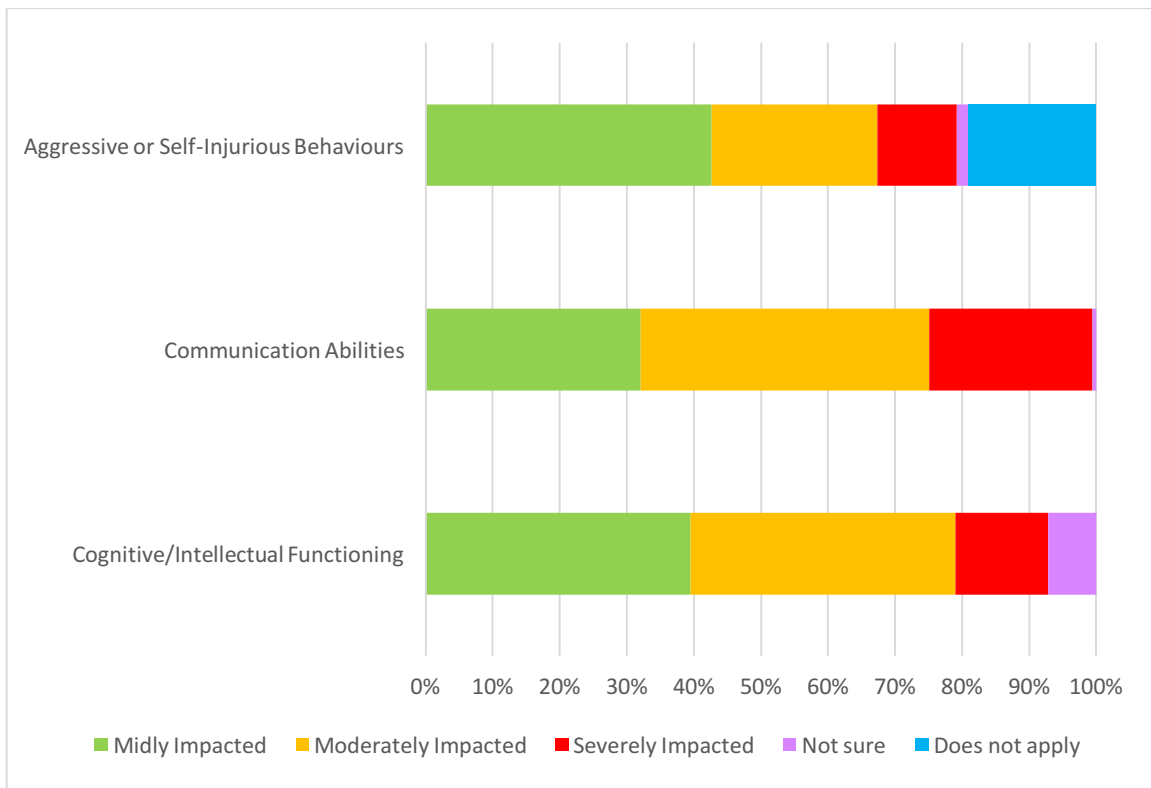


Figure 5-2 ASD Related Behaviours Among Respondent's Children

Note By definition ASD impacts an individual's communication abilities, so respondents did not have the option to have indicate that their child's communication abilities were not affected. Individuals with ASD may or may not have impacted cognitive abilities and aggressive or self-injurious behaviours, so the 'does not apply' option was available for these questions.

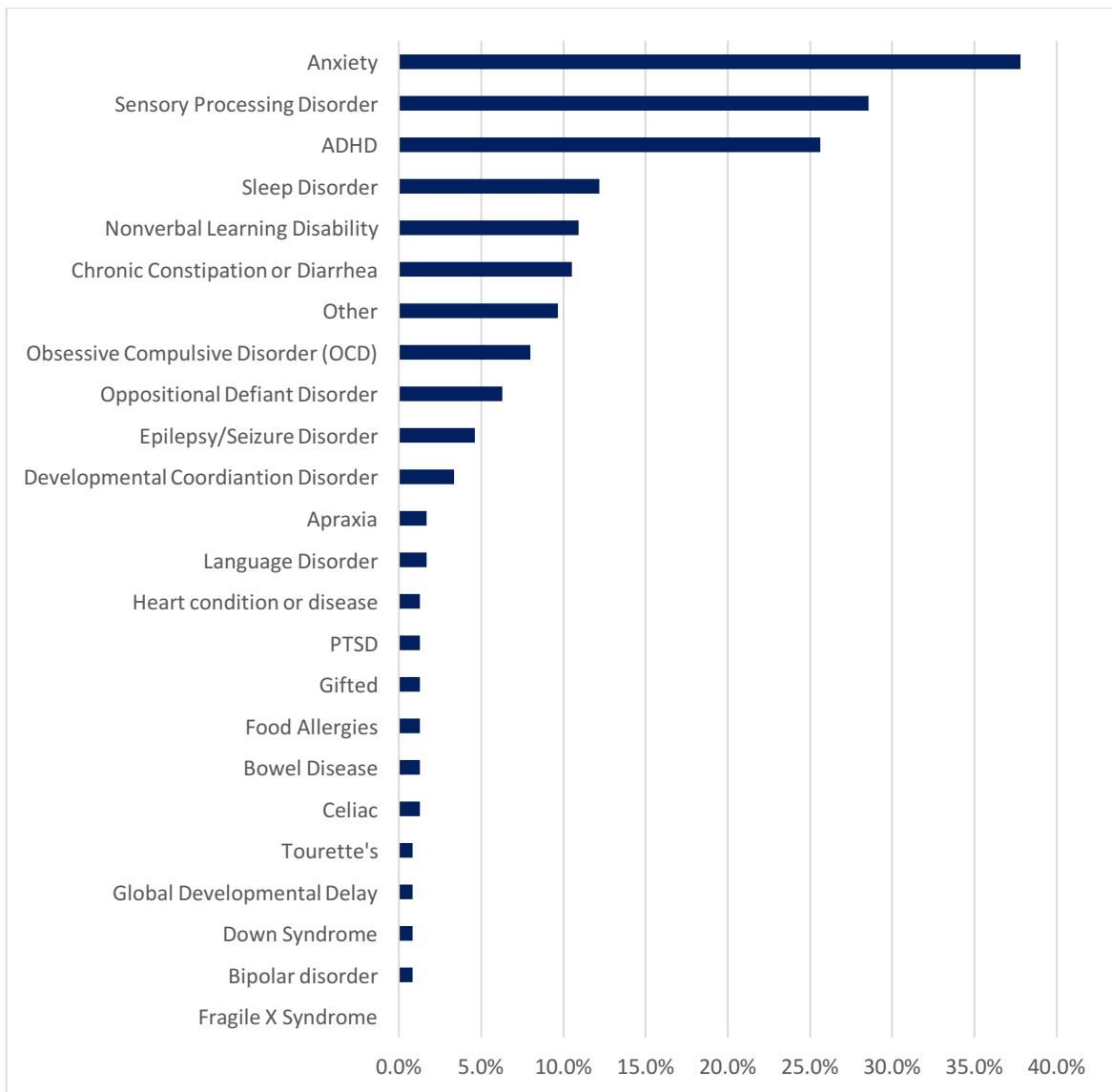


Figure 5-3 Prevalence of Comorbid Conditions Among Respondent's Children

Note Celiac disease, food allergies, global developmental delay, developmental coordination disorder, Tourette's syndrome, post traumatic stress disorder (PTSD), apraxia, heart conditions or disease, language disorders, and being gifted were not listed as options in the survey questionnaire. Respondents used the 'other' category to indicate that their child(ren) are diagnosed with these comorbid conditions. A wide variety of comorbid conditions were listed using the 'other' category, however, only answers that were listed by two or more respondents were included in this graph. The remaining answers are listed under 'other.'

5.2. Impact of ASD Related Caregiving on Parental Employment and Income

Respondents reported that caring for a child with ASD had a number of effects on their employment status and income. Three quarters of respondents reported experiencing an interruption to their paid work or career path due to their child's diagnosis. Of these parents, 36% left the labour force voluntarily, and 15% left involuntarily. The bulk of these employment changes were due to the emotional stress of caregiving, and the time consuming nature of medical and therapy appointments for ASD.

5.2.1. Employment Effects

Respondents were asked to indicate their current employment situation. Although the majority were engaged in paid work in some capacity, a significant number (37%) were stay-at-home caregivers.

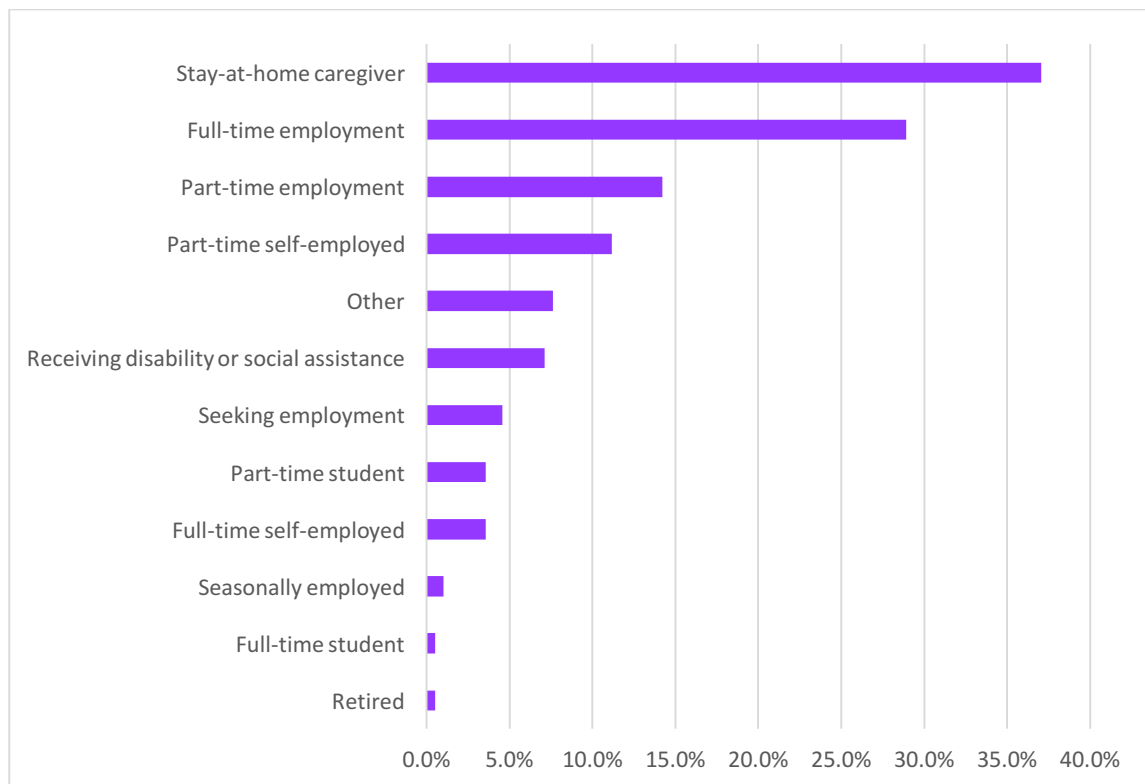


Figure 5-4 Current Employment Status of Respondents

Note Respondents were told to select all options that applied. Full-time work defined as 30 or more hours per week.

Importantly, three quarters of respondents reported a career or paid work interruption beyond the typical parental leave period, due to their child's ASD. This figure indicates how commonplace employment effects are among parents of children with ASD.

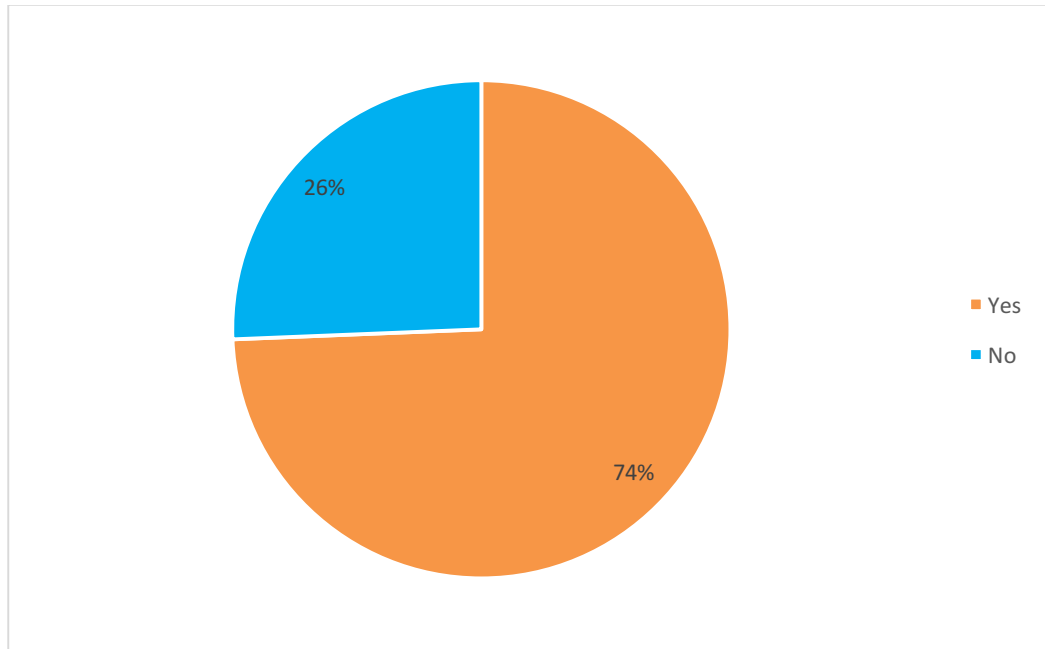


Figure 5-5 Career or Paid Work Interruption Beyond the Typical Parental Leave Period Due to Child's Diagnosis

Note n = 196

Highly educated participants were more likely to report that their child's ASD caused an interruption in their paid work activities or career, perhaps because they are more likely to work full-time. However, career interruptions were not significantly linked to household structure, or a child's communication and cognitive abilities. There was a small relationship between career interruption and severe aggressive or self-injurious behaviours exhibited by the child with ASD.

Table 5-1 Career Interruption and Education Level

Highest level of education attained	No	Yes
High School Diploma or its equivalent	33.30%	66.70%
Post secondary certificate or diploma	24.50%	75.50%
University degree at a bachelor level (including LLB)	29.10%	70.90%
Above a Bachelor's degree	19.20%	80.80%

Respondents who reported that they had experienced a career or paid work interruption were asked to indicate the type(s) of interruption they had gone through. Respondents reported a number of changes to their working situation – switching to part-time work (30%), changing positions within career for more flexibility (27%), changing career paths to something more flexible (20%), starting self-employment (18%), and reducing hours at a full-time job (12%). The most common type of interruption was leaving the workplace voluntarily to care for their child. It must also be noted that 15% of respondent left the labour force involuntarily – not an insignificant number. These result show an even bigger impact than the survey of parents in Washington and Oregon, which and found that 19% changed jobs due to their child’s condition, and 53% worked fewer hours (Baker & Drapela, 2014, p. 7). These figures are significantly higher than the Canadian statistics on parents of children with any disability under the age of 14, where 17% stopped working, 30% worked fewer hours, and only 4% were terminated (Statistics Canada, 2008, p. 10-11).

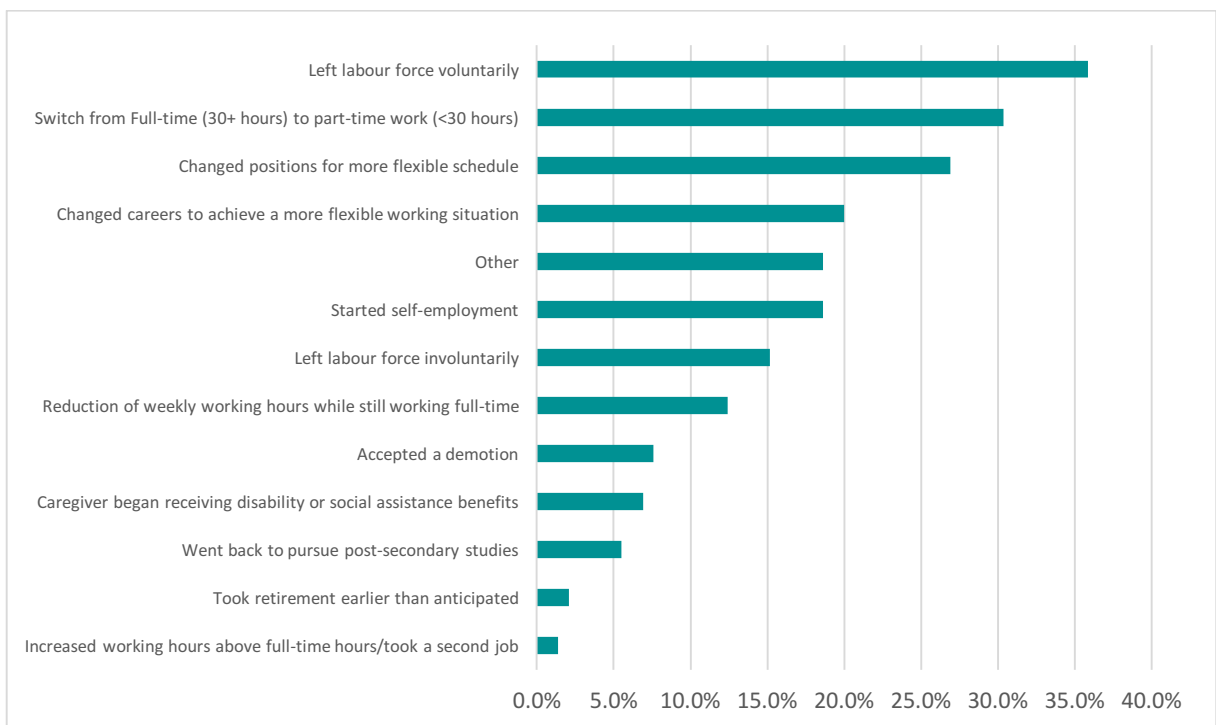


Figure 5-6 Type of Career or Paid Work Interruption

Note Respondents were told to select all options that applied. Full-time work defined as 30 or more hours per week.

Respondents were asked to give the reason(s) behind any interruptions in paid work or their career. Their answers indicate extremely high levels of emotional stress – nearly 90% reported a career interruption due to their own emotional stress. Levels of emotional stress were high regardless of the parent’s education level and income. This stress leads to health issues for the parents. Consequently, 30% reported a career or work interruption related to their own medical or therapy appointments. Emotional stress was more common than financial stress, which 68% listed as a reason for their career or work change.

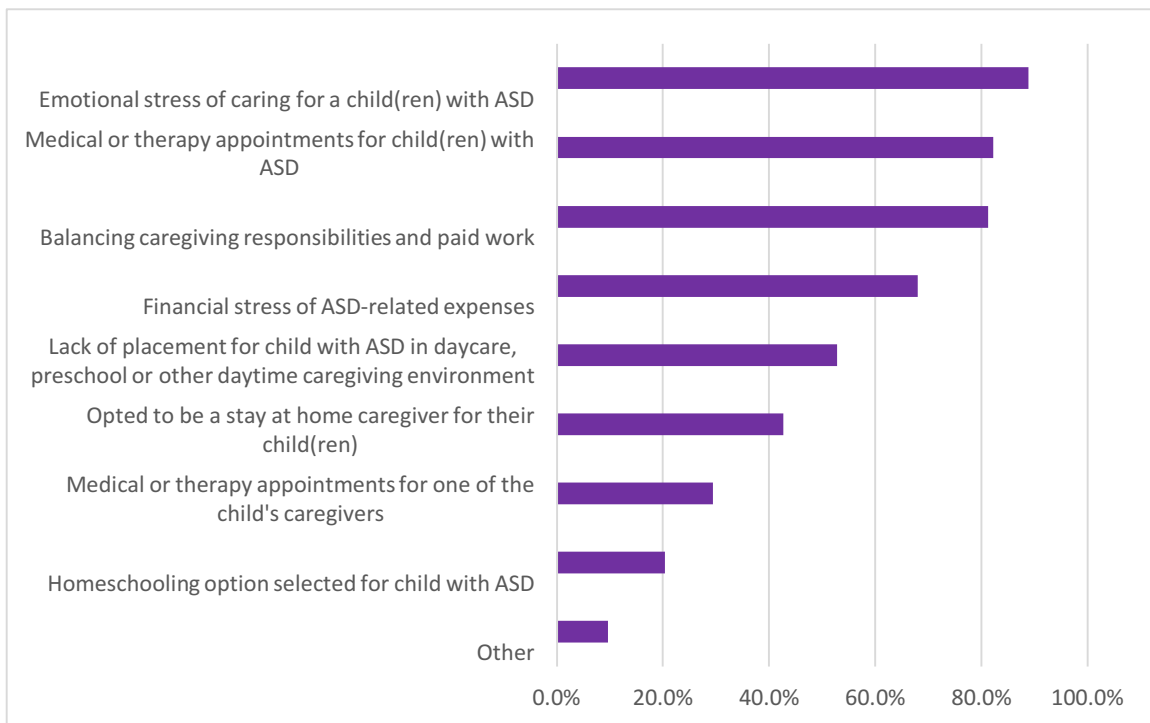


Figure 5-7 Reasons for Career or Paid Work Interruption

Note Respondents were told to select all applicable options.

Notably, respondents were more likely to indicate that their career had been strongly negatively impacted by their child’s diagnosis than their spouse’s career. This is due to the high number of female respondents and the gendered nature of caregiving. Mothers bear the brunt of the negative career impacts of raising a child with special needs. However, it is possible that respondents underestimated the impact of their child’s diagnosis on their spouse’s career. Future research could survey both parents for a more comprehensive look at the employment effects of caregiving.

It is also important to recognize that a minority of respondents had their careers strongly positively impacted by their child's condition. It inspired some parents to pursue a new, more fulfilling career path – one respondent became a school trustee; another became an Executive Director for a charitable learning centre for children with ASD. Others took pride in homeschooling their children and/or being stay-at-home parents. Research by Scott also found that a child's disability can lead to new careers for mothers, particularly in positions where they provide services to other families impacted by disability (2010, p. 689). The impact of ASD on families is not uniformly negative.

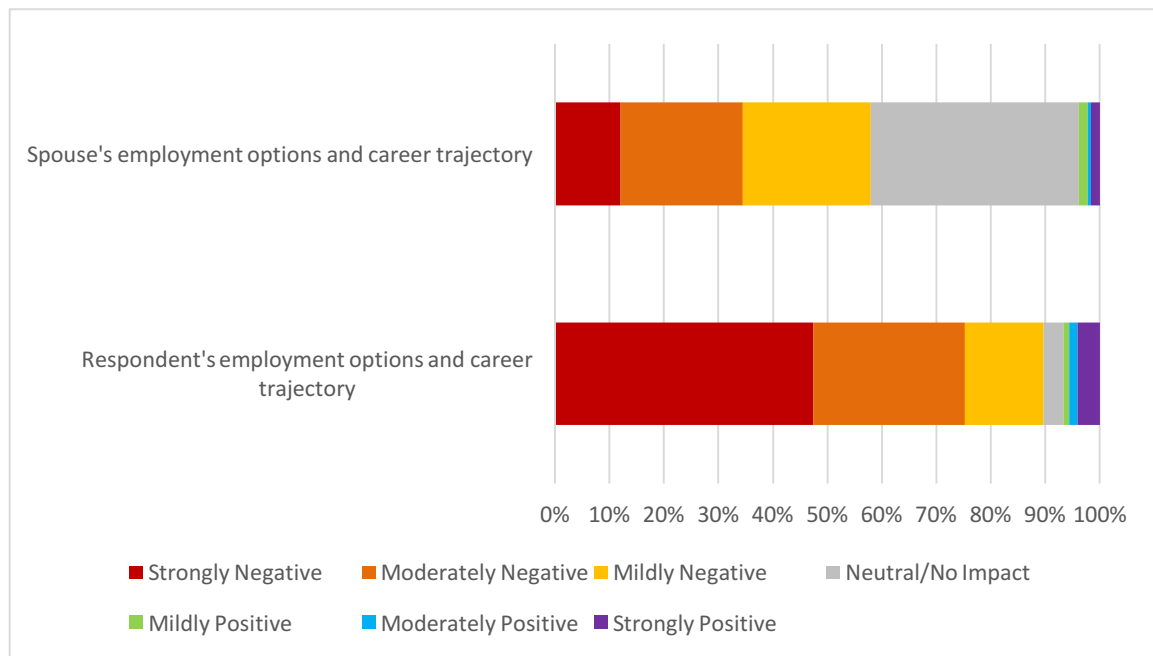


Figure 5-8 Impact of ASD Related Caregiving on Respondent and Spouse's Career Trajectory

Employment and Education

The survey respondents were significantly more educated than the Canadian population. The majority of respondents were college or university graduates.

Table 5-2 Respondent Education Levels Compared to the Canadian Average

Highest Level of Education Attained	Survey Respondents	Canadian Average
Less than high school	1.5%	12.70%
High school diploma or equivalent	12.4%	23.20%
Registered apprenticeship or trade certificate/diploma	8.2%	12.10%

College Diploma	25.3%	21.30%
CEGEP, or other non-university certificate or diploma	2.6%	4.90%
University degree at a bachelor level (including LLB and university certificate above bachelor level)	33.0%	19.20%
Masters Degree	14.4%	5.10%
University degree in medicine, dentistry, veterinary medicine or optometry	1.0%	0.70%
Doctorate (Ph.D.) Degree	1.5%	0.90%

Although they survey respondents were highly educated, many were not working full-time. The likelihood of working full-time increased with a greater level of educational attainment. This result indicates that parents with low levels of education are particularly impacted by their caregiving duties.

Table 5-3 Education Level and Full-Time Employment

Highest Level of Education Attained	Percentage of respondents working full-time
Less than high school	0%
High school diploma or equivalent	19.05%
Post secondary certificate or diploma	28.57%
University degree at a bachelor level	35.94%
Above a Bachelor's degree	47.22%

Note Full-time employment defined as 30 hours of work per week or more, including employment and self-employment.

Employment and Gender

Women were more likely than men to experience a career interruption due to their child's diagnosis, reflecting the gendered impact of caregiving on paid work. The results for this table are not significant ($p=0.17$) due to the small number of male respondents, but they do indicate a general trend. This result is in line with research by Parish et al., which found that fathers of children with disabilities, unlike mothers, tend not to work less than the norm (2004, p. 414). Research by Cidav, Marcus & Mandell also found that the work hours and the income of fathers of children with ASD was not significantly impacted (2012, p. 621).

Table 5-4 Career Interruption by Gender

	Female	Male	Grand Total
No career or paid work interruption	24.18%	41.67%	25.26%
Career or paid work interruption	75.82%	58.33%	74.74%
Grand Total	100.00%	100.00%	100.00%

Employment and Age of Youngest Child with ASD

The rate of full-time employment for parents of children with ASD rose slightly as their children grew older, but did not rise significantly, indicating that the caregiving responsibilities of raising a school-aged child with ASD continue to preclude paid work for many parents.

Table 5-5 Full-Time Employment by Age of Youngest Child with ASD

Age Range	Currently Engaged in Full-Time Paid Work	Not Engaged in Full-Time Paid Work	n
Under 6	30.51%	69.49%	59
6 to 18	33.64%	66.36%	107

5.2.2. Income Effects

The majority of survey respondents were low-income earners, due to their low employment rate. Over a third of participating parents earn less than \$10,000 per year because they are stay-at-home parents or work very few hours.

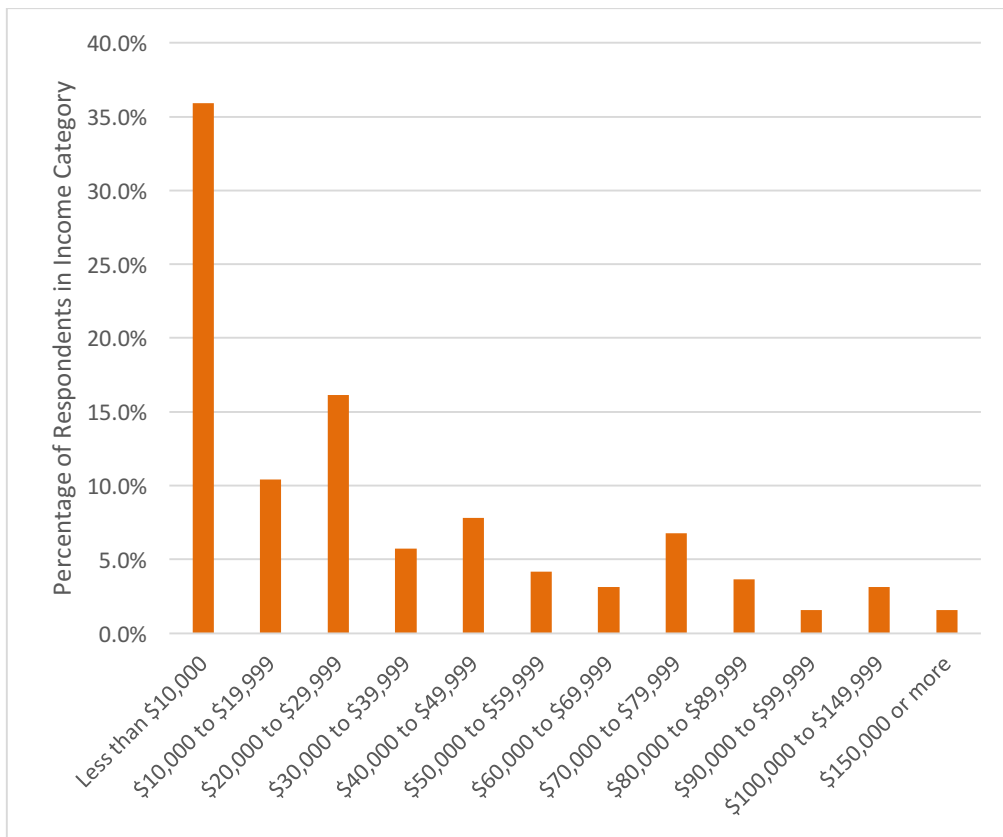


Figure 5-9 Individual Annual Gross Income of Respondents by Income Level

At the household income level, families impacted by ASD fared better. The difference between the individual respondent's income and the household income is due primarily to the income of their partner. Without their partner's earnings, many of the respondent's would be living in poverty.

Over a quarter of families represented in the survey were earning over \$100,000 annually. However, the majority earned close to or below \$76,000, the median family income for BC. Even with their partner's income, a number of households represented in the survey are living in poverty. 8.4% of households reported living on less than \$20,000 per year, and 24% are living on less than \$40,000. These families are not able to afford any additional costs related to their child's ASD without serious sacrifices, and would not be able to afford much in the way of ASD related services without the assistance of MCFD.

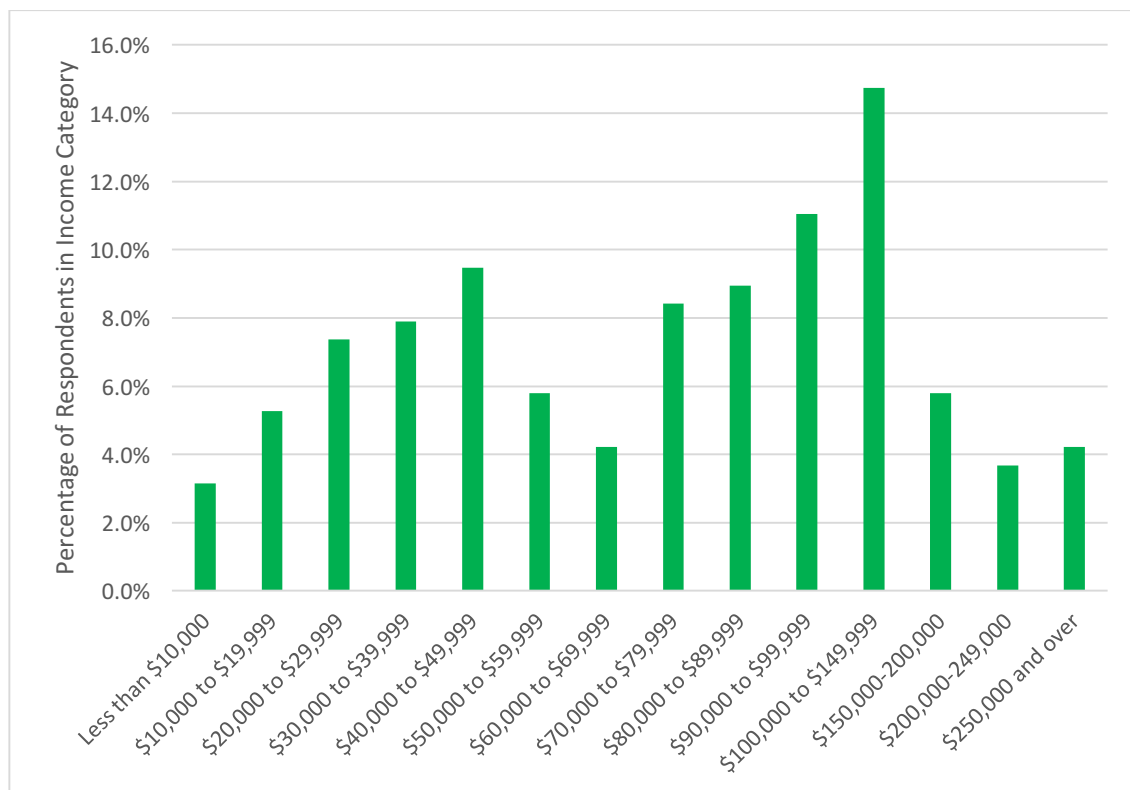


Figure 5-10 Household Annual Gross Income of Respondents by Income Level

When asked directly about the impact of their child's ASD on their individual income, nearly half of participants reported a strongly negative effect. This effect was slightly less pronounced for their household income (which would be mediated by their partner's income, if they are a two-parent household), but still overwhelmingly negative. Moreover, families reported that their child's diagnosis impacted the accumulation of new debt, demonstrating the lengths BC parents are going to in order to pay for ASD related services.

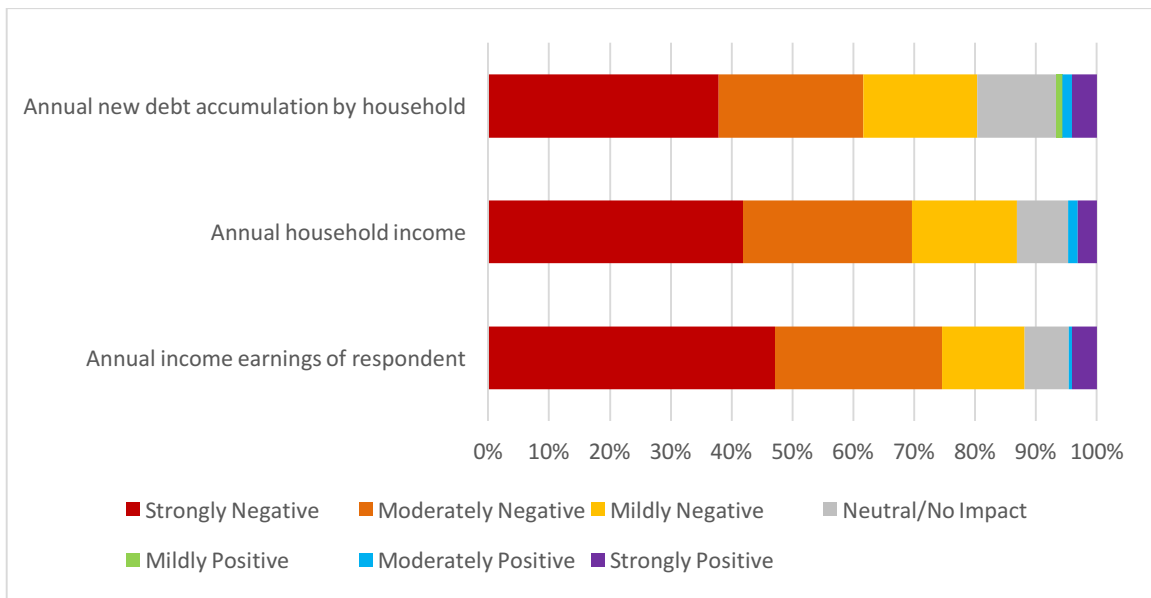


Figure 5-11 Impact of ASD Related Caregiving on Individual Income, Household Income and Debt Accumulation

5.3. Financial Issues

The survey respondents indicated spending a significant amount on ASD related expenses, although the amount spent on out-of-pocket therapies and activities varied widely. Out-of-pocket costs are part of the “double whammy” that parents of children with ASD face – they have to reduce their income by working fewer hours or leaving the labour force entirely, at the same time they have to pay for their child’s therapy and other related expenses. Consequently, it is not surprising that respondents reported significant financial concerns regarding their child’s future as well as their own retirement and financial security.

5.3.1. Out of Pocket Costs

Respondents reported a wide range of out-of-pocket spending. A number of respondents claimed no out of pocket expenses, while the highest amount was \$57,000 annually. Another respondent wrote that they had spent \$250,000 to redo their home to better suit their child’s needs in addition to their ongoing annual costs. However, the average total annual out-of-pocket spending was \$6,745 and the median was \$4,000. This

data was not normally distributed – the majority of respondents spent under \$10,000, but outlying families spent several times that amount per year. It must be acknowledged that several parents wrote in the survey that they wished they could spend more on out-of-pocket expenses – they believe that more services would help their child, but they simply cannot afford to pay for them under the current MCFD programs.

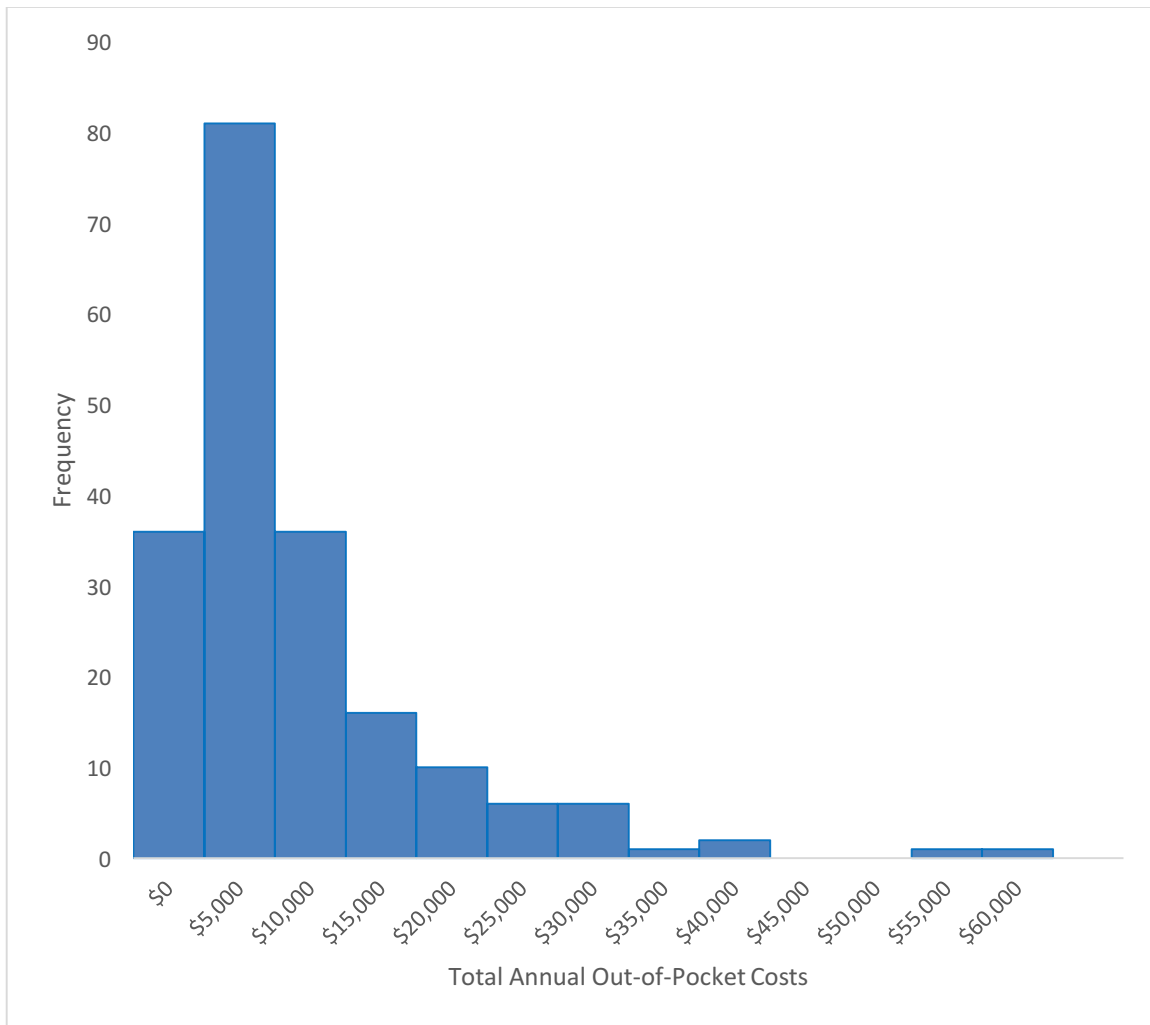


Figure 5-12 Histogram of Total Annual Out-of-Pocket Costs

The most bulk of these out-of-pocket costs went towards behavioural therapy and other therapy, indicating that parents are using their own funds to supplement the MCFD funding. It is important to note that all of these out-of-pocket cost categories are considered “eligible expenses” by MCFD (Ministry of Children and Family Development, 2012). Since the MCFD funding is not sufficient for many children, families are left to cover the costs of

these necessary items. The amount parents spent on these categories varied widely, as evidenced by the difference between the average and the maximum costs. The out-of-pocket expenses reported here are considerably larger than the costs reported by American parents in research by Parish et al. (2015).

In terms of the “other” category for out-of-pocket costs, the bulk of this category went towards travel costs (e.g. gas, parking, specialized van) for medical and therapy appointments. Parents also reported spending significant amounts on educational materials, books, and games for their child’s ABA based home program or homeschooling, Nutritional supplements and specialized food for children with dietary issues was also indicated as an uncovered, out-of-pocket expense.

Table 5-6 Type of Out-of-Pocket Costs

Type of Out-of-Pocket Cost	Average Out-of-Pocket Cost	Maximum Out-of-Pocket Cost
Behavioural Therapy and Other Therapy	\$2,046.31	\$50,000.00
Respite care (does not include daycare or childcare costs)	\$1,336.85	\$25,000.00
Therapy - Paraprofessionals (OT, PT, SLP)	\$742.19	\$50,000.00
Specialized services tailored to individuals with ASD – camps, tutoring, social skills groups	\$603.52	\$8,000.00
Medical professionals - registered psychologist, counsellors, fee for services not covered by MSP	\$562.92	\$7,000.00
Medical Supplies - incontinence supplies, sensory (e.g. “chewelry”, weighted blankets), pharmacological, G tube, not covered by MSP or private insurance	\$384.52	\$5,000.00
Technology – iPad and applications, dynavox, etc.	\$328.78	\$5,000.00
Other	\$285.87	\$12,000.00
Therapy - Other services (music, equine, etc.)	\$191.17	\$3,500.00
Administration - invoicing, laminating, printer supplies etc.	\$157.38	\$2,000.00
Legal – lawyer fees, documentation	\$120.41	\$10,000.00

Note Categories left blank by respondents or indicated as 0 were both counted as 0 within the average out-of-pocket cost calculations. These could also be interpreted as non-responses because the survey did not force participants to answer.

Out-of-Pocket Costs and Annual Household Income

Remarkably, out-of-pocket costs was not associated with household income, perhaps due to the wide variance of out-of-pocket spending. Higher income families actually reported spending less on out-of-pocket ASD related expenses than middle or lower income families in absolute dollar values. The reasons for this are unclear, but it nonetheless raises significant questions about equity. Based on this data, a family with little to no annual income (\$10,000 or less) spends 109% of their income on out-of-pocket costs. A family earning \$40,000 can expect to spend 29% of their income on their child's condition, while a family earning \$250,000 spends just \$1.2% of their household income. A child with ASD in a family who cannot afford to supplement the MCFD funding with their own out-of-pocket spending may be less likely to reach their potential than a child in a wealthier family. Interestingly, two parent families are not spending more on out-of-pocket costs than single parents. Perhaps this is because of the high number of stay-at-home mothers – many two-parent households already have just one income.

Table 5-7 Average Total Out-of-Pocket Costs by Household Income Level

Household Income Level	Average Total Annual Out-of-Pocket Costs	n
Less than \$10,000	\$10,990.00	6
\$10,000 to \$19,999	\$3,917.00	10
\$20,000 to \$29,999	\$8,695.54	13
\$30,000 to \$39,999	\$11,239.67	15
\$40,000 to \$49,999	\$11,581.94	18
\$50,000 to \$59,999	\$3,686.36	11
\$60,000 to \$69,999	\$5,612.50	8
\$70,000 to \$79,999	\$6,382.50	16
\$80,000 to \$89,999	\$2,842.94	17
\$90,000 to \$99,999	\$7,301.43	21
\$100,000 to \$149,999	\$5,542.32	28
\$150,000 to \$200,000	\$8,495.45	11
\$200,000 to \$249,999	\$3,784.29	7
\$250,000 and over	\$2,975.00	8
Total	\$6,790.35	189

Out-of-Pocket Costs and Child's Abilities and Behaviours

Parents had greater out-of-pocket costs for children who were moderately or severely impacted in terms of communication and cognitive abilities. Interestingly, spending did not increase for children who exhibit severe aggressive or self-injurious behaviours – parents actually reported spending less out-of-pocket costs for these children. The reason for this result is unclear, and may be due to small sample size (only 20 children in the sample display severe aggressive or self-injurious behaviours). Aggressive behaviours during tantrums can cause damage to furniture, walls and other household items (Fletcher et al., 2012, p. 52), and parents did report spending for these types of expenses. Broadly speaking the trend is that the parents of children greatly impacted by ASD face higher out-of-pocket spending. The MCFD funding is not enough to cover all of their costs.

Table 5-8 Average Total Out-of-Pocket Costs by Child's Abilities

Column1	Cognitive Abilities	Communication Abilities	Aggressive and/or Self-Injurious Behaviours
Mildly impacted	\$6,336.26	\$4,613.88	\$7,771.18
Moderately impacted	\$7,106.67	\$7,653.97	\$5,116.02
Severely impacted	\$9,067.96	\$7,859.09	\$4,725.50
Not sure	\$4,075.00	\$4,500.00	\$5,167.33
Does not apply	-	-	\$9,109.12

Out-of-Pocket Costs and Conditions Comorbid to ASD

Having more comorbid conditions was associated with lower out-of-pocket spending. The reasons for this are unclear, but perhaps it is because many of the comorbid conditions are covered under the healthcare system. This result indicates that it is the nature of a child's ASD, not their other conditions, that are serious enough for parents to spend thousands of dollars per years on treatment.

Table 5-9 Out-of-Pocket Costs and Number of Conditions Comorbid to ASD

Number of Conditions Comorbid to ASD	Average total annual out-of-pocket costs per child	n
0	\$8,099.53	53
1	\$8,476.67	39
2	\$5,796.50	40
3	\$6,032.69	26
4	\$4,701.78	18
5	\$3,106.36	11
6	\$4,116.67	6
7	\$4,300.00	1
8	\$12,900.00	2

Out-of-Pocket Costs and Child's Age

Parents are spending a significant amount on children with ASD who are in school. Out-of-pocket spending increases after the MCFD funding drops at age 6, indicates that this policy burdens families of older children.

Table 5-10 Out-of-Pocket Costs by Child's Age

Age	Average Total Out-of-Pocket Costs	n
Under 6	\$6,059.83	59
6 to 18	\$7,400.05	107

5.3.2. Parental Retirement Savings

Respondents reported that raising a child with ASD impacted their ability to save for retirement – nearly half of respondents said that it had a strongly negative impact on their savings.

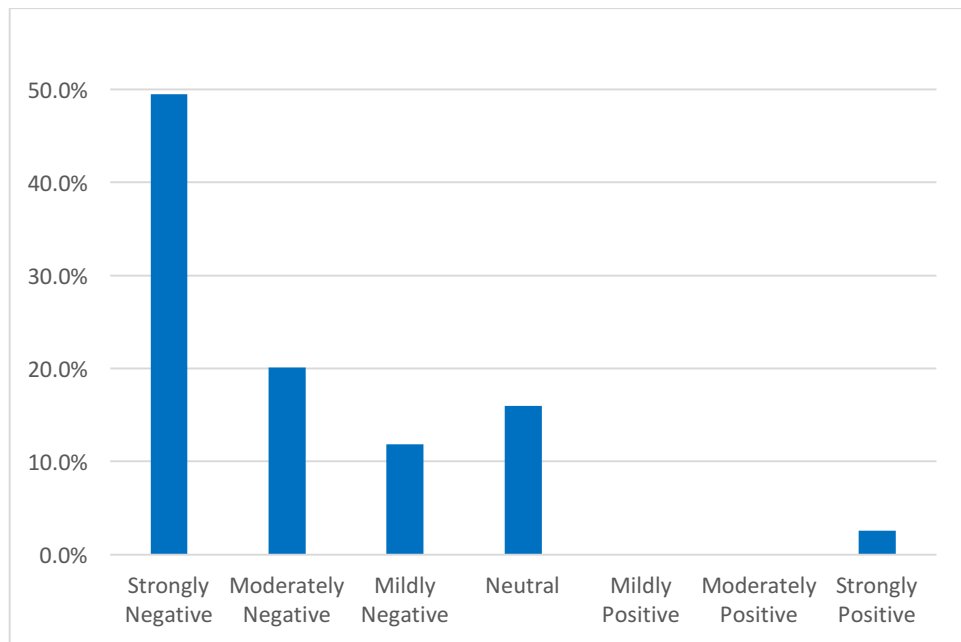


Figure 5-13 Impact of ASD Caregiving on Retirement Savings

When asked to rate their level of concerns about aspects of their child’s financial future and their own, respondents were more concerned about their child’s financial future and being able to support their child than they were about their own finances. All of these options were concerning to respondents – over half of parents reported that they were “very concerned” about these issues. Only a handful of respondents indicated that they were not concerned at all.

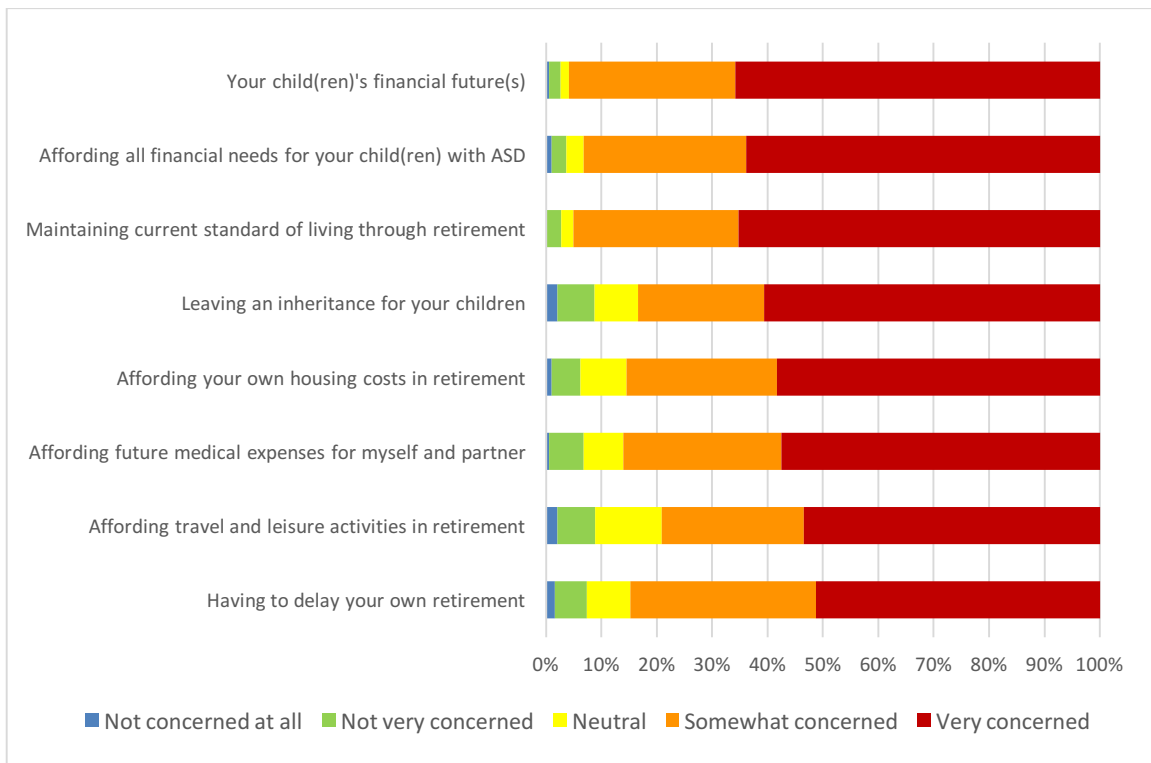


Figure 5-14 Types of Concerns about Financial Future

Additionally, the respondents reported lower levels of home ownership than the BC average, perhaps due to decreased earnings. 56% of survey respondents owned their home, compared to the BC average of 70% (Statistics Canada, 2011). This result indicates a lack of financial security among families impacted by ASD, and is notable given the high levels of education among respondents. One would expect that a group of highly educated British Columbians would be more likely to be higher income and own their home, but this is not the case for the educated parents of children with ASD. Not owning a home can lead to financial vulnerability and poverty in their later years – many of these parents will not have property they can sell to fund their own retirement and eldercare.

5.3.3. Concerns for Child's Financial Future

When asked about their top three concerns for their child's financial future, concern about a lack of government benefits for their child was the top concern, and it was shared by 60% of respondents. This fear is not unfounded, given the lack of public policy and jobs training programs aimed at adults with ASD. Nearly 60% parents were concerned about

a lack of employment opportunities for their child, which is a reasonable fear given the scarcity of skills training programs aimed at people with ASD, and discrimination and a lack of understanding on behalf of employers. This result is similar to findings in a survey of American parents of adults with ASD, where 73% were worried their child would never work outside the home (Graetz, 2010, p. 41).

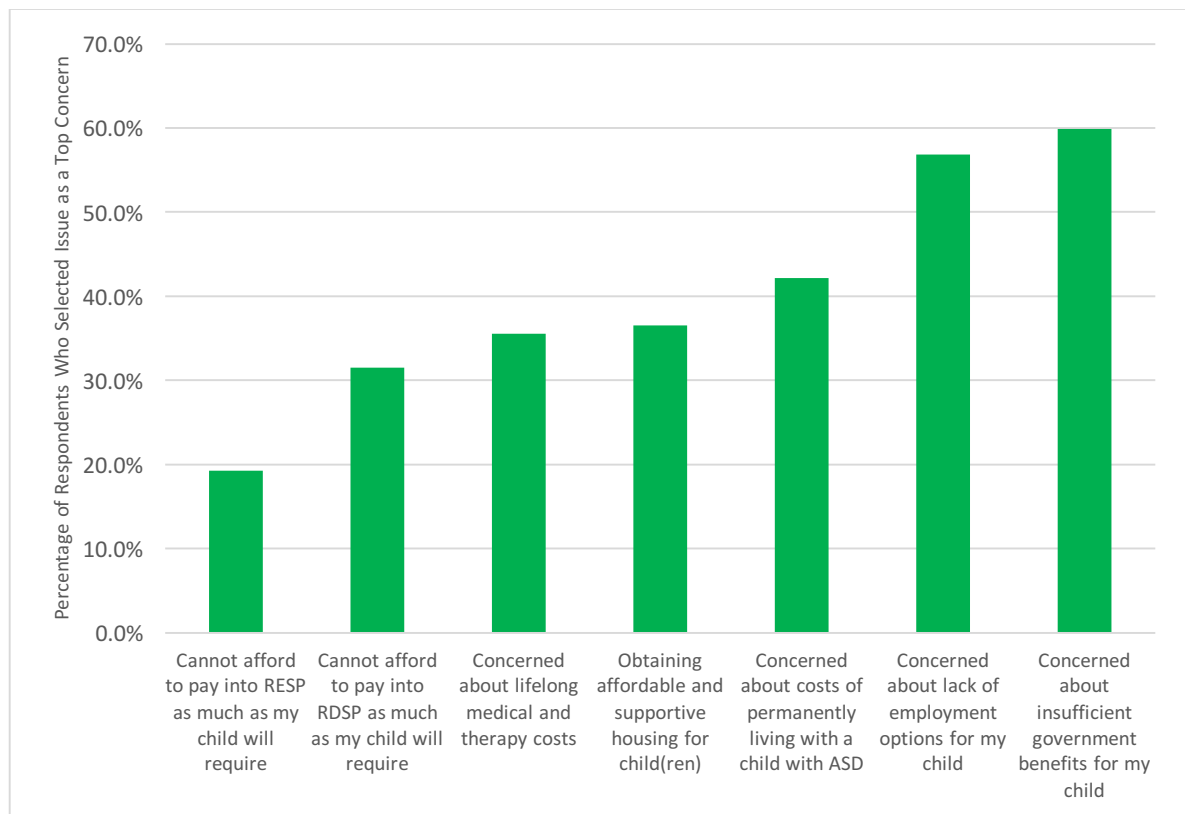


Figure 5-15 Respondent's Top Three Financial Concerns for the Future

Note Respondents could only select their top three financial concerns

Contributing to their child's RESP and/or RDSP were the least worrying concerns for parents, yet the relatively low number of children who had an RESP and/or RDSP demonstrates that families are not able to take advantage of these federal policies or not aware of them. Only a third of children in this survey had an RDSP. Interestingly, children were more likely to have an RESP than an RDSP, despite the fact that RDSPs are on the most efficient way to provide for the financial future for people with disabilities – the federal government will match RDSP contributions up to a certain dollar amount, dependent on family income.

5.4. Respondent's Opinions on Policy

Respondents were asked to reflect on their own career path, and think about which policies or other supports would help them achieve their ideal employment situation. Their open ended answers to this question are analyzed here. Respondents suggestions for policy change fell into seven interrelated categories – workplace accommodations, government funding, childcare, the quality of support staff, respite care, issues with the public school system, and wait times for diagnosis.

Struggling to Balance Caregiving with Paid Work

Parents caring for a child with ASD reported difficulties in balancing paid work with their caregiving responsibilities, and a lack of workplace accommodations caused emotional and mental stress. This is especially notable given that high levels of emotional stress had an impact on the careers of 88% of respondents who experienced a career interruption. One parent noted that a lack of workplace accommodations *“definitely impacted my health and stress while trying to care [for my child] and seek help and diagnosis.”*

A lack of flexibility within the workplace makes it hard for parents to arrange and attend their child's various therapy appointments. Juggling their child's appointments with paid work is a delicate balancing act. A respondent described the stress and precarity of this situation by explaining *“I'm so distracted all the time trying to keep on top of things that it's a wonder I haven't been fired yet.”* One respondent felt that a lack of workplace flexibility was stalling their career and consequently lowering their income, stating that *“if we had career options that were flexible, we could jump from being super low income to making a middle class income in one fiscal year.”* Respondents expressed strong support for workplace accommodations, particularly for flexible scheduling and more vacation time. Flexible scheduling was especially needed to deal with their child's appointments. It was suggested that since this flexibility is difficult to obtain from employers, there should be *“protection under employment law of ASD caregivers responsibilities of ____ amount of time for ASD related activities, i.e.) therapy and counseling commitments.”* A parent recommended that governments create *“incentives for workplace accommodations...subsidized salaries [and] additional funding for organizations who hire*

parents of children with autism... it allows parents to receive something if they work and it may motivate employers to hire them and tolerate periodic absences.” One respondent proposed long term leave as a policy that would better support families impacted by ASD – in particular, they suggested that this leave be available for parents with children with special needs under age 6.

A lack of flexibility in the workplace was detrimental not only to careers but also to plans for post-secondary education. One parent requested *“government grants to go back to school to upgrade skills so that I can go back into the workplace,”* and another suggested that parents of children with ASD should receive discounted tuition or scholarships. A respondent explained that due to their child’s condition, *“I’ve had to take too much time off of my studies, and I’m getting precariously close to becoming redundant educationally.”*

However, respondents recognized the limits of workplace accommodations. Even parents who had flexible scheduling at their workplace reported high levels of emotional and financial stress. A working parent remarked that *“my employer has been flexible regarding my hours but I can’t remember the last time I had a full cheque.”* Other parents felt that workplace accommodations were not possible or practical, especially in certain professional fields, like law.

For some respondents the time required to care for their child and manage their child’s at-home treatment precluded their ability to work outside the home, and no amount of accommodations could change that. One respondent explained that *“I don’t see how I could work more and follow my career and STILL be available enough to deal with my child’s many therapists and appointments.”* Another respondent stated that *“running a home therapy program is a full time job of over 40 hours per week as it is”* and workplace accommodations would not have changed their situation. For parents who have already left the labour force to care for their child, workplace accommodations may not be enough to bring them back into the labour force. Time was the most scarce commodity for these families. A parent described their caregiving duties as being:

the CEO of a child's overall multi-disciplinary treatment program... no one can replace you as a parent - I have been the glue holding all the pieces

together and being there every time a home-based therapy session was cancelled, being there for my child when he needed downtime in between various therapies. It's hard to hire someone to play that role even if you have the money.

For some parents, their time spent at home with their child(ren) with ASD has been invaluable. A parent explained that *"if I was not able to stay at home, I'm sure they would not have been able to achieve the success that they have."*

Workplace accommodations, particularly flexible schedules that allow parents to attend and manage their child's treatment, would undoubtedly benefit many families impacted by ASD. Nevertheless, they are not a panacea.

Insufficiency and Dysfunction of MCFD Funding

Increasing the dollar amount of provincial government funding for ASD treatment was the most frequently wished for policy change, and was specifically cited by 80 survey respondents in response to the open-ended question. The way in which increased government benefits from MCFD and more therapy hours would help parents achieve their desired employment situation was not specified by most of the respondents. However, it was suggested that it could reduce financial and emotional stress on parents and enable one parent to stay home and manage their child's at-home ABA program full-time. With more government funding, the working parent's salary would not be *"split between therapy costs and household [expenses]."* Respondents wished that they could use the MCFD funding to stay home with their child and manage their care, explaining that *"I can use funding to pay other people but not to pay for my time."* One parent postulated that *"IDEALLY, the government NEEDS, to pay one parent \$30,000 a year to stay home to look after their specials needs children. This life is just WAY TOO HARD!!!!"*

In particular, parents reported needing more funding for children over the age of 6, and adults. One respondent hoped for greater *"recognition that supporting teen boys with ASD requires a lot more money [than MCFD provides]."* Another noted that *"once funding and child tax credit stops, there is significantly less money to budget with."* They felt that more funding would benefit their children and help them reach their optimal outcome –

more therapy will *“increase their abilities and skills that would help them cope with daycare settings and routine changes.”*

Respondents also reported being dissatisfied with the way MCFD operates. Parents felt the rules for eligible expenses were inflexible – they were dissatisfied that they cannot use the funding for childcare expenses, and that there is not enough coverage for specialized food items and sensory friendly clothing. Dealing with the bureaucracy is *“very time intensive.”* The MCFD invoicing system is viewed as inefficient, and one parent argued that MCFD and service providers need another agency to oversee their billing:

Have a government agency to watch over how service providers are billing the AFU. Through 2 separate providers, our child's funding was billed in excess and as a result, he had to go several months without therapy due to their greed. I also had to leave work several times when the agencies didn't have their communication between workers and staff together on cancelations having me miss work on the day of to pick up my son when no one would be there to get him. Have agencies that aren't just in the autism business for the money who don't just want to gain access to your child's funds and then not help our family with our child's target symptoms, leaving us with an academically smarter kid who can't self regulate.

Coordinating a child's care between MCFD, the public school system, and professionals and support workers was difficult – parents want *“a more cohesive overseeing of autism - so many different organizations that manage funding, and my children's care and education, make for so many appointments that it's really difficult to work at all let alone full time.”*

Childcare

Respondents reported great difficulty in accessing childcare. This problem is not unique to parents of children with ASD – there is a severe shortage of licensed childcare spots in BC (Childcare Advocates of BC, 2014). However, even many licensed childcare centres are ill equipped to care for children with ASD and will deny children with ASD a spot in their daycare. Childcare centres are not required to accept children with special needs and often lack the knowledge of how to meaningfully integrate children with special needs into their programs (Halfon & Friendly, 2013, p. 12). A respondent stressed that her family needs *“better day care options”* including *“finding a place where my son's dx [diagnosis] is not a reason to be denied entry.”*

The lack of childcare centres that accept children with special needs leads to long wait times. One parent reported that their 14-year-old son with ASD has been on a wait list for a special needs after-school program for over 7 years. It is especially difficult to find childcare options for parents who work shiftwork, and one respondent reported that she could only find a daycare that offered weekday hours. Finding care for older children and teenagers was noted as particularly difficult to obtain, as was care for the winter break summer holidays. After-school care that included transportation from the school to daycare was difficult to find, and without it, parents cannot work a 9 to 5 job. Childcare that includes transportation is highly sought after. Although the Infant Development Program and the Supported Child Development Program are supposed to provide support for children with special needs to fully participate in childcare settings, parents reported that they need *“more support workers for my son to be able to attend daycare like other children.”*

Access to affordable and high quality childcare is important because it enables parents to work outside the home if they so choose. A parent stated that *“better childcare options for special needs families would be the biggest boost for our family”* in terms of finances and career advancement. A lack of childcare access for children with ASD hinders paid work and lowers parental income – a survey participant explained that *“I need to stay home since I am very reluctant to have my child at day care given his diagnosis.”* The stress of finding appropriate childcare detracted from paid work activities, with one respondent arguing that *“I’d be able to focus much better at work if there were decent daycare options.”*

Support Staff Issues

Respondent indicated that they were dissatisfied with the availability of BIs, respite workers, and other support staff. This result is in line with research from CASDA, which found that a lack of trained professionals was identified as a barrier to receiving services by 49% of parents of school-aged children with ASD (Weiss et al., 2014, p. 44). Finding highly trained workers was especially difficult in rural areas, and respondents reported paying additional out-of-pocket costs to travel to areas where services were offered.

Survey participants also noted issues with the quality of support staff. For one parent, her only wish was to have *“a caregiver who could actually handle my daughter’s behaviors, but that will never happen!”* One respondent directly linked the limited MCFD funding to the difficulty of finding highly trained staff, explaining that *“I could not find qualified care for her due to lack of funding to fill a full time position at competitive pay rates.”* One parent wanted *“better training programs for BIs. We could hire one but can’t find one right now”*. Another parent wished she could *“be able to pay a living wage”* for workers, and have *“better options for service providers to provide supports for children and teens with ASD.”*

Respite Care

Respite care provides parents with a much needed break from their caregiving duties. It reduces caregivers’ stress, helps caregiver’s complete other tasks, and provides parents with time to spend with their other children. Ultimately it can help families to live *“a more ordinary life”* (Harper et al., 2013, p. 2605). Respite care is important for all caregivers, regardless of whether they work outside the home or not. One respondent explained that *“just because I am a stay at home mom doesn’t mean I don’t need it, having no support system around it makes it specially [sic] difficult.”*

Technically MCFD provides funding for respite care, but the wait list is long. One respondent reported waiting for 5 years to receive respite funding. Even with funding support from MCFD, respite care is hard to obtain. One respondent explained that although she receives funding, she must *“pay \$25 an hour for a babysitter when I can find someone. On average, they babysit about 10 times before quitting.”* The quality of respite care was also called into question, with a parent explaining that *“if I had any access to special needs care or non-sketchy respite...then I could have had the opportunity to continue in my studies and would be working in my field by now.”*

Fifty participants specifically noted their need for respite care. In the out-of-pocket costs section of the survey, several parents indicated they had spent nothing on respite, but desperately wished they could afford to. However, some parents did not feel that respite was as important an issue as government funding and childcare access.

Respite wouldn't matter because you can't use respite care to go work. And if you're working 24/7, you're not likely to leave your kid in respite just to get a few chores done - you'll choose to spend time with the child instead.

Failed by the Public School System

Respondents reported that their children with ASD were not being properly educated in the school system. Special education is supposed to replace the \$16,000 drop in funding when a child turns 6, but parents stated that “*schools are not equipt [sic] to provide the speech and OT my children need and \$6,000 a year [from MCFD] just does not cut it.*” Due to this lack of support, 20% of survey participants left the workforce to home-school their child, saying “*there is not enough support in our local schools for my children to attend public school.*” This is a common issue among parents of children with special needs. In a survey by the BC Parents of Special Needs Children, half of their respondents removed their child from the public school system due to concerns over the lack of supports. 44% reported lack of access to speech therapy, occupational therapy or other supports, 45% reported there were not enough educational assistants, and 42% said the educational assistants were not well trained to deal with their child’s condition (BC Parents of Special Needs Children, 2015). Notably, no respondent specifically called for ABA to be included in the public school system, but broadly speaking respondents wanted to see more supports within the public school for their children. Respondents also hoped for more support for parents who homeschool children with ASD.

The respondents linked the lack of support for children within the public school system as a reason for home-schooling, and consequently leaving the labour force and losing income. Respondents reported delaying kindergarten, and not returning to work, so that their child could continue therapy. This has a serious financial impact on families, and one parent argued that:

if a caregiver is forced out of work because the school district cannot provide proper/adequate support, and the ASD child is forced to be a homelearner, offset income should be granted to compensate the parent for 1) potential earnings, 2) skills lost due time out of their career prior to being forced home.

Waiting for a Diagnosis

Respondents wanted shorter wait times for assessments and diagnosis of ASD. BC has shorter wait times for an official diagnosis compared to other provinces, but the wait times were long enough to cause problems for children with ASD and their parents. Parents described not receiving a diagnosis until their child was already in school, and therefore ineligible for the highest amount of MCFD funding - *“my son wasn’t diagnosed until 8 and it took about 2 years to get that.”* Another survey participant described the stress that the uncertainty of waiting for a diagnosis created, and linked it to their inability to return to work after the standard parental leave period.

“My son wasn’t diagnosed until he was 3.5 years old. But over those years, I knew the difficulties we were having and how drained we were. There was no way I could trust any daycares to provide the care he required, yet there was no diagnosis in those early years that I could provide so that people would understand and then be able to accommodate with proper support. I think then that early diagnosis and intervention is actually one of the policies that helps support parents getting back into the workforce, at least in some capacity.”

Although it was not specifically mentioned by any survey respondents, some families choose to pay for a private assessment and avoid the wait list for BCAAN services (this may be accounted for, to some extent, in the medical professional category of the out-of-pocket costs section). Paying for a private assessment by a child psychiatrist or registered psychologist can cost thousands of dollars, which many families cannot afford, especially they are anticipating paying for autism treatment as well. Waiting for a diagnosis means that children are not eligible to receive ASD funding from MCFD, although even without an official diagnosis they may be eligible for the Infant Development Program, or special education assistance in the public school system.

5.5. Discussion

The results from this survey of parents of children with ASD in BC demonstrate widespread discontent with the status quo. Parents reported significant employment effects – nearly half of respondents reported that their child’s condition had a strongly negative impact on their career trajectory and their income. Three quarters of respondents

have experienced a career interruption, above and beyond the typical parental leave period, due to their child's ASD. For 88% of respondents, emotional stress was a key reason for this interruption, followed by medical or therapy appointments for their child (82%) and balancing caregiving and paid work (81%). More than 90% of respondents were very or somewhat concerned about their children's financial future and affording all future financial needs for their child.

The average out-of-pocket spending per child with ASD was nearly \$6,800 per year. This is a very significant expense, especially given that most respondents were from middle class households. Consequently, more than half of respondents reported that their child's condition had a strongly negative or moderately negative impact on their household's accumulation of debt. Out-of-pocket spending was not related to household structure or income, but it was related to a child's communication and cognitive abilities, indicating these children need greater state support than they are currently receiving.

Some parents felt that workplace accommodations – specifically, flexible scheduling so that they could take times off for their child's appointments – would help them achieve their desired employment situation and increased their earnings. Respondents also described the difficulties of finding a suitable childcare provider that would accept their child, and the challenge of finding, and paying for, respite care. Inadequate support for children with ASD within the public school system was also a problem, and led some families to homeschool. There was strong support for increasing the amount of MCFD funding among survey respondents – this was the most commonly hoped for policy change. However, it must be noted that the very high levels of educational attainment among the survey sample, and the nature of the survey dissemination, may skew these results. Parents who are members of the ASBC and/or online ASD parent groups may be involved in advocacy efforts and have stronger political opinions than the true population of parents of children with ASD in BC. Lower income and less educated parents, who were not well represented in this survey, may have different needs for ASD related services, and differing opinions on the status quo.

These results gauge the scope of the policy problem, and demonstrate the weaknesses of existing government policy. Despite MCFD funding, parents of children

with ASD are paying significant out-of-pocket costs and taking on new debt, all while they are having to work less or leave the labour force entirely. In many ways these results are not unexpected – parents have been advocating for change by telling their stories in hopes of better educating people on the realities of raising a child with ASD in BC, and anecdotally it is well known that ASD is an expensive condition. However, the extent of the problems faced by families impacted by ASD is striking, and being able to better gauge the impact will help inform policy makers. In particular, the sheer number of unprompted complaints regarding a lack of childcare and inadequate support within the school system, was unexpected. These results help formulate the argument for policy change in the upcoming chapters.

Chapter 6. Policy Options

This project evaluates four policy options for ASD policy with the status quo. These policy options are derived from existing government policy, suggestions from the survey, and reforms proposed by advocacy groups. These policy options are aimed at the government of BC; reforms at the federal level were not included in this analysis.

6.1. Option #1: The Status Quo

In order to make a fair and balanced policy analysis, it is necessary to consider the status quo. Policy makers do not necessarily have to change their policy, so it is fair to ask what happens if they do nothing. As described in Chapter 2.4, currently children with ASD are eligible to receive up to \$22,000 annually prior to turning 6, at which point they are only eligible for \$6,000 of funding for treatment. Children with ASD attending public schools receive special education assistance, but their aide may not or may not be trained in ABA methods. The MCFD funding is not means tested, indexed to inflation, or tied to a child's needs – it is a “one size fits all” approach. The funding is provided to the child's parents, who then manage their child's home team and hire support staff. MCFD argues that this model “allows families maximum choice and flexibility” (Ministry of Children and Family Development, n.d.). Yet the funding is not enough to cover the full cost of treatment for many children with ASD, and parents make choices to homeschool their children, pay for additional treatment hours out-of-pocket, and change their employment situation based on this policy.

6.2. Option #2: Increase and Target Funding Under the Existing MCFD Model

The BC government could increase funding for children with ASD under the existing Autism Funding Unit at MCFD. This option would not require creating new government programs or bureaucracy; it involves only minor reforms to an existing program. This policy option recognizes that a child with ASD needs ABA and/or other specialized services throughout their elementary school and high school years, and this

option does not automatically reduce funding at age 6. The funding would be increased to \$29,000 per year for children under 6 to cover the average out-of-pocket costs for this age group. The amount of funding would be indexed to inflation and updated annually. This funding would not be means-tested, since there was not an association between income and higher out-of-pocket spending – the larger factor in these expenses was a child’s functioning. For children between the ages of 6 and 18, funding above the \$6,000 would be based on individual need, rather than the “one size fits all” approach of the status quo. There would be no limit on the amount of annual funding, although funding above the standard \$6,000 allotment would need to be justified by the child’s level of functioning in terms of cognitive and communication skills, as well any aggressive behaviours. Documentation and justification of the need for these services would need to be provided to the MCFD by a qualified medical professional (e.g. child psychiatrist or psychologist, similar to how the BCAAN diagnosis process operates). Some children have more success with early intervention than others, and may not need as much intervention during their school years – often, intense ABA intervention is only needed for several years. Children who are greatly impacted by their ASD will require continue to require intensive intervention and support, and these services would be funded. Moreover, travel costs would not be counted against a child’s funding. This is in line with the coroner’s inquest into the Robinsons’ deaths, which recommended that MCFD ensure that transportation issues are addressed separately from autism funding, and consider increasing funding for older children with intense needs (Ministry of Justice, 2015a, p. 9). By not counting travel costs towards the MCFD funding amount, children and parents in rural areas are not unduly punished merely for where they live.

This policy would direct funding towards the older children who need it most, while also supporting providing significant support to all young children prior to entering the school system. This policy option reduces the out-of-pocket expenses for families, gives children with ASD the best start during their early years, and provides continuity of treatment for children as they age. More therapy hours for more years should help more children with ASD reach their optimal outcome, no matter where they live in the province.

This policy option can be interpreted as providing “special” treatment to children with ASD. Governments have finite resources, and this was a consideration when

designing the existing MCFD program. While this option would be supported by ASD stakeholders, it may not be as popular to the government due to its focus exclusively on ASD. Research by Waddell and Shepherd found that policy makers “encountered resentment that autism has taken up too much government time and money” compared to other disabilities and mental health issues among children (2015, p. 3357). However, the ASD programs were seen as examples that could be used for other conditions. One researcher argued that “I don’t think we should not do something for some children because we can’t do it for all. I think we should be trying to do more for all” (Waddell & Shepherd, 2015, p. 3562). Alberta’s program is available to all children with developmental delays or special needs, not just those with ASD. BC could address these equity concerns by following their example, although policy for children’s disabilities and mental health more generally is outside the scope of this capstone.

6.3. Option #3: Healthcare Coverage for ABA

Under this policy option, ABA would be covered under the Medical Services Plan (MSP) as a healthcare service, rather than a social service issue under the MCFD. A child’s care would be managed primarily by healthcare professionals, not bureaucrats, parents, and employees hired directly by the parents. Treating ASD therapies as any other medical treatment is an idea extolled by advocacy groups like Medicare for Autism Now and Families for Early Autism Treatment (FEAT), who argue that access to intervention services like ABA is a right. They argue that children with ASD possess a positive substantive right to healthcare, and consequently governments have a duty to provide it (Stone, 1998, p. 209).

To implement healthcare coverage for ABA, the province of BC would need to add ABA based programs as a “supplementary benefit” under MSP⁶. Under the *Canada Health Act* provinces are compelled only to cover core “medically necessary” services from physicians and hospitals. However, provinces can add additional coverage for their residents. BC has already done so for eye exams, chiropractic care, naturopathic medicine, physiotherapy, massage therapy, acupuncture, etc. for people on MSP Assistance, inmates, refugees and other select vulnerable groups.

Due to the Auton ruling, any changes to healthcare coverage for ASD would need to come from legislation, or internal government policy, not litigation. This would require significant political will within the provincial government and would be a complex and lengthy process. It would require dismantling the Autism Funds Units of the MCFD, and transferring responsibility to the Ministry of Health. The billing and invoicing systems of MCFD would be eliminated, and ASD professionals and paraprofessionals, who are not currently billing to MSP, would have to be integrated into that system. Qualified ASD professionals would decide how much intervention a child needs, and for how long. Families would never see a bill for these covered services, although some specialized services (e.g. music therapy, equine therapy) would be excluded from coverage and would need to be purchased out-of-pocket if desired.

6.4. Option #4: Integrate ABA into the Public School System

In order to better support school aged children with ASD, ABA could be implemented into the public school system. Aides would be trained in ABA and be integrated into a child’s home team. This policy option is based off of Surrey’s policy innovation, where ABA trained aides work within the school system. Currently, in other BC

⁶ This project focuses on policy recommendations for the provincial level, so this option describes a potential way to change provincial healthcare coverage. However, ASD intervention services could be covered nationally by amending the *Canada Health Act*. This would require legislative action by the federal government. This is the option favoured by advocacy groups like Medicare for Autism Now. However, multiple efforts to amend the *Act* have failed, as described in Chapter 2.3. Moreover, the *Canada Health Act* does not deal with coverage for specific diseases or conditions, and it concerns physician and hospital services, not services from other professionals (Canada, Parliament, Senate, 2007, p. 13).

school districts many aides working with children with ASD are not trained in ABA methods, and there is little continuity between a child's home team and their experiences at school. This policy would be combined with the existing MCFD program, so children with ASD would still receive some level of funding for at-home therapy and eligible specialized programs and camps for the summer months. However, the bulk of ABA programming for school-aged children would occur in the school setting. This policy involves considerable bureaucratic changes and some administrative costs for the Ministry of Education and local school districts, but would not change the costs for MCFD.

6.5. Option #5: Include Workplace Accommodations in Provincial Labour Codes

The province could make it easier for parents to take time off work to attend appointments for their child's treatment. This could be accomplished by amending the family responsibility leave section of the *Employment Standards Act* to allow parents of children with special needs to take additional time off. Currently, the *Employment Standards Act* allows parents to take up to 5 days off per year to "meet responsibilities related to (a) the care, health or education of a child in the employee's care, or (b) the care or health of any other member of the employee's immediate family" (*Employment Standards Act*, 1996). Taking leave for part of the day, even one hour, counts as taking a full day. This leave is unpaid⁷ (Ministry of Labour, n.d.). Provinces have significant latitude to change this policy. Already, Quebec and Ontario offer 10 days per year of unpaid family leave, Newfoundland offers 7 days, and Saskatchewan, Manitoba and New Brunswick offer 3 days.

The *Employment Standards Act* could be amended to specifically allow parents of children with disabilities to take unpaid time off to attend to their child's appointments and other relevant needs. This policy would allow parents to take 15 days off per calendar year to care for their child with ASD. Since this leave is unpaid, it would not present a significant burden to employers or the state. Since this family leave would be regulated and protected

⁷ Since Employment Insurance (EI) is a federal program, family leave paid through EI would require federal action.

by law, employers would not be allowed to discriminate against employees who used this policy. By making work scheduling more flexible, this policy addresses a key issue identified by survey respondents. In order to make this policy a success, the provincial government would need to educate employees and employers about this policy, so that parents could take advantage of it, and employers would understand their obligations.

Chapter 7. Criteria and Measures

The following section provides an evaluative framework to measure and compare policy options for implementation in Canadian provinces. Broad objectives guide the criteria for analysis: supporting families impacted by ASD, and ensuring that children with ASD receive the services they need to reach their optimal outcomes. To assess the advantages and disadvantages of the policy options, the five criteria applied are equity, efficacy, stakeholder acceptability, cost to government, and implementation complexity, with specific measures for each. The first three criteria are focused on the impact of policy on children with ASD and their families. The final two criteria, cost to government and implementation complexity, represent the perspective of government and the practical considerations of implementing new public policy. These criteria are unweighted – by having three criteria representing the needs of children with ASD and their families, and only two representing government concerns, the analysis inherently gives more credence to the needs of children and families impacted by ASD.

7.1. Equity

Equality requires that everyone is treated the same in absolute terms. Yet children with ASD and their families have unique and often challenging needs – this is why a focus on equity, rather than equality, is needed. In order to be treated equitably, they cannot receive the same treatment as the rest of the population. They need individualized supports and policies tailored to their needs to achieve their best outcomes.

This equity criterion focuses on financial equity between families impacted by ASD and the general population. It has two measures – the change in out-of-pocket spending for ASD related costs, and the change in the percentage of parents of children with ASD who experience a career interruption. This policy is designed to get at the impacts of ASD caregiving on a family, not just the child with ASD (that aspect is addressed in the next criterion). If the policy option creates little to no improvements in equity for families, it scores a 1. Moderate increases in equity are ranked as 2, and significant increases in equity score a 3.

7.2. Efficacy

This criterion assesses whether a given policy effectively meets the needs of children with ASD. It is based off the knowledge that children with ASD should receive early intervention services to reach their best outcomes, and assesses whether the policy will change the number of children with ASD who are receiving a sufficient amount of support services (e.g. 25+ hours per week of an ABA based program for young children). If the policy increases access to effective services for all children, the policy scores highly (3). A policy that ensures most children can access services scores a 2, and a policy that does not improve access scores a 1.

7.3. Stakeholder Acceptability

Given the history of litigation over ASD funding in BC, and an passionate community of parent activists, stakeholder acceptability is a key component of successful public policy. In the past, parents of children with ASD have felt shut out of the policy making process for policies that deeply affect every facet of their lives. This criterion assesses the anticipated percentage of parents and parent run advocacy groups who support the policy. If there are high levels of support, the policy scores highly (3). Moderate support earns a medium score (2), while low levels of support receive a score of 1. This criterion does not consider government as a stakeholder, since their views are represented in the subsequent two criteria. Parents of children with ASD are the primary stakeholders for these policies – the policies impact their lives deeply, and since their children are minors, they are not yet able to advocate for themselves. The opinion of the general public was not considered for this criterion since ASD related policies are largely irrelevant to the general public.

7.4. Cost to Government

This criterion is used to gauge the extent to which additional resources will be needed to carry out policy change. Because this policy analysis is aimed at the BC government, it focuses only on the costs to provincial government. The criterion assumes that lower costs are preferable. This criterion assesses the change in the cost to government per child with ASD. If a policy option creates a significant cost increase for government it scores a 1, a moderate increase scores a 2, and a little to no increase in the cost to government scores a 3.

7.5. Implementation Complexity

Implementation complexity assesses the degree of administrative and legislative change required for a successful execution of a policy option. A key aspect of implementation complexity includes the length of time needed to implement the policy – for politicians, who survive in an election cycle environment, policies that require large time horizons can be less appealing. Another aspect of implementation complexity is the degree of bureaucratic structural change required to implement the policy. Bureaucracies will resist changes that decrease their power. The degree of legislative change is also considered, because legislative change requires political will and a degree of bipartisanship. Policies that require a high degree of implementation complexity score low, moderate complexity scores a 2, and negligible amount of implementation complexity is ideal, and scores a 3.

7.6. Criteria and Measures Matrix

This criteria and measures matrix lays out the criteria, their definition, the considerations of the definition, and the scoring system. The criteria and measures are applied to the policy options in Chapter 8, and the subsequent recommendation is discussed in Chapter 9.

Criteria	Definition	Considerations	Scoring Measures
Equity	1. How well does the policy promote financial equity between families impacted by ASD and the general population?	1. Change in the out-of-pocket ASD related costs for families impacted by ASD 2. Change in the percentage of parents of children with ASD who experience a career interruption	High: significant reduction in out-of-pocket costs; significant reduction in the number of career interruptions experienced by parents of children with ASD Medium: moderate reduction in out-of-pocket costs; moderate reduction in the number of career interruptions experienced by parents of children with ASD Low: little to no reduction in out-of-pocket costs, little to no reduction in the number of career interruptions experienced by parents of children with ASD
Efficacy	1. Does the policy improve access to effective levels of ASD support services? (e.g. 25+ hours per week with a professional for young children with ASD)	1. Change in the number of children with ASD who are receiving an effective amount of support services	High: policy ensures that all children with ASD receive effective support services Medium: policy ensures that most children with ASD receive effective support services Low: policy ensures that some children with ASD receive effective support services
Stakeholder Acceptability	1. Would the policy receive support from parents of children with ASD, and ASD related advocacy groups?	1. Percentage of parents and advocates who support the policy	High: high levels of support Medium: moderate levels of support Low: low levels of support

Cost to Government	1. Does the policy minimize the cost to government?	1. Cost to government per child with ASD, relative to the status quo	<p>High: cost per child is similar to, or less than, the status quo</p> <p>Medium: cost per child moderately exceeds the status quo</p> <p>Low: cost per child significantly exceeds the status quo</p>
Implementation Complexity	1. How complex is it to implement the policy?	<p>1. Length of time needed to implement the policy</p> <p>2. Degree of bureaucratic structural change required for policy change</p> <p>3. Degree of legislative change required for policy change</p>	<p>High: negligible implementation complexity</p> <p>Medium: moderate implementation complexity</p> <p>Low: high implementation complexity</p>

Chapter 8. Evaluation of Policy Options

This section will discuss the policy options outlined in Chapter 6 in relation to the five criteria and measures discussed in Chapter 7. The policy options will be ranked in relation to each other and this will lead into a recommendation for ASD related public policy in BC.

8.1. Option #1: Status Quo

Equity

The status quo does not do enough to promote equity between families impacted by ASD and the general population. This is evident from the survey results, which indicate that families impacted by ASD are experiencing high levels of financial stress and career interruptions due to their caregiving responsibilities, and this impacts their income and ability to plan for their child's long term needs. The current policy is of course better than having no funding, and BC's program is relatively generous compared to other provinces, but the equity concerns in BC are still serious. Having difficulty affording services is an issue for more than half of families impacted by ASD (Weiss et al., 2014, p. 44). The status quo scores a 1 for this criterion.

Efficacy

Although the status quo allows children with ASD to access eligible therapies, the funding is limited. This option is moderately effective, and scores a 2. The prevalence of out-of-pocket costs among survey respondents, combined with high levels of financial stress and low incomes, indicates that some families are struggling to afford an adequate amount of help for their child. The long wait lists for diagnosis also indicates that services are inadequate at dealing with the increasing demand. Despite the MCFD policies, research by the Canadian Autism Spectrum Disorder Alliance (CASDA) found that a lack of resources was a barrier to services for over 70% of children with ASD in BC (Weiss et al., 2014, p. 44).

Stakeholder Acceptability

The status quo is unpopular with parents of children with ASD and with parent led advocacy groups, but so far MCFD has resisted their calls for change. Survey respondents report that the current MCFD funding is not enough to meet their child's needs, and they hope for more funding.

Cost to Government

Since this policy option is already in effect the direct costs of maintaining this policy is low. However, continued increases in the costs of the MCFD program can be expected due to the rising prevalence of ASD.

It must also be acknowledged that there is a social cost to keeping the status quo and doing nothing. The survey results reveal some of these costs – 74% of parents are experiencing a career interruption due to their child's diagnosis, over a third of parents left the labour force to care for their child, and on average families are spending \$6,745 annually on ASD related out-of-pocket costs. Continuing with the status quo poses costs to society. The lower labour force participation of parents of children with ASD impacts their productivity and contribution to the province's economy, and also impacts their ability to financially provide for their future and the future of their child(ren). Parental stress can negatively impact their health and raise healthcare costs. It must be noted that 7% of survey respondents began receiving disability benefits or social assistance benefits after their child's diagnosis.

Social costs also arise if the policy is not helping children with ASD achieve their best outcomes and improve their functioning as adults. The costs of caring for an adult greatly impacted by ASD totals \$5.5 million (Dudley & Emerson, 2014, p. 17), so even a small increase in their independence and functioning can lead to significant cost savings in terms of caregiving and support costs. Improved access to highly quality ABA based intervention services will reduce these costs for the majority of children with ASD (Jacobson, Mulick & Green, 1998). One way or another, many of the costs associated with ASD will appear on the province's ledger. As the Senate proclaimed in 2007, government can "pay now or pay later." With the current MCFD policy, some of these costs are being paid for later and not accounted for in terms of ASD policy.

Implementation Complexity

This policy is already implemented. It is not complex to maintain this policy since the bureaucracy and administrative procedures are already in place.

8.2. Option #2: Increase and Target Funding Under the Existing MCFD Model

Equity

This policy option would improve equity between families impacted by ASD and the general population. It would do so primarily through reducing, if not eliminating, the out-of-pocket costs for an at-home ABA program and other supports. Based on the survey responses, this would save families an average of \$6,745 per year. This money could be allocated towards the child with ASD's future care and/or education, or other household expenses. Although the relationship between more government funding and reduced employment effects is less clear, respondents did indicate that more funding would reduce their financial stress and able them to work less and spend more time caregiving for their child with ASD.

Efficacy

This option would improve access to effective ASD interventions by providing families with the funding to purchase more therapy hours. This was a common request among survey respondents. Furthermore, the targeted funding for children over age 6 ensures that children will continue to receive effective and adequate support as they grow up.

Stakeholder Acceptability

This option would receive broad support among parents. As evident in their survey responses, parents of children with ASD strongly support increases in funding. They feel that better funding would provide their child with more therapy hours, improve their outcomes, and even improve their own employment situation by lessening their stress.

Cost to Government

The increase in costs to government from this policy is moderate. The administrative costs for running the Autism Funds Unit of the MCFD bureaucracy would not change. But the annual funding per child with ASD would increase – for children under 6, this would represent a 31% increase from the status quo, from \$22,000 to \$29,000. For children between the ages of 6 and 18, the costs over \$6,000 would be based on need, so it is difficult to estimate the cost increase. Moreover, overall costs could increase as families of children with ASD move from other provinces to access this program. However, the long term social costs of ASD could be reduced through better access to effective interventions – in the long run, this policy could be quite cost-effective.

Implementation Complexity

This policy involves using the existing MCFD bureaucracy to administer a minor change in programming, so there the complexity is very low. MCFD employees would have to evaluate claims for additional funding for children over 6, but this represents a relatively minor change to their responsibilities. The MCFD already oversees travel costs for those who use 20% of their MCFD for travel expenses, so this does not represent a significant increase in administrative burden or complexity.

8.3. Option #3: Healthcare Coverage for ABA

Equity

This policy option would increase equity by reducing the out-of-pocket costs for parents. Parents would no longer need to pay for ABA programs, or spend valuable time managing the administrative side of their child's care, since it would all be billed through MSP.

Efficacy

This option would improve access to effective services for children with ASD. Additionally, integrating ASD interventions into the healthcare system might better

coordinate their care. This is key, given the high number of comorbid conditions observed in the survey results.

Stakeholder Acceptability

This policy option would be very popular with parent led advocacy groups, although they would continue to push for national coverage and nation wide equity. It would satisfy the requests of survey respondents to increase coverage for therapy.

Cost to Government

The increase in costs to government from this policy is moderate. There would be administrative costs for shifting responsibility for ASD to the Ministry of Health, and for changing the MSP billing system. However, the MCFD funds would go towards these efforts, so the net increase would be moderate.

Most likely families from other provinces would move to BC to access this healthcare coverage, which could strain the provincial system. Without an increase in transfer funds from the federal government, the province would be left to pay for these additional therapy costs as well as additional administrative costs for bringing autism therapies under MSP.

Implementation Complexity

This would be politically difficult and not at all easy to implement. The provincial government has not shown any interest in pursuing this option. If implemented at a provincial level, BC could end up with more children with ASD, as “Medicare’s orphans” flock to the province. This effect discourages provincial policy experimentation. The administrative costs of shifting responsibility to the Ministry of Health would be large, especially since the billing and invoicing practices would need to change. Although it scores well on the other criterion, the logistical and practical realities of covering ASD within the healthcare system make this option less attractive.

8.4. Option #4: Integrate ABA into the Public School System

Equity

This policy option would increase equity for families impacted by ASD because it would reduce their out-of-pocket costs. If children receive more intervention at school, the parents have less to monitor, and less hours to pay for, in regards to their child's home team. 20% of survey participants reported altering their career path to homeschool, and improving supports for children with ASD within the school system could help these parents re-enter the workforce and raise their income, if they so choose.

Efficacy

This option would improve access to intervention services, but only moderately. Intensive early intervention would require time spent on weekends and after school, and during the summer months. Moreover, this option would not help children under 6, who are not yet a part of the public school system.

Stakeholder Acceptability

This would have a moderate level of support among parents, but likely would not receive the same support as increased MCFD funding and healthcare coverage for ASD. Survey respondents did express concerns about the lack of quality support for their children within the school system – they want “more integrated choices within the school system as we often have to organise private therapy in school hours,” and to reduce the “huge communication gap” between their child's school and other professionals.

Cost to Government

The increase in costs to government from this policy is moderate. There would be administrative costs for increasing the role of the Ministry of Education, teachers and support staff in ASD policy and service provision. However, since many children with ASD already have an aide with them during school hours, the cost of providing better training for that aide is minimal. However, there is a chance that “Medicare's orphans” or “autism refugees” would start coming to BC to access this program, and increase the overall cost.

Implementation Complexity

This policy would be moderately difficult to implement. Though the current MCFD funding and bureaucracy would stay the same, the Ministry of Education would need to increase their involvement in ASD related policy. Local school boards would have to be involved, as would individual teachers and support staff. This sounds daunting, but in reality it is relatively easy for all support staff working with children with ASD to become certified BIs. The certification course only takes a weekend. ABA methods would become part of standard special education methods, and children's IEPs.

8.5. Option #5: Include Workplace Accommodations in Provincial Labour Codes

Equity

This policy option would improve equity for families impacted by ASD by reducing career interruptions. 80% of respondents who experienced a career interruption attributed it in whole or in part to their child's numerous medical or therapy appointments. This policy option is the only option that directly addresses this specific issue, and provides parents with the flexibility to attend their child's appointments as needed. However, since the leave is unpaid, it does not ameliorate the financial impacts of taking time off of work. This option would particularly improve equity for mothers of children with ASD, whose careers are disproportionately impacted due to the gendered nature of caregiving.

Efficacy

This option would not directly improve access to adequate services for children with ASD since it only addresses their parent's needs, so the policy option scores low for this criterion.

Stakeholder Acceptability

Many survey respondents strongly supported workplace accommodations and flexible scheduling, but others felt it would not improve their situation. Additionally, some survey respondents suggested paid leave, or even receiving a guaranteed annual income

for caring for a child with ASD (these options were not considered due to the improbability of their adoption). This leave is unpaid and would not meet all of their expectations. Therefore, this options earns a medium score.

Cost to Government

The increase in costs to government from this policy is moderate. There would be some administrative costs for amending the legislation and for adjudicating disputes between employers and employees. To ensure the policy is useful and understood by both employees and employers, the Ministry of Labour would have to educate the public about family responsibility leave for parents of children with disabilities, and there would be some costs involved with this. Again, there is the chance that “Medicare’s orphans” or “autism refugees” would come to BC from other provinces and raise the overall costs of the policy.

Implementation Complexity

This policy would be moderately difficult to implement, since it would involve amending the *Employment Standards Act*. This would require time, an element of policy change for the Employment Standards Act, and political will. It would involve the Ministry of Labour increasing their involvement in disability related policies. However, the policy change is relatively minor, and it is not an overly complicated amendment.

8.6. Summary Matrix of Policy Evaluations

A criterion which scores highly receives a 3 (indicated in green), a medium score is a 2 (orange), and a low score earns a 1 (red). The higher an overall score of a policy option, the more desirable the policy is.

	Status Quo	Increase and Target Funding under Existing MCFD Model	Healthcare Coverage for ABA	Integrate ABA into the Public School System	Include Workplace Accommodations in Provincial Labour Codes
Equity	1	3	3	3	2
Efficacy	2	3	3	2	1
Stakeholder Acceptability	1	3	3	3	2
Cost to Government	3	2	2	3	3
Implementation Complexity	3	3	1	2	2
TOTAL SCORE	10	14	12	13	10

Chapter 9. Policy Recommendations

9.1. Recommendation for ASD Related Policy in BC

This project recommends that the province of BC increase and target funding for children with ASD under the existing MCFD model. By increasing the funding enough to cover the average out-of-pocket costs for children under 6, tying the amount of inflation, and covering travel costs separately, the financial burden on families will be reduced. By providing the base amount of funding for older children, along with targeting additional funds towards children over age 6 who are greatly impacted by ASD, the policy acknowledges the needs of children with ASD as they grow up. Parents of children with lower levels of functional independence report having more unmet needs (Brown et al., 2011, p. 1299), and this policy would provide additional supports for this group. This reformed policy would not include travel costs against a child's funding allotment. Parents could be reimbursed for the cost of in-province travel for eligible ASD services - the policy would no longer unfairly punish children in rural areas. Policy makers are aware of this issue - in interviews with Waddell & Shepherd, one policy maker noted that they struggle to ensure children in "a smaller community at one end of the province or a bigger community at the other end" receive the same level of services. (2015, p. 3561). This policy options satisfies the equity, efficacy, stakeholder acceptability and implementation complexity criteria very well. It does moderately increase the cost to government per child, but the costs will ultimately benefit vulnerable children and their families, and reduce the social costs of ASD. This should be an attractive option for government because it reduces the long term social costs of ASD – providing supports for children with ASD helps them reach their best outcomes, potentially increasing their educational attainment and employability, while also reducing the strain on caregivers. This policy change can, and should, be implemented quickly. This is not a difficult change to implement, since the bureaucracy will not change and it does not require legislative change, but it does require political will on behalf of the province.

In the long term, this report also recommends that the province consider following Surrey's example by integrating ABA into the school system. Interviews of parents, researchers and policy makers by Waddell and Shepherd revealed that the public school

system is the “most regressive and unaccountable system that we have left in the province.” Interviewees contended that the “lack of staff with the training and experience to support students with autism” compounded the problem - the province needs to “make sure that there are a broader set of people within the school system who have the basic understanding and skills needed to interact with kids with autism” (Waddell & Shepherd, 2015, p. 3560). Although this policy would take longer to coordinate and implement through the Ministry of Education and local school districts, it would better support school-aged children with ASD. Furthermore, the province should also amend the *Employment Standards Act* so that parents can take unpaid time off to attend to their caregiving duties. Implementing additional family responsibility leave for parents of children with disabilities and/or extensive medical needs acknowledges the stress faced by parents who are balancing caregiving for a child with ASD and paid work. On their own, these two long term options are not ideal. But together with the short term recommendation for increased funding, they will create a society where children and families impacted by ASD are treated equitably and supported to reach their optimal outcomes.

9.1.1. Supporting Recommendations

In addition to the main recommendation of increasing and targeting funding under the existing MCFD program, several complementary policy changes are recommended. Children with ASD need to be quickly referred by a physician to BCAAN and then diagnosed. The longer the wait, the longer a child goes without early intervention and financial support from the province. Survey respondents reported that long wait times negatively impacted their child’s progress and their own return to work, ultimately harming their income and their ability to support their child with ASD. It is possible to screen toddlers for ASD, and physicians and other medical professionals should not “wait and watch.” Once a pediatrician has identified a child as being at risk for ASD, the child should be evaluated as soon as possible. This can be accomplished through better education of physicians and pediatricians, and by allocating more resources to BCAAN, who is funded and administered by the Provincial Health Services Authority. As Crane and Winsler argue, it is in “our best interests as a society to fully fund training programs for pediatricians, parent and consumer education about early child development, and early evaluation programs for children” (2008, p. 251).

As indicated by survey respondents, children with ASD in rural areas need more access to support services. Even with increased funding, if there are no local medical professionals able to screen for and diagnosis ASD, no one to hire for respite care, or no one to carry out an ABA based intervention program, the policy is ineffective. The provincial government could offer financial incentives for behavioural interventionists (BIs) to work in rural areas, and support establishing training programs for BIs in rural areas. Offering BI training workshops in rural areas can attract people to the profession, and create jobs in rural areas while simultaneously helping children access services. Addressing the geographical discrepancy in ASD related services will significantly improve equity for these families.

The province should also provide education to childcare providers, as well as increased financial support, so that daycare centres will accept and support children with special needs. The Infant Development and Supported Child Development Programs should be expanded, specifically for older children and teens, and wait lists should be shortened. In response to an open ended question, 67 survey respondents specifically noted they had difficulties accessing suitable childcare for their child with ASD. This has been an ongoing issue for parents of children with special needs - in the 2006 PALS survey by Statistics Canada, more than 20% of parents of a child with a disability reported that a childcare provider had refused to care for their child (Statistics Canada, 2008, p. 19). Not all childcare centres have the knowledge or ability to adequately support children with ASD and/or other special needs. Childcare centres are not required to accept students with special needs, and should not be compelled to if they truly do not have the capacity to sufficiently care for a child. However, more needs to be done to support the inclusion of children with ASD in childcare centres. Currently, the lack of supportive childcare spaces impacts children's ability to participate in early childhood education programs, their parent's ability to work outside the home, reduces their income, and therefore reduces their ability to pay any out-of-pocket costs for their child's condition and plan for the future.

Furthermore, there is an appalling lack of supports available for adults with ASD. Increasing supports for children with ASD from diagnosis through to age 18 is a crucial undertaking, but the supports must not stop at 18. Many of the issues respondents reported in the survey results – a lack of respite care and childcare, intense financial

stress, and the struggle to balance caregiving with paid work – are relevant for caregivers of adults who are greatly impacted by ASD. When children with ASD become legal adults, and leave behind the MCFD funding and the public school system, there are even fewer options for assistance. Many adults with ASD do not qualify for existing disability programs. Adults who are greatly impacted by ASD “become more invisible to the general public and their existence is even more dependent on their caregiver” (Graetz, 2010, p. 35). Adults who are moderately or marginally impacted by their ASD are also completely ignored by policy makers, perhaps even more than those severely impacted. This lack of support creates extreme stress for families - over 60% of survey respondents said that insufficient government benefits for their child is one of their top concerns for the future. 57% are concerned about a lack of employment options for their child. Over half of survey respondents are seriously concerned that they will have to delay their own retirement to pay for their child’s living expenses, and are concerned they will be unable to afford their own housing and medical costs in old age. If the province is truly committed to equity and providing sufficient services to people across the spectrum, they should create policies aimed at supporting people with ASD, and their families, throughout their lifespan.

9.2. Conclusion

This project focused on surveying families impacted by ASD in BC and developing recommendations for the provincial government. Prior academic research has demonstrated the high levels of parental stress involved with caregiving for a child with ASD on parental stress, and indicated the prevalence of career interruptions and out-of-pocket costs in other jurisdictions. An original online survey was used to attempt to gauge the effects of caregiving for a child with ASD on parental employment and income, as well as the extent of out-of-pocket costs faced by these families, in the BC context. The survey respondents were members of the ASBC and online ASD parent groups. The 197 BC residents who responded to the survey demonstrated that the status quo is failing their children and themselves.

Families impacted by ASD reported that their child’s diagnosis has severely negatively impacted their own income, their household income, and the household’s accumulation of new debt. Notably, 74% of primary caregivers of children with ASD

experienced a career or paid work interruption related to their child's condition. Mother's careers were particularly impacted. For over 80% of those who experienced an interruption, emotional stress and the challenges of juggling their child's medical and therapy appointments were key factors. A third of survey respondents became stay-at-home parents due to their child's needs. At the same time that their income was being reduced, they were faced with ASD related out-of-pocket costs. Although parent's reported a wide range of out-of-pocket spending, from \$0 to over \$50,000 per year, the average total was \$6,745 and the median was \$4,000. This a significant ongoing annual cost for families, especially for lower-income families. Participants expressed severe concerns over their ability to afford lifelong expenses for their child, and wondered whether there would ever be job opportunities for their child with ASD. Most parents were seriously concerned about a lack of government benefits for their child. They want more government funding and flexible workplace scheduling, as well as better access to childcare, respite care, and improve supports within the public school system. Only a handful of the nearly 200 survey respondents did not indicate great concern with the way these issues are currently handled by the BC government. As one participant exclaimed, "*this life is just WAY TOO HARD!!!!*" In the case of Angie and Robert Robinson, the stress of dealing with ASD in an area where provincial supports were meagre and difficult to access led, in part, to their tragic deaths.

The data from this survey, as well as information gathered from the academic literature, was used to evaluate policy options for ASD funding and support services. Along with the status quo, four policy options are considered: increasing funding under the existing Ministry of Children and Family Development program, adding coverage for autism treatment within the healthcare system, integrating ABA into the public school system, and offering leave for parents to care for their child. Ultimately, increasing and targeting funding under the existing MCFD program received the highest score based on its positive impact on equity, efficacy and stakeholder acceptance, as well as its relatively small cost to government. This policy reduces the costs for families, and improves services for older children, like Robert Robinson, who have intense needs and require support throughout their lifespan. The implementation of this policy should be supported by decreasing the wait times for an ASD diagnosis, increasing the availability of supportive childcare, and improving access to services in rural areas. Over the long term, the province

should also better integrate ABA methods into the public school system and allow parents to take unpaid leave to care for their child. Although policy for adults with ASD is outside the scope of this capstone project, the province must also create policies aimed at that population. ASD is a lifelong condition, and the supports should not stop at age 18.

This research points towards future projects that could focus on the needs of teens and adults with ASD, and include their voices in the research. The needs of their caregivers (if applicable) should be examined too - the needs of aging parents caring for adults with ASD may differ from the needs of parents of children under 18. Given the lack of supports for adults with ASD, the needs of older parents may be more intense. Furthermore, the limitations of this project could be addressed in future research projects. This survey did not ask respondents about the type of industry they work in, or whether they were union members. Going forward, research should examine whether certain industries are more flexible and supportive for parents of children with special needs. The survey also did not ask about parents' salary and career histories prior to their child's diagnosis, which would enable researchers to better estimate the economic impact of caring for a child with ASD. Significantly, this survey did not examine the effect of race, ethnicity, aboriginal identity, and immigration status on families impacted by ASD. It is not known how these factors influence employment and ASD caregiving in BC or Canada. This survey did not include many voices of fathers, lower income women, and women with lower levels of education. In the future, researchers should make a greater attempt to reach these populations – their needs may be different than those better represented in this survey.

Other jurisdictions can take away lessons from this research – even with moderate levels of government support, families impacted by ASD are struggling, and cannot afford to access adequate levels of early intervention programs, respite care, and childcare, let alone plan for the financial future of their child and themselves. Without a national policy regarding ASD, Canada is left with serious inequities between provinces and within provinces. BC is relatively generous with ASD related supports compared to most other provinces, but survey respondents still reported high levels of financial stress, employment effects, and significant out-of-pocket costs. In the rest of Canada, with the exception of Alberta, it is likely that the situation is even more dire. The survey results painted a dismal

picture of families impacted by ASD in BC. But the status quo can, and should, be changed. There is a lack of federal leadership in this area, but the government of BC has an opportunity to become a leader in ASD related policy by increasing and targeting funding towards children with ASD.

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Appendix.

Survey Questionnaire

The Hidden Costs of Autism: Income and Employment Effects of Caregiving for Children with Autism Spectrum Disorder

Q1 . You are being invited to participate in a research study titled The Hidden Costs of Autism: Income and Employment Effects of Caregiving for Children with Autism Spectrum Disorder. This study is being conducted by principal investigator Dr. Sherri Brown of Simon Fraser University, and co-principal investigator Ms. Allison Rounding, a Masters Candidate in the Public Policy Program at Simon Fraser University. The purpose of this research study is to develop a more complete and multi-dimensional understanding of the out of pocket costs related to Autism Spectrum Disorder (ASD), the impact of ASD caregiving on household income, parental employment options and trajectories, and household finances.

The survey is open to adults ages 18 and older who are primary caregivers of a child under age 18 with ASD. A primary caregiver carries primary responsibility for the health, safety, and caregiving of a dependent child. The survey is only open to BC residents at this time, and we request that only one adult primary caregiver per household completes the survey. If you agree to take part in this study, you will be asked to complete an online survey. This survey will ask about your child(ren)'s diagnoses and behaviours, your level of education and income, your employment status, out-of-pocket costs related to your child's ASD, and planning for the financial future of you and your child(ren).

Your participation in this study is completely voluntary, and you can withdraw from the survey at any point. You are free to skip any question that you choose. The survey will take you approximately 15 - 20 minutes to complete. You can only complete the survey once.

Permission has been obtained from the Autism Society of BC to distribute this survey through their online newsletter and through their Facebook page. Permission to advertise this survey on Facebook groups for parents of children with ASD has been obtained from the administrators of those online Facebook groups. You will not directly benefit from this research; however, we hope that your participation in the study will contribute to a better understanding of the significant costs faced by parents of children with ASD. The results of this survey will be reported in a graduate capstone project, and may also be published in journal articles and books, and shared at academic conferences. There are no known risks associated with this research study. Your responses will remain confidential. Your privacy will be ensured by storing the online survey results on a Canadian server, and only the co-principal investigators will have access to the survey data. After the results are downloaded by the researchers, all IP addresses

will be purged from the data set. All data that will be printed will be stored in a locked file cabinet. The data will be stored by the co-principal investigators for 5 years, after which it will be purged.

If you have questions about this project, you may contact Dr. Sherri Brown at [...], or Allison Rounding at [...]. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, you may contact Dr. Jeffrey Toward, Director, Office of Research Ethics at [...]@sfu.ca or [...].

By submitting this survey and clicking “yes” below, you are consenting to participate in this research study. If you wish, you may print a copy of this page for your records. We thank you for your time and interest in this survey.

Yes

No

Q2 . Are you the primary caregiver of child(ren) under age 18 with an autism spectrum disorder diagnosis? A primary caregiver is defined as the person who assumes the primary and majority responsibility for the daily caregiving needs of a dependent child(ren).

Yes

No

Q3 . Please enter your postal code.

Postal

Code :

Q4 . Do you rent or own your current full-time residence?

Select One...

Rent

Own

Other

Q5 . Please indicate your sex.

Male

Female

Other

Q6 . Please indicate your age range

18-24

25-34

35-44

45-54

55-64

65-74

75 years and older

Q7 . Please indicate your relationship to the child in the household with autism spectrum disorder.

Select One...

Mother (by birth or adoption)

Father (by birth or adoption)

Foster parent

Grandparent

Other

Q8 . Please indicate your current household structure.

Select One...

Single-parent

Single-parent with shared custody

Two-parent household

Other

Q9 . Please indicate how many children in your household have an autism spectrum disorder diagnosis.

One

Two

Three

More than Three

Q10 . What is your child's (with an autism diagnosis) year of birth? If you have more than one child with ASD, list your youngest child's birth year here and use the next question(s) to list your other children's birth years (with ASD)

Q11 . Second child's year of birth with ASD

Q12 . Third child's year of birth with ASD

Q13 . Does your child with autism spectrum disorder have any additional co-morbid diagnoses? Answer for your youngest child with autism spectrum disorder if you have multiple children with ASD.

Epilepsy/Seizure Disorder

Bowel Disease

Chronic Constipation or Diarrhea

ADHD

Obsessive Compulsive Disorder (OCD)

Sensory Processing Disorder

Nonverbal Learning Disability

Oppositional Defiant Disorder

Bipolar disorder

Fragile X Syndrome

Down Syndrome

Sleep Disorder

Anxiety
Other

Q14 . If you selected other above, please list other co-morbid conditions for your child with autism spectrum disorder.

Q15 . Does your child have any additional co-morbid diagnoses? Answer for your second youngest child with autism spectrum disorder if you have multiple children with ASD.

Epilepsy/Seizure Disorder
Bowel Disease
Chronic Constipation or Diarrhea
ADHD
Obsessive Compulsive Disorder (OCD)
Sensory Processing Disorder
Nonverbal Learning Disability
Oppositional Defiant Disorder
Bipolar disorder
Fragile X Syndrome
Down Syndrome
Sleep Disorder
Anxiety
Other

Q16 . If you selected other above, please list other co-morbid conditions for your child with autism spectrum disorder.

Q17 . Does your child have any additional co-morbid diagnoses? Answer for your third youngest child with autism spectrum disorder if you have multiple children with ASD.

Epilepsy/Seizure Disorder
Bowel Disease
Chronic Constipation or Diarrhea
ADHD
Obsessive Compulsive Disorder (OCD)
Sensory Processing Disorder
Nonverbal Learning Disability
Oppositional Defiant Disorder
Bipolar disorder
Fragile X Syndrome
Down Syndrome
Sleep Disorder
Anxiety
Other

Q18 . If you selected other above, please list other co-morbid conditions for your child with autism spectrum disorder.

Q19 . Where would you place your child on the autism spectrum in terms of the impact of ASD on the child's cognitive (intellectual) functioning?

Mildly impacted
Moderately impacted
Severely impacted
Not sure /Not affected

Q20 . Where would you place your child on the autism spectrum in terms of the impact of ASD on the child's communication abilities?

Mildly impacted
Moderately impacted
Severely impacted
Not sure

Q21 . Where would you place your child on the autism spectrum in terms of the impact of ASD on the child's aggressive or self-injurious behaviours?

Mildly impacted
Moderately impacted
Severely impacted
Not sure
Does not apply

Q22 . What is the highest level of education you have attained?

Select One...
Less than high school
High School Diploma or its equivalent
Registered apprenticeship or trade certificate/diploma
College Diploma
CEGEP, or other non-university certificate or diploma
University degree at a bachelor level (including LLB)
Masters Degree
University degree in medicine, dentistry, veterinary medicine or optometry
Doctorate (Ph.D.) Degree

Q23 . What is your current employment status? Check all that apply.

Full-time Employment (30 hours + weekly)
Part-time Employment (less than 30 hours weekly)
Full-time (30 hours + weekly) Self-Employed
Part-time (less than 30 hours weekly) Self-Employed
Seasonally Employed
Seeking employment
Stay at home caregiver
Receiving disability or social benefits

Retired
Full-time Student
Part-time Student
Other

Q24 . If you checked other for the previous question, please provide details:

Q25 . Please indicate your total INDIVIDUAL annual gross income (include total wages and salaries, including commissions, bonuses, tips, taxable benefits, research grants, royalties, etc., before any deductions)

Less than \$10,000
\$10,000 to \$19,999
\$20,000 to \$29,999
\$30,000 to \$39,999
\$40,000 to \$49,999
\$50,000 to \$59,999
\$60,000 to \$69,999
\$70,000 to \$79,999
\$80,000 to \$89,999
\$90,000 to \$99,999
\$100,000 to \$149,999
\$150,000 or more

Q26 . Please indicate HOUSEHOLD total annual gross income (include total wages and salaries, including commissions, bonuses, tips, taxable benefits, research grants, royalties, etc., before any deductions)

Less than \$10,000
\$10,000 to \$19,999
\$20,000 to \$29,999
\$30,000 to \$39,999
\$40,000 to \$49,999
\$50,000 to \$59,999
\$60,000 to \$69,999
\$70,000 to \$79,999
\$80,000 to \$89,999
\$90,000 to \$99,999
\$100,000 to \$149,999
\$150,000-200,000
\$200,000-249,000
\$250,000 and over

Q27 . Have you, since the birth of your child with an ASD diagnosis, experienced a career or paid work interruption, above and beyond the parental leave period, to care for your child with the ASD diagnosis?

Yes
No

Q28 . If you answered YES to the previous, please select any of the following ways in which your career has been affected by an autism diagnosis in your household.

Switch from Full-time (30+ hours) to part-time work (<30 hours)
 Increased working hours above full-time hours/took a second job
 Reduction of weekly working hours while still working full-time
 Left labour force voluntarily
 Left labour force involuntarily
 Accepted a demotion
 Changed positions to allow for more flexible household scheduling (e.g. one parent took night shifts)
 Changed careers to achieve a more flexible working situation
 Started self-employment
 Took retirement earlier than anticipated
 Went back to pursue post-secondary studies
 Caregiver began receiving disability or social assistance benefits
 Other

Q29 . If you checked other for the previous question, please provide details:

Q30 . Reflecting on your own career path, what types of policies or other supports would help you to achieve your desired employment situation? (eg. better daycare options, more government funding for therapy, more therapy hours, more respite care, workplace accommodations)

Q31 . How would you rate the impact of caregiving for a child with autism spectrum disorder in the following domains?

	Strongly Negative Impact	Moderately Negative Impact	Mildly Negative Impact	Neutral/No Impact	Mildly Positive Impact	Moderately Positive Impact	Strongly Positive Impact
Your employment options and career trajectory :							
Your spouse/partner's employment options and career trajectory :							
Your total annual income earnings :							
Your total annual household income :							

Your total
annual
household
debt
accumulation
(new debt) :

Q32 . What, if any, aspects of caregiving for a child with an ASD diagnosis, have affected your employment options and trajectory?

Emotional stress of caring for a child(ren) with ASD
Medical or therapy appointments for child(ren) with ASD
Financial stress of ASD-related expenses
Balancing caregiving responsibilities and paid work
Medical or therapy appointments for one of the child's caregivers
Lack of placement for child with ASD in daycare, preschool or other daytime caregiving environment
Homeschooling option selected for child with ASD
Opted to be a stay at home caregiver for their child(ren)
Other

Q33 . If you checked other for the previous question, please provide details:

Q34 . In the past 12 months, please estimate the total out-of-pocket expenses (costs not covered by insurance, MSP, or government funding) related to your child(ren) with autism that your household has incurred in the following categories:

Total annual respite care (paid caregiving/babysitting expenses; does NOT include daycare, preschool, or out-of school care expenses) :
Specialized services tailored to individuals with ASD (camps, tutoring, social skills groups) :
Behavioural Therapy and Other Therapy - consultants, therapists, school aide, other (non-behavioural) consultants, and supplies (therapy related toys, reinforcers, timers) :
Medical professionals - registered psychologist, counsellors, fee for services not covered by MSP (doctors letters) :
Therapy - Paraprofessionals (OT, PT, SLP) :
Therapy - Other services (music, equine, etc) :
Medical Supplies - Incontinence supplies, sensory (chewelry weighted blankets), pharmacological, G tube, not covered by MSP or private insurance :
Administration - invoicing, laminating, printer supplies etc :
Technology - iPad and applications, dynavox, etc :
Legal - lawyer fees, documentation :
Other: Please specify expense and amount :

Q35 . Please rate the following:

Strongly Negative Impact	Moderately Negative Impact	Mildly Negative Impact	Neutral/No Impact	Mildly Positive Impact	Moderately Positive Impact	Strongly Positive Impact
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How have
your
retirement
savings
been
impacted by
caregiving
for a
child(ren)
with ASD? :

Q36 . Does your child(ren) [all children diagnosed with ASD) have a Registered Education Savings Plan (RESP)?

Yes
No

Q37 . Does your child(ren) (all children diagnoses with ASD) have a Registered Disability Savings Plan?

Yes
No

Q38 . Please estimate the total annual contributions made to your child with Autism Spectrum Disorder's: (If you have more than 1 child with autism, please provide the average of the total annual contributions per child)

Registered Education Savings Plan -RESP
Registered Disability Savings Plan- RDSP

Q39 . Please rate your level of concern in the following areas:

	Not concerned at all	Not very concerned	Neutral/Does not apply	Somewhat concerned	Very concerned
Your child(ren)'s financial future(s) :					
Having to delay your own retirement :					
Being able to afford all financial needs for your child with ASD :					
Being able to leave an inheritance for your children :					
Being able to afford future medical expenses for myself and partner, including elder care :					
Being able to afford your own housing costs in retirement :					
Being able to afford travel and leisure activities in retirement :					
Maintaining current					

standard of living
through retirement :

Q40 . If you have identified any level of concern for your child(ren)'s (with ASD) financial future, please check your TOP THREE (3) concerns.

Cannot afford to pay into RDSP as much as my child will require
Cannot afford to pay into RESP as much as my child will require
Obtaining affordable and supportive housing for child(ren)
Concerned about lifelong medical and therapy costs
Concerned about costs of permanently living with a child with ASD
Concerned about insufficient government benefits for my child
Concerned about lack of employment options for my child