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REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

# British Columbia's Autism Funding Policies: Benefits and Gaps

# Politiques de financement de l'autisme en Colombie-Britannique : les avantages et les lacunes

**Elliot Gustafson** 

#### Abstract

Autism Spectrum Disorder (ASD) affects one out of 100 children worldwide (World Health Organization, 2023). In Canada, public debates about policies related to autism funding have been ongoing. This research paper provides an analysis of the autism funding policies in British Columbia from inception to present day. Using an economic, social, and educational lens, this paper will examine the progress that has been made to support children living with ASD over two decades and the issues that exist within current autism funding policies that require addressing to improve access and quality of care, support services, and education for those with ASD.

Resumé

Les troubles du spectre de l'autisme (TSA) affectent 1 enfant sur 100 dans le monde (Organisation mondiale de la santé, 2023). Au Canada, les débats publiques sur les politiques liées au financement de l'autisme se poursuivent. Cet article de recherche fournisse une analyse des politiques de financement de l'autisme en Colombie-Britannique de leurs débuts jusqu'à aujourd'hui. Dans une optique économique, social et éducative, cet article examinera les progrès accomplis pour soutenir les enfants vivant avec un TSA au cours des deux dernières décennies, ainsi que des problèmes que posent les politiques actuelles de financement de l'autisme et qui doivent être résolus pour améliorer l'accès et la qualité des soins, des services de soutien et de l'éducation pour les gens avec un TSA.

#### Keywords

Autism; autism policy; early intensive behavioural intervention (EIBI); Canada; British Columbia (BC)

Mots-clés

Autisme, politique de l'autisme, intervention comportementale intensive précoce (ICIP), Canada, Colombie-Britannique (CB)

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#### Introduction

The purpose of this study is to conduct a policy analysis and evaluation of the British Columbia (BC) Autism Funding Policy. Specifically, this paper explores the progression of the Autism Funding Policy in BC, how the policy has changed and developed over the years, and what gaps exist in the funding policy. I will also explore the impacts of this policy at a community level and provide potential recommendations and/or revisions to the current Autism Funding Policy.

To begin, it is important to define Autism Spectrum Disorder (ASD). ASD is a complex condition, which can manifest itself differently for individuals. ASD is classified as a pervasive neurodevelopment disorder that affects verbal and nonverbal communication, social interaction, and life skills development (Whitman, 2004). The Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-V) issued by the American Psychiatric Association (APA) offers a lengthy and clinical definition of ASD. Although, the definition has changed over the years, it has consistently referenced impairments in communication and social interactions, as well as repetitive, stereotypical behaviours and limited interests, and sensory processing difficulties. Clearly a deficit framed definition of a neurodevelopment condition focused on examining the impairments.

In 2013, the DSM-V, merged autism, Asperger's syndrome, childhood disintegrative disorder (CDD) and pervasive development disorder - not otherwise specified (PDD-NOS) into autism spectrum disorder. However, it is again important to note that autism presents differently from person to person. In BC, to assess for ASD, two main standardized tools are used including the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) and Autism Diagnostic Interview Revised (ADI-R) (Dua, 2003). Both tools cover the autistic behavioural features presented in the DSM-V and rely on observations using a quantitative checklist and self-reporting of parents/ guardians through an interview and survey (Dua, 2003).

In recent years, the prevalence of ASD has increased significantly relative to other developmental conditions (Centers for Disease Control and Prevention, 2020). The World Health Organization estimates the prevalence at 1%, affecting 1 in every 100 children (World Health Organization, 2023). Although, there is no clear evidence as to what causes ASD and how to treat it, there are a multitude of treatment approaches. There are on-going debates on which "treatment" is the best, yet there is no effective "one size fits all" treatment approach for people living with ASD. Over the decades, the predominant approach to supporting children with ASD is early autism intervention, also called Early Intensive Behavioural Intervention (EIBI) (Kent, 2000). Intervention is meant to help minimize disruptive behaviours while offering an educational approach to teaching life skills, improving communication abilities to allow someone with ASD to live a more independent life (National Research Council, 2001).

EIBI dates to the 1960s and was developed by Ole Ivar Lovaas at the University of California. EIBI is rooted in Applied Behaviour Analysis (ABA) developed by B.F. Skinner in the 1930s. The strategies of ABA include the use of functional analysis of behaviour, followed by reinforcement, prompting, correcting, and shaping the behaviour to what is expected (Wong et al, 2015). EIBI programs are individualized to the needs of the child. Some children with ASD may need a combination of speech therapy, occupational therapy, physiotherapy, and autism behaviour modification, while others may not.

Supporters of EIBI by Lovaas claim it is the only effective method for treating ASD (Kent, 2000).



For EIBI to be successful, it must be implemented between two and six years of age and for a minimum of 20 hours a week (Lovass et al, 1973; Klintwall & Eikeseth, 2014). The Lovaas EIBI method becomes a critical player in the creation of the BC Autism Funding policy and will be discussed further in this paper.

## Situating Myself in this Research

I was diagnosed with ASD in 2005 at age two. Little was known about ASD at that time, leaving a void that was filled by a few troubling social touchpoints. One standout includes the character Raymond Babbitt, an autistic savant played by Dustin Hoffman in the movie "Rain Man." Hoffman's portrayal has been polarizing (Ikalyuk & Kuzmyn, 2015; MacLeod, Lewis, & Robertson, 2013) with some feeling that the movie helped to portray autism from a perspective of being gifted, while others felt the movie perpetuated a stereotype of people on the spectrum having gifts with patterns and numbers, but being plagued by fits of hysteria (Ikalyuk & Kuzmyn, 2015). Another standout is Jenny McCarthy's "educational" campaign which, in direct opposition to the medical community, claimed that early childhood vaccines led to cognitive delays in children resulting in ASD (Yochim & Silva, 2013).

This was the social context at the time of my diagnosis. Soon after, I was enrolled in the autism funding policy offered by the Ministry of Children and Family Development (MCFD). My family opted not to receive the funding directly but rather work with the multi-disciplinary, integrated early intervention autism program at Queen Alexandra Hospital in Victoria, BC. From the age of three to six, when I aged out of the program, I attended the EIBI programs, for four hours a day, five days a week. When I started kindergarten at age five, I attended half-day kindergarten in the mornings and autism intervention in the afternoons, which meant I was in some form of formal education/training from 8:30 to 5:00, Monday to Friday. Once I turned six, my family received \$6000 a year in support, which included ongoing educational psychology assessments, speech therapy, and social group programming with an occupational therapist.

As someone who has received funding for ASD, I have a personal interest in the topic of autism funding policy. I have been curious about how this funding came about, how it supports children with ASD and their families, and what are the limitations of this funding policy. I am also interested in this topic from the perspective of an undergraduate student in economics.

# Program/Policy History

In 2002, MCFD became responsible for providing autism funding to parents and guardians with children diagnosed with ASD. To support an analysis of the Autism Funding Policy in BC, below is a brief historical overview of the policy. Although individual funding was sent to families as early as 2001, there was limited support available in terms of behaviour intervention, speech therapy, occupational therapy, and physical therapy. The genesis of the current Autism Funding Program was precedent-setting litigation known as "The *Auton* Decision" (MCFD-funded services for Children with ASD, 2013). This decision resulted from a small group of families, coordinated by Families for Early Autism Treatment of BC (FEAT), who collectively launched a lawsuit against the provincial government. The litigation took place from 1998 to 2004. The families involved were seeking funding for the Applied Behaviour Analysis (ABA) treatment program for their children (Manfredi & Maioni, 2005, p.111). The FEAT group of families argued that the Lovaas EIBI method



was the only proven treatment for autism. However, families for EIBI were individually paying up to \$70,000 a year for the intensive therapy (Kent, 2000). Up until the litigation, funding requests for treatment were denied. In the court proceedings, the families argued that by denying funding for ABA, provincial authorities had violated the constitutional rights of citizens to treatment for autism within its public healthcare system. Using a rights-based litigation approach towards healthcare policy reform, arguing that if the province paid for the cost of early intervention, it would mean less draw on healthcare in the future. In 2004, the Supreme Court of BC ruled in favour of the families for ABA (MCFD-funded services for Children with ASD, 13).

Under the Christy Clarke government, in 2009, significant changes were made to the services for children and youth diagnosed with ASD and their families to equalize access and improve service levels. In a CBC article *BC cut back autism funding* posted on September 16, 2009. Mary Polak of MCFD claimed the province wanted to offer treatment to more children than the current policy allows. Polak references that the "creation of the BC early intensive therapy program was partly in response to a court battle, but that the time had come for more equality in allocating support" (CBC, 2009).

According to to a September 16th, 2009 News Release by the BC Government, the following changes were made:

- o An increase to under-age-six funding from \$20,000 to \$22,000 per year.
- o Funding discontinuation for the province's Early Intensive Behavioural Intervention (EIBI) programs.
- o Budget reallocation for the creation of a new provincial outreach program for young children with ASD to improve access to professional services, particularly in rural and remote communities (Ministry of Children and Family Development, 2009).

#### Methods

For this paper, I employed a qualitative research approach to examine the effectiveness of the Autism Funding Policy and Eligibility Policy in BC, and to identify potential policy gaps and challenges. In my analysis, I also use a content approach, descriptive approach, and evaluation approach (Delaney, 2017) to examine how effective these policies are in creating an efficient yet inclusive society. From here, I will look at the policy frames and discourses that are evident among the policy makers in the making of said policy. Finally, using a critical policy lens (Delaney, 2017) I will analyse and determine who benefits from the policy as well as who should benefit.

To accomplish this study, I analyzed relevant literature found through library databases, web searches, and policies made available through MCFD staff. I also conducted a library database search, utilizing archive.org, the Legislative Library of British Columbia, and Government Archives. The search terms included autism, autism department, autism spectrum disorder (ASD), autism policy, autism funding, and autism intervention and yielded 147 articles. From there I reduced the articles to the 24 most relevant to my study. I mainly focused on articles in relation to BC but did also compare articles and research papers about autism policies in other provinces.

Most of the articles found related to ASD and education in public school, ASD and counselling, and intervention approaches. Although these articles related to my topic, they were not specific to issues regarding funding policies and were thus excluded from my review. I also conducted a web search for non-academic materials that would also provide additional relevant



context such as ministry reports, articles related to the *Auton* litigation and the *Anderson* class action. This includes news releases from local papers, op-ed pieces, government news releases, and parent blogs. Lastly, relevant data was supported through correspondence with the Ministry of Children and Family Development (MCFD) staff.

### Policy bias - from Disease to Disability

The Auton litigation began in 1999 with the filing of a writ of summons (a legal document that requires someone to attend court), then a statement of claim and an application for certification of the action (Class Proceedings Act, R.S.B.C. 1996, c.50). The litigation sought a declaration that the denial of funding for Lovaas treatment discriminated based on mental disability against those who had been diagnosed with autism and any other neurological condition (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299). However, once the Auton litigation reached the Supreme Court of Canada in 2004, the ruling was made that the government of British Columbia did not infringe on the petitioners' s.7 rights of the charter of rights and freedoms (Auton et al v. Attorney General of British Columbia, 2001 BCSC 220).

Legal scholars and academics looking back on the decision say that the "Auton [ruling] is no longer good law, and there is nothing precluding 'social assistance' being a 'service' subject to the protections afforded by the Act and in accordance with principles of substantive equality" (Disability Rights Coalition v. Nova Scotia (Attorney General), 2021 NSCA 70). From this ruling, the Anderson class action focused on arguing that the lack of government funding towards autism intervention services was a violation of their s.15 rights in the Charter of Rights and Freedoms (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299). As stated by the council for the petitioners, "they have failed in their attempts to obtain public funding for intensive behavioural autism treatment based on the Lovaas Autism Treatment method. The petitioners now seek relief under s.24(1) of the charter in respect of a breach of their s.15 equality rights" (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299, p.2/12). By September 9th, 2003, The Honourable Justice Pitfield, ruled that the crown had violated the infant petitioners' rights under s.15 of the Charter of Rights and Freedoms (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299).

From here, the Canadian government had to treat autism as a disability and not a disease, which demanded a redesign of provincial and federal autism policies - access to funding for autism treatment had become a human right.

#### Autism Diagnosis, Autism Treatment, and Funding Models

Many provinces had their finance departments do internal audits on how to refinance themselves to make the changes that were now being required of them. All provinces including British Columbia found three main things that they need to make sure are addressed in the redesigning of the policy: (1) family capacity (2) program expectations (3) use of funds. In summary, most provinces in their internal audits had discovered that ministries across the country and specifically in BC were not prepared or able to meet these demands given the available resources. The recommendations were as follows:

"We recommend that the ministry consider a range of strategies to improve the program's ability to manage these risks, including: structured orientation and training program's for parents; additional supports and resources for parents such as a central call centre;



additional programming choices for families who are unable or unwilling to participate in individualized funding; better communication of program expectations, possibly in additional languages; more appropriate resourcing for program administration, such as a centralized resource for monitoring parents' expenditure reporting; and specific procedures for following up questionable use of funds, and for dealing with parents who have misused funding." (MacPhail et al, 2004, p.2).

Provinces now were given clear details from their internal audits of what needed to be addressed, on top of the federal requirements of allowing parents to secure funding for autism treatments such as EIBI.

Autism related policies in BC are divided into two types: eligibility and funding, both of which fall under the order of the "Supply Act" and court ruling of the Anderson class action. The Ministry of Children and Family Development (MCFD) was now required to provide autism programs for eligible children and their families. The purpose of the policies and accompanying standards was to provide clarification regarding the criteria and process used to determine eligibility for the autism funding under age six and autism funding between ages six and 18. Families of children with ASD under the age of six could receive up to \$22,000 per year for purchasing eligible autism intervention services, based on the best practices, that promote their child's communication, social-emotional, pre-academic and functional life skills development. Autism funding for ages six to 18 program provides up to \$6,000 per year to assist with the cost of out-of-school autism intervention services that will promote their child's communication, social-emotional life skills development.

To provide each eligible child access to the funding for these services, the BC government developed a behavioural plan of intervention (BPI). According to the government website, the BPI "is an individualized plan of intervention designed for a specific child or youth that focuses on identifying areas where intervention is needed. The BPI should have a multidisciplinary focus that emphasizes academics, communication, social/play skills, emotional/self regulation, motor/ sensory functioning, [and] independence/life skills" (Government of BC, 2015). With the BPI, governments and parents can measure the success of autism intervention programs/services for their children's lives in relation to social expectations.

Looking at the anecdotal research done by both government internal audits and researchers contracted to review the supports, its seems that early intervention is critical for children with autism and ASD. Beginning in 2001, the University of British Columbia conducted research funded by the province over a three-year period on 70 children under six who were receiving autism intervention. The research found that parents, on average, saw significant improvements in their children and were satisfied with the effects of the services. The research also found no significant outcome differences between direct-funded, government-run intervention and contracted intervention services. However, there is no empirical evidence to indicate which children are most likely to benefit from intervention or to benefit from intervention at all. There is also no evidence to indicate whether additional intervention hours would benefit the children (Government of BC, 2015).

Researchers in the academy continue to conduct research projects related to the benefits of early intervention (Bottema-Beutel et.al, 2021; Tarbox et.al, 2014; Hunter, 2023). Autism intervention services, although not perfect, seem to have a positive effect on kids according to their parents. Parents recorded in multiple interviews assert that their kids' lives have improved with intervention services.



However, most parents still struggle with their kids' challenges in the school system, including a lack of staff with the training and experience to support students with autism (Sheppard and Waddell, 2015). One parent stated that "the school system is probably the most regressive and unaccountable system that we have left in the province" (Sheppard and Waddell, 2015). Many parents also reported that social experiences such as bullying, and loneliness were particularly difficult for children with autism (Sheppard and Waddell, 2015).

#### Literature Review

I began the literature review with the goal of finding studies that focused on the effectiveness of autism/ASD policies in BC and Canada. It is clear given in the background section up above, that there is a need for more analysis of autism policies in BC as well as in Canada generally.

I have also identified four key findings related to autism supports and services and associated funding and eligibility policies. One, there is a clear conflict in the definition of autism. The research literature describes autism is a neuro-disorder and a disability. Two, the policies are structured as gatekeepers to limit the amount of money allocated to those on the spectrum while satisfying the federal standard. Three, there is a lack of empirical evidence to measure the effectiveness of the policies as well as the EIBI services that the policies are designed to support. Lastly, there is a woeful lack of literature analysing the progress and gaps of autism policies in general.

#### **Results and Analysis**

The original autism funding policy in BC grew out of contentious litigation. Families with children on the spectrum made the case that receiving funding to treat autism as a human right much like receiving medical attention for a disease or other medical condition. This litigation was heavily influenced by the only research done on autism treatment at the time, the Lovaas treatment method, that required intensive daily treatment of speech therapy, occupational therapy, physiotherapy, and autism behaviour modification. Although the litigation started in the late 1990s, the litigators were relying on original research done on the Lovaas method from 1987 (Kent, 2000). Accordingly, the BC Office of Health Technology's assessment of the research on Lovaas therapy is lacking. Dr. Bassett stated "In his program, Lovaas provides a detailed manual, but the extent to which it was followed in his own studies is unknown. You can't even tell whether what is going on now is similar to what went on in the original study." (As quoted in Kent, 2000, p. 1181).

A systematic review by Bassett, Green, and Kazanjian (2000) indicated that there was only one controlled clinical trial regarding autism treatment through the Lovaas method (p. ix). They also point out the study involved only 19 children in the treatment group with little information about the children beyond the diagnosis of ASD. Furthermore, they mention that there has been little corroboration through independent studies regarding the Lovaas method (p. ix). The research done by Lovaas is therefore problematic. The lack of follow up, the lack of a control group, and a lack of empirical evidence on how well this treatment correlated with the success of autistic children integrating into society is concerning. That's why, as part of this paper, I examined key statistics highlighting the progress of autistic people. For example, I looked at the employment rates and labour force participation rate for autistics before EIBI/Lovaas treatment and after, as well as for those living independently or on welfare/assisted living. I believe that looking at the empirical evidence will help determine the success of the policies made by the BC government.



Year	% of employed	# on welfare	Total population	% on welfare
1995	25	19,902	3,700,000	0.54
2015	65	82,987	4,600,000	0.02
2022	69	103,513	5,400,000	0.02

## Table 1: *Peoples with disability in* employment vs on welfare (Statistics Canada 2023)

Unfortunately, the province does not collect statistics specially related to experiences of ASD individuals. Statistics that would help the claims made earlier in the litigation against the province listed better employment rates resulting from autism funding. However, I have examined more general statistics related to disabilities. According to the statistics collected by the Ministry of Social Development, in 1995, the number of citizens in British Columbia living on social welfare was 19,902 out of 3.7 million (0.54% of the population) (Stat Can, 2023) (Government of BC, 2023). In 2015, the number of citizens in British Columbia living on social welfare was 82,987 out of 4.6 million (0.02% of the population) (Stat Can, 2023) (Government of BC, 2023). In 2022, the number of citizens living in British Columbia living on social welfare was 103,513 out of 5.4 million (0.02% of the population) (Stat Can, 2023) (Government of BC, 2023). Looking at employment rates from the Ministry of Labour, in 1995, 25% of those with a disability were employed for at least a year, whether part time or full time (Government of BC, 2023). In 2015, 65% of those with a disability were employed for at least a year (Government of BC, 2023). In 2022, 69% of those with a disability were employed for at least a year (Government of BC, 2023). It is difficult to determine the number of individuals who may be on the spectrum out of the 69% identifying as disabled. However, in general employment numbers for peoples living with a disability have improved.

#### Discussions

This paper has provided a detailed historical and contemporary look at autism policies in BC. In this section, I revisit several important ideas revealed through this study. These include three important themes: the need to develop more effective research and policy evaluation strategies, the need to work with agencies and government to move away from deficit thinking to inclusive forms of thinking about people with ASD, and the need to develop principles of inclusion to guide how funding is provided. These key themes are important to explore as part of developing policy that helps integrate those with ASD, such that they may thrive in their communities. More effective research is needed. I found few sources for my analysis, and parameters are lacking in both academia and government to measure the effectiveness of policies. Therefore, I developed a way to measure policy goals through employment rates and labour force participation rates for autistics and those living independently or on welfare/assisted living. The government does not track these statistics, so one could infer that the government does not want to know the long-term impacts of the policy, which might indicate why funding and supports are inadequate. Instead, they group in autism and all other mental and physical impairments into one category: disabled. This makes it much harder to measure the effectiveness



of the policy as there aren't any targeted areas to help improve the lives of those with ASD or to help them access the workforce.

With humans in general, there is a tendency to measure progress that emphasizes deficit and scarcity thinking over sustainability and integration. This comes from our innate understanding of resources and life being finite. This pattern of thinking leads us into a negative spiral and thus inevitably into a negative view of life as a competition for finite resources. Thus, it makes sense that humans, when coming up with solving any problem, will come up to the plate with a deficit mindset. Since it is possible to create and maintain a sustainable society where everyone's needs to survive are met, it should come with a mentality of accessibility for all.

Developing a model to calculate how much a policy needs to be funded year after year is quite difficult. It makes sense that governments revise annual budgets to try and provide services to the best of their abilities. That's why funding for projects and models are kept to whole numbers and are quite vague and limited for scarcity. That is a key theme and a prevalent situation for families with autistic children trying to attain or afford the services their child needs. This causes distrust and a disconnect from those in government in relation to the individual in the system.

#### Recommendations

Based on the research for this paper and analysis of the BC Autism Funding policy, three clear recommendations come to mind.

1) To better serve children and families, autism funding policy needs to be revised considering the current and relevant literature about ASD. Earlier ASD research has primarily been done by researchers not on the spectrum. There are more researchers now who are on the spectrum studying the spectrum and their research needs to be considered. As the Lovaas research is quite dated and has significant concerns regarding the methodology used in the original study.

2) The collection of more nuanced statistics is needed. Statistics specifically related to people on the spectrum including high school graduation rates, post-secondary degree completion rates, employment access, income levels, and access to independent living should be collected to measure the integration of people with autism in society. This data would help to establish new funding priorities and inspire new research on intervention and other forms of treatment.

3) Overall, more research needs to be conducted on the benefits of intervention programs to include more methodologies beyond EIBI. The current funding policy relates to only one intervention method and, considering ASD is a spectrum condition, more models are needed that are grounded in research to support people on the spectrum.

#### Conclusion

The BC autism funding policy is meant to support children on the spectrum to receive autism intervention, speech, and life skills. The origins of the funding policy came from litigation. However, there are many issues regarding the funding and the foundational bases for the policy creation. It is important to recognize that checks and balances are needed for all programs designed to provide services effectively to those who need it. Without proper parameters and measurements, there is no empirical evidence that the policies are working. As presented in the recommendations section, to better serve families with autistic children, the autism funding and eligibility policy needs to be revised with the current and relevant literature about ASD, what is



ASD, and what interventions and supports work. Earlier ASD research has primarily been done by researchers not on the spectrum or not specialized in neurodevelopmental disorders. Today more researchers are on the spectrum studying the spectrum as well as being specialized in neurodevelopmental disorders. Their research needs to be considered. The Lovaas research and Dr. Strain's research are now out of date and there is criticism regarding the methods used in the original study by Lovaas.

In addition, to support any policy revisions, a collection of more nuanced and specific statistics is needed. Statistics specifically related to people on the spectrum including high school graduation rates, postsecondary degree completion rates, employment access, income levels, and access to independent living would be helpful to see the level of integration of people with autism in society. Overall, more research needs to be conducted on the benefits of intervention programs to include more methodologies beyond EIBI. The current funding policy relates to only one intervention method and considering ASD is a spectrum condition, additional models are needed that are grounded in research to support people on the spectrum and any development of policies that are meant to support people with ASD.

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