

**Autistics' Perspectives of Autism Funding in Ontario**

**by**

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## Abstract

Ontario overhauled their autism program in 2019 seeking to replace the flexible service- or funding-based 2018 Ontario Autism Program with a cash-based benefit called the Childhood Budgets program. Using Grounded Theory and Participatory Action Research, with a Structural Social Work and Critical Autism Studies lens, I used one-to-one interviews to ask four autistic adults in Ottawa, Ontario, their perspectives of autism funding and Applied Behaviour Analysis in Ontario. Participants reflected on how they identified with autism to frame their discussions in this research using prevalence rates of autism to exemplify a need to "demystify" and "de-monstrify" autism (Participant 'Tom,' A personal communication, Sept 25, 2019). Participants highlighted the importance of enjoying supports and services. They identified that supports could improve through increasing adult services and by teaching self-advocacy skills. Some participants did not trust the school system because of inadequate or inappropriate provision of support. Participants found that schools could improve by giving autistic students skills to "work in the real world" and de-instituting exclusionary practices (Participant 'James,' A personal communication, Oct 29, 2019). The lack of adequate funding, services, and supports for autism in Ontario may have increased some of the participants' use of medication. Participants acknowledged that medications could help and harm, but "can't really solve a problem." (Participant 'Tom,' A personal communication, Sept 25, 2019) Participants wanted inclusive policy-making opportunities for autistic people. All agreed that some of the costs for services should be covered, because paying can "sometimes make it look like the autistic child's a burden." (Participant 'Philip,' A personal communication, Oct 22, 2019) This research

demonstrates that autistic adults are willing to take part in policy discussions surrounding autism while advocating that autistic perspectives be considered when creating new autism programs.

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# **Title: Autistic Perspectives of Autism Funding in Ontario**

## **Chapter 1: Introduction**

### **Research Question**

What are the opinions of autistic adults in Ottawa about autism funding, services, and related policies in Ontario?

### **Organization of thesis**

My thesis research asked four autistic adults to share their opinions surrounding autism funding, services, and policies in Ontario. This thesis begins by overviewing necessary definitions and my connection to the research question. I next provide a narrative literature review in Chapter two that surveys perceptions and definitions of autism; Applied Behaviour Analysis (ABA) a common type of service implemented for autistic children in Ontario; policies surrounding autism in Ontario; and literature informing the methodology and methods chosen in this research. Chapter three reviews methodology and methods. I summarize a cursory content analysis that I performed of *The Ottawa Citizen* which aided in the development of sensitizing concepts prior to formal investigation. This content analysis is followed by the explanation of Grounded Theory and Participatory Action Research methodologies, and describes the population interviewed. In this chapter, I explain the research protocols, actions, and analysis, and offer ethical considerations and dilemmas that arose during the research. Chapter four explains the findings of this research, featuring dominant themes and quotes deriving from interviews. The themes that emerged during data analysis included: the importance of autism as identity; the support and service preferences of participants;

identifying the role of medicine and the education system as supports and service mediums for autism; and the multiplicity of opinions surrounding autism policy and funding in Ontario. In chapter five I discuss the themes that arose during research, attempting to tell a story which advocates that autistic persons are experts in autism, and that their opinions are integral in discussions autism service, support, funding, and policy. The research conducted was approved by Carleton's Research Ethics Board (CUREB-A) and the Department of Social Work (See Figure 1 & 2 for Clearance Certificate and Departmental Approval Form).

### **Defining Terms**

In order to comprehend the research question and how it is addressed, I have included synopsis of terms that will help the reader understand the specific language, theories, methodologies, policies, and programs discussed in this research.

There is a debate in discourse surrounding autism and whether one should use person-first or identity-first references to autism. The American Psychological Association identifies that when using language with respect to disability, a simple solution is to "call people what they want to be called." (APA, n.d., n.p.) For consistency, this thesis uses the identity-first term 'autistic people,' 'autistics,' and 'disabled people' based on literature in Critical Autism Studies and Critical Disability Studies, and in solidarity with autistic friends and acquaintances (Sinclair, 2013; Stace, 2014). Know that these references are used with respect. I may use the terms 'Autism Spectrum Disorder' and 'Asperger's Disorder/Syndrome' in referencing other material or when acknowledging the significance of diagnosis. Another debated term in the autism discourse is neurodiversity.

Neurodiversity is a term traced to Judy Singer and Harvey Blume, originally to promote a non-medical and positive view of autistic difference in society (Armstrong, 2015). It has recently become a more encompassing term to recognize neurological differences that are beyond autism. These include cognitive, social, and emotional differences, such as ADHD, dyspraxia, schizophrenia, depression, anxiety, and more (Armstrong, 2015; Baron-Cohen, 2019; Johnson, 2014). This paradigm has been criticized by some autistic advocates (Woods, Milton, Arnold, & Graby, 2018). However, I appreciate the neurodiversity paradigm which depathologizes my own mental health experiences, being diagnosed at many times in my life with various 'disorders' including eating disorders, Generalized Anxiety Disorder, Major Depressive Disorder, Bipolar Disorder, and Borderline Personality Disorder. Therefore, I identify as neurodivergent (not autistic), and believe that I share some autistic qualities of restrictive interests, repetitive behaviours, love for routines, and discomfort in social settings. To avoid confusion, I use the term 'non-autistic' rather than 'neurotypical,' recognizing that the term 'neurotypical' is much broader than strictly meaning not autistic. Disclosing my own self-location is a critical component of completing research in harmony with the guiding theories of this research.

The guiding theories of this research included Structural Social Work, Critical Disability Theory, and Critical Autism Studies. The Structural Approach to Social Work in Canada was developed under the leadership of Maurice Moreau at Carleton University in 1974, influenced by social, political, and economic developments during the late 1960s and early 1970s. The development at Carleton University was heavily influenced by the Structural Approach at universities in the United Kingdom, including

that at the University of Warwick under the direction of Peter Leonard (Moreau & Leonard, 1989). Traditional social work may perceive individual problems as deriving from personal deficit, and requiring individual intervention and solutions. Structural Social Work offers an alternative, depathologizing personal problems reframing them as wider societal issues. This structural alternative identifies that social problems are influenced, caused, and maintained by external social and political structures. Therefore, the role of social work becomes political, looking to provide individuals with short-term immediate tension relief while working towards long-term systems change (Carniol, 1992).

Critical Disability Theory also looks to offer alternative understandings of personal problems, framing disability as a structural and social issue. Critical Disability Theory stems from the social model of disability, which was developed in reaction to biomedical models of disability. It determines that disability and impairment are socially constructed worldwide, and that it is the physical and socio-economic environments, social oppression, and discrimination that 'disable' people who deviate from normative bodies and minds. Consequently, Critical Disability Theory understands disability as a "cultural, historical, relative, social, and political phenomenon" often working towards activism (Hall, 2019, n.p.) Critical Autism Studies is an emerging field of scholastic research which stems from Critical Disability Theory. As a field of study, it centers autistic persons as experts in autism, exploring and challenging power narratives surrounding autism. It identifies autism as a concept manufactured by society through inadequate acceptance and support. Further, Critical Autism Studies actively criticizes biomedical and deficit-based narratives of autism (Woods et al., 2018). Critical theories

are complemented by the inductive, qualitative research methods of Grounded Theory and Participatory Action Research.

The methodologies employed in this research were Grounded Theory and Participatory Action Research. Grounded Theory is a methodology which is fluid in collecting and analyzing data and creates themes when concepts become repetitive, to reach data saturation. These themes are established, compared, and related to one another in order to develop a small-scale theory “to uncover relevant conditions... [and] to determine how the actors respond to changing conditions and to the consequences of their actions.” (Corbin & Strauss, 1990, p. 5) Participatory Action Research seeks to improve the world by creating positive social change through participant agency. Paulo Freire, a foundational influence in this field, demonstrated that research could be used to enable critical consciousness raising, and that research could be used to instigate social change (Coghlan & Brydon-Miller, 2014). Participatory Action Research enables action, focuses on power relations, and identifies participants as central partners in research (Baum, MacDougall, & Smith, 2006).

Policies and programs that will be discussed in this thesis include the Ontario Autism Program (OAP) and Ontario Disability Support Program (ODSP). The OAP will be defined in more detail in the literature review (Chapter 2), but simply stated, can be broadly defined as funding and supports available to eligible residents of Ontario: children under 18 who have a written diagnosis of Autism Spectrum Disorder by a qualified professional (Ministry of Children, Community and Social Services, 2019a). Funding and services through the OAP focus on evidence-based behavioural services, additional qualified services and specialized therapies, respite services, family service

planning and support, and may provide funding for some technology (Ministry of Children, Community and Social Services, 2019b). The evidence-based service prioritized in the OAP is called Applied Behaviour Analysis (ABA). ABA is based on the principles of behaviour, using experimentation to improve socially-significant behaviour and to create behaviour change. ABA focuses on operant conditioning principles, through reinforcing prosocial behaviours, often with the intention to replace maladaptive behaviours, and to extinguish maladaptive behaviours. There may also be punishment involved in reducing maladaptive behaviours (Cooper, Heron, & Heward, 2014). Intensive Behaviour Intervention (IBI) is defined by the Ministry of Children, Community and Social Services (2016a) as “an application of ABA that teaches new skills in an intensive format, about 20 or more hours per week, primarily in a one-to-one setting.” (n.p.) Not all autistics benefit from these therapies, and many autistic advocates have spoken out about the potential and past harms of these programs (A4A, 2018; McGuire, 2011a; Yergeau, 2017).

By contrast, while ABA is often aimed at younger patients, autistic adults sometimes struggle to find supports. ODSP is a social assistance program targeted for disabled residents of Ontario over the age of 18 who are in financial need. It provides income and employment supports to eligible disabled Ontario residents. Income support and employment support can either be accessed together or separately. People apply to this program through an ODSP caseworker. Criteria for ODSP defines disability under the *Ontario Disability Support Program Act (1997)* as “a substantial physical or mental impairment that is continuous or recurrent, and is expected to last a year or more.” (Ministry of Children, Community and Social Services, n.d., p. 2) Now that

foundational terms have been explained, I now turn to how I became interested in this research.

## **Research Interest**

My research question was inspired by my lived experiences working as an Instructor Therapist during the summer of 2018 and through engaging with media which presented the redevelopment and restructuring of the Ontario Autism Program (OAP) in early 2019.

On February 6, 2019, the Ontario government announced changes to the OAP, the program under which I was once employed (Children's Treatment Network, Feb 13, 2019). At this time, the 'Childhood Budgets' program was proposed, and it was later implemented in April 2019 by the Ontario government attempting to replace the service- or cash-based OAP by offering an age-based cash-benefit contingent on a diagnosis of autism. This program differs from the OAP, where families could choose between a direct-funding or direct-service option. These options provided ABA-based services for children under 18 (Ministry of Children and Youth Services, 2018).

My educational background in the OAP began by completing the Autism and Behaviour Sciences Post-Graduate Certificate at Toronto's George Brown College in 2018. After this program I was employed in the OAP direct-service option in Toronto between May and September of 2018. As an Intensive Behaviour Intervention (IBI) Instructor Therapist, I provided one-to-one ABA-based services intensively for six hours, five days per week. During this time, I questioned whether government-funded ABA services were appropriate for all autistic children and their families. I also questioned the divide between children who accessed the program through the direct-service option

and the children who accessed ABA programs privately and received (perhaps limited) compensation through the direct-funding option.

When the Childhood Budget's program was announced, I was approached by many people who, knowing my interest in autism, asked my opinion about the changes. I found that I could not give an educated answer, because I did not have the true experience of being autistic. I tried to access this information through the media and did not see autistic adults represented in stories surrounding the new Childhood Budgets program. My present involvement in the Ottawa Adult Autism Initiative, presenting in and attending the Critical Disability Studies Association Conference at The Congress of the Humanities and Social Sciences, and in my Research Assistant work also heightened my awareness of the lack of investigations surrounding autistic adults. Because of my interest in Critical Autism Studies and its priority on autistic people as the true experts in autism, I sought to fill a gap in knowledge by asking autistic adults what supports and services they wanted to see funded by the Ontario government (Woods et al., 2018).

### **Research Intent**

Parent and caregiver roles in policy development are often centered in discussions about preferred funding, supports, and services (Bowker, D'Angelo, Hicks & Wells, 2011; Douglas, 2014). Shepherd & Waddell (2015) interviewed parents, policymakers, and researchers about autism policy in Canada. However, their research did not cover autistics' perspectives of autism policy in Canada. In asking autistic adults their opinions about autism policy, programs, and funding in Ontario, my intentions for conducting this research were:

1. To offer alternative opinions regarding autism services, policy, funding, and programs in Canada,
2. To fill a gap in literature surrounding the service preferences of autistic adults in Ontario, and
3. To promote autistic adults' perspectives in the development of autism services, funding, and policies

This research sought to offer another perspective to improve autism policies and programs in Ontario. Because of this, I recognize that my research is not impartial. As a researcher, I have been actively involved in the community which I am studying. Using Participatory Action Research, I saw myself as working collaboratively with my participants and other community members in pursuit of developing broader social understanding that autistic adults should hold authority when defining programs and policies for autism. Guided first by Critical Autism Studies, which advocates autistic perspectives as critical and integral to the creation of knowledge surrounding autism, and second by Structural Social Work, I have conducted this research to demonstrate allegiance with broader social movements of neurodiversity, social perspectives of disability, and Critical Disability Studies. My research also aimed to contribute to the destigmatization of autism. Grounded Theory offered me the opportunity to conduct inductive research and develop a small-scale theory about how autistic adults identify preferred supports and services, and what life experiences contribute to their opinions about autism policy, programs, and funding.

I also sought to contribute to emerging scholarship in the field of Critical Autism Studies. While much its literature promotes that it is a field of autistic persons producing

autism scholarship (Woods et al. 2018), I inquire as to whether allies of autistic peoples, who seek to center the positions of autistic persons, can contribute to this emerging field. In identifying policy, program, and funding recommendations based on the opinions of participants, I hope this research provides a strengths-based and person-centered perspective to autism policy and programs in Ontario.

### **Problem Statement**

This research intended to engage in discussions with autistic adults located in Ottawa, Ontario, about autism policy, funding, programs, and services in Ontario. This was done through qualitative interviews of four autistic participants which focused on their lived experiences in past and present programs or services and collected their suggestions for changes to policy, programs, funding and services.

### **Problem Significance**

Autistic adults remain under-represented in research about autism. Since early 2019, the government of Ontario instituted changes to the OAP (Children's Treatment Network, Feb 13, 2019). As a result of collective organization and pushback, the Ontario government has since instituted a number of revisions to this re-developed program (McQuigge, Feb 25, 2019). The changes have left a number of children who were receiving OAP services in their current services and funding contracts, while new children introduced into the program are funded under the Childhood Budgets program. The Ontario government also responded through the creation of an advisory panel who published a report in October 2019, and through introducing an implementation group which will work towards creating a new program to start in April 2021 (Ministry of Children, Community and Social Services, 2019f).

This is not the first time that there has been pushback to autism policy development in Ontario. In 1999 the Ontario Ministry of Community and Social Services introduced the Early Intervention Program for children aged 2 to 5 years old. This program was implemented in 2000 (Perry, 2002). There were challenges to this program between 2000 and 2006 including *Ontario and Deskin et al. v. Ontario (Wynberg Deskin)* due to the early age cut-off. *Wynberg Deskin* was a class action that included 35 autistic children as plaintiffs and their families. These families argued that failure to provide special education to children over five years old was discriminatory under the *Canadian Charter of Rights and Freedoms*, sections 7 and 15 (Supreme Court of Canada, 2016). The Ontario Court of Appeal did not support the families claims of discrimination. The Court ruled that autistic children did not require ABA/IBI to access public education, and identified that ABA/IBI was not the only effective therapy for autistic children (Weir, 2006).

In August 2006 the Early Intervention Program was redeveloped into the Autism Intervention Program. At this time, an “Expert Clinical Committee” was established for the program, which in turn set clinical practice guidelines for IBI services (Ministry of Children, Community and Social Services, 2010, n.p.) While this program focused on IBI services for children under age six, the Ontario Liberal government made promises that children would not be discharged from the program on the basis of age and the program would be accessible regardless of age (Ministry of Children, Community and Social Services, 2007). However this program was changed. In 2012, the government announced the creation of “a special panel of experts” to make recommendations for a new program (Monsebraaten & Talaga, Dec 12 2012, n.p.) In 2016 the provincial

government announced that children in IBI services over the age of five would be transitioned to “more clinically appropriate” ABA services (Ministry of Children, Community and Social Services 2016b, n.p.) More clinically appropriate may refer to providing services at a lesser intensity, such as the group-based ABA offered by the Children's Hospital of Eastern Ontario (CHEO) for two hours per week for 11 weeks (CHEO, n.d.; Ministry of Children, Community and Social Services 2016b).

It was not until 2017 that a new program, named the Ontario Autism Program (OAP), was introduced. It was rolled out in two stages, first introduced in 2017 and then fully developed by 2018. Now, in early 2019, the OAP has been deemed insufficient due to concerns about leaving children on the waitlist for years, and awareness that families are paying out-of-pocket for services and supports (Fee, 2019). It is important to note that these programs run on the myth that the “window of opportunity” for ABA is age five or under (Prizant, 2009, n.p.) This myth promotes the idea that ABA is best suited for preschool aged children, and does not recognize that ABA is not exclusive to autistic children. Because ABA is a set of scientific behavioural principles aimed to create socially significant behaviour change, it is appropriate for many people, at many ages, within different diagnostic and environmental contexts (Prizant, 2009).

While parents and caregivers are directly affected by autism funding, supports, and services, they do not have the same experience as autistic persons themselves. Many autistic adults may have been in similar programs and services that parents advocate for. Other autistic adults may have been without these programs and services, and may have opinions based on their experiences growing up without government funding or appropriate care. Further, the quote “autism doesn’t end at five” was a central

mantra of many families and caregivers during the development of autism supports and services in Ontario (Jones, Apr 5, 2016, n.p.) While current supports cut-off at 18, higher funding opportunities are still awarded to families with children under age six (Ministry of Children, Community and Social Services, 2019a). There is little inquiry about appropriate supports for transitioning young adults into adult services, and little push for autism-specific policy for adults. To create a more complete picture of what services and supports are necessary for autistic people in Ontario, we need to ask autistic adults, often ignored in public conversations, their opinions of policy, programs, services, and funding.

## **Chapter 2: Literature Review**

### **Introduction**

This chapter is a narrative literature review which draws upon bodies of academic and policy literature pertaining to my research. This includes academic literature related to historic descriptions of autism, behaviourist approaches to autism, literature deriving from Critical Disability Studies and Critical Autism Studies, policies that affect autistic Ontario residents, and other research which inspired the methodology and methods I employed. The chapter begins by exploring the development of the definition of autism in Canada. Next, it reviews one of the state-funded evidence-based approaches used for autistic children in Ontario: Applied Behaviour Analysis (ABA), and the differing opinions surrounding this therapy. The Ontario Autism Program (OAP) is dissected in-depth. Finally, this chapter concludes by reviewing literature which informed the methodology and methods used in my research.

### **What is autism?**

As an advocate for autistic self-determination, I recognize that I cannot define autism myself. This section provides an overview of differing perspectives which have attempted to define autism. Historical, biological, and psychological perspectives are first explored, followed by autistic definitions of autism. While I am tempted to 'define' autism using a dictionary definition, autism is a contested term and therefore is too complex for a simple dictionary definition.

### ***Biomedical Definitions of Autism***

The term "autism" was coined by psychiatrist Eugen Bleuler in 1911 (Milton, 2014b, p. 1). According to WebMD, the term autism has the Greek root 'autos' meaning

'self' referring to the removal from social interaction characterized in many autistic persons (n.d.) The term and subsequent diagnosis of autism is often credited to two central figures. These "two pioneers of autism," are the American psychiatrist Leo Kanner and the Austrian pediatrician Hans Asperger (Lyons & Fitzgerald, 2007, p. 2002 in Maich & Hall, 2016, p. 4). Kanner published the article "Autistic Disturbances of Affective Contact" in 1943. This article was limited to a description of the characteristics of autistic children and their families, who were described as "cold-hearted yet highly intelligent." (Kanner, 1968, in Maich & Hall, 2016, p. 5) Evidenced by the fact that autism was often referred to as "Kanner's Syndrome," Kanner's works overtime became well known (Maich & Hall, 2016, p. 4).

In 1944, Asperger, a distinguished Austrian pediatrician, published "Autistic Psychopathology in Childhood." (Asperger, 1991) This article depicted a group of highly intelligent boys who were described as having difficulties with respect to social, emotional, and academic behaviour (Maich & Hall, 2016). Asperger's work did not become well known until 1981, when Lorna Wing (1981) coined the term 'Asperger's Syndrome' and published "Asperger's Syndrome: a clinical account" which described Asperger's Syndrome as a subset of autism, classified by "impairments" in social, communication, and imagination skills (p. 115). Asperger's (1944) "Autistic Psychopathology in Childhood" was subsequently translated into English by Uta Frith in 1991 (Maich & Hall, 2016). The historian Herwig Czech (2018) recently discovered that the intentions of Asperger's work may not have been well-intentioned, revealing that Asperger cooperated with Nazis by classifying and justifying the euthanasia of children who were "genetically incapable of social conformity" or who had "physical or

psychological ‘defects.’” (Baron-Cohen, Klin, Silberman, Buxbaum, 2018, p. 1)

However, Falk (2019) argues that there is little evidence that Asperger was aware of the euthanasia programs of the Nazis.

Early scholars described autism as a pathology and this did little to promote a positive image of autism. Kanner’s (1968) descriptions also led to lasting stereotypes about ‘cold’ parenting practices causing autism. This assumption was later developed into the notion of the ‘refrigerator mother’ by Bruno Bettelheim (1972), a disturbingly patriarchal attribution which blamed mothers for their children’s autism (Douglas, 2014; Laidler, 2004). Asperger’s description of “the highly original genius...to...mentally retarded individual” (Asperger, 1944, n.p. in Pearce, 2005) may have led to increased clinical and societal stereotypes of autism (Draaisma, 2009).

It was not until the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III, 1980) that autism was a distinct diagnosis. Until then, autism was often described as, and conflated with, “childhood schizophrenia.” (Milton, 2014b, p. 1) Autism is included in the DSM because it was initially considered childhood schizophrenia, a psychiatric condition, dating back to Kanner’s descriptions of autism. In the DSM-II (1952), autism was referred to as childhood schizophrenia. Autism and childhood schizophrenia were separated in the DSM-III (1980) due to research which distinguished between developmental disorders and psychotic disorders, bringing autism under a class of disorders called ‘Pervasive Developmental Disorders.’ (Rapoport, Chavez, Greenstein, Addington, & Gogtay, 2009). When the DSM-III was revised, the criteria for autism were broadened by adding a diagnosis at the “mild end of the spectrum – pervasive developmental disorder-not otherwise specified (PDD-NOS).”

(Zeldovich, 2018, n.p.) The DSM-IV (1994) and revised edition DSM-IV-TR (2000) listed five 'Pervasive Developmental Disorders' which included 'Autistic Disorder,' 'Asperger's Disorder,' 'Rett's Disorder,' 'Childhood Disintegrative Disorder,' and 'Pervasive Developmental Disorder Not Otherwise Specified.' (PDD-NOS) (Autism Society, 2019; Maich & Hall, 2016; Zeldovich, 2018)

Today, autism is defined by medical professionals using a biomedical model. A biomedical model defines autism as purely biologically-based and, as McGuire (2011a) states, considers autism as "a biological problem needing a biomedical solution, needing to be stopped, cured, fixed, eliminated." (p. 18) The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5, 2013) defines autism using the following criteria for diagnosis:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history... (examples have been removed)
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history... (examples have been removed)
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level

(American Psychiatric Association, 2013, pp. 50-51 in Maich & Hall, 2016, p. 35).

Moreover, the DSM-5 identifies that autism exists along a spectrum. This differs from previous editions of the DSM, which had differentiated between 'types' of autism

(Volkmar & Reichow, 2013). The DSM follows a biomedical and deficit-based definition defining autism by the differences that exist between an autistic person and an imagined 'normal,' non-autistic person. This is consistent with many discriminatory opinions surrounding disability (Titchkosky & Michalko, 2009).

Over the years autistic people have been researched and referred to using deficit-based models in Canada. In 1953, Daniel Cappon, writing for the *Canadian Medical Association Journal* defined autism as “a fundamental disarticulation between [a] child and his world” existing on a “spectrum in which at one end there is the average child, and at the other end there is the grossly disturbed child.” (p. 44) In the 1960s, dominant discourses of autism in *The Globe and Mail*, a popular Canadian newspaper, used psychiatric experts to explain autism, under the name 'childhood schizophrenia' and 'childhood psychosis.' This historic news piece is an example of the popular depictions of autism during the time. It shows that dominant care for autistic persons attempted to find a root cause of autism, speculating that autism is linked to: (1) brain damage; (2) chemical imbalances; and (3) the social effects of having a 'refrigerator mother.' (Kirkwood, 1967)

The understanding of autism as 'psychosis' continued well into the 1970s, characterising autism as affecting one with so-called “emotional disturbance.” (Friedman, 1975, p. 405) By 1980, when the DSM began to make references to autism under the term 'Pervasive Developmental Disorders.' During this time, Wing also coined the term 'Asperger's Syndrome,' and publications in Canada by Dr. M. Mary Konstantarea argued that linguistic deficits were a central consideration in autism (Oxman & Konstrantraeras, 1981; Wing, 1981).

A biomedical framing of autism continues in contemporary society. The DSM-5 labels autism as Autism 'Spectrum' Disorder (shortened to ASD). This edition adopted the idea of a continuous spectrum because there was a lack of understanding in genetics of autism and diagnoses were inconsistent, sometimes swayed by parental activism for particular diagnoses in order to attain funding and services (Zeldovich, 2018). Some researchers looking at the genetic mutations which are associated with autism have argued that the plural term "autisms" is more appropriate rather than the singular "autism," due to the genetic variability of autistic persons (Scherer in Boggs, 2015, n.p.; Mitchell, 2014, n.p.)

Lai, Lombardo, Chakrabarti, & Baron-Cohen (2013) argue that the DSM-5 diagnostic criteria increase specificity in diagnoses, and that the 'spectrum' can be understood in three ways. First, 'spectrum' identifies that cardinal features of autism are diverse; second, the term 'spectrum' can identify that there is continuity between those who are autistic and the "general population," (non-autistic) and finally, 'spectrum' can refer to the subgroups that the DSM-IV encompassed (Lai et al., 2013, p. 2).

Autistic self-advocates have re-evaluated the spectrum to be more than a linear tool. All autistic individuals may have strengths and deficits in different areas which make them 'high-functioning' by certain standards and 'low-functioning' in others. For example, an individual could be a so-called 'savant' in math but lack vocal communication abilities. In this case, how does one evaluate a functioning level? Therefore, the 'spectrum' is one which is multifactorial and each autistic person has different strengths and challenges (Burgess, 2019). My friend and reader, Christine Jenkins, identified that a prism may provide a useful visual to understand the spectrum.

The spectrum varies from one person to the next, impacting each person differently (see Illustration 1). The reason that I include this image is because often persons recollect an autism spectrum which is linear, with persons who are 'low functioning' on one side, and persons who are 'high functioning' on the other. I challenge this image of the autism spectrum, rather identifying it as multifaceted. It is based on normative assumptions that persons are identified as 'high functioning' – how much they can 'mask' their autistic traits, passing as non-autistic. Camouflaging one's autism can be exhausting and threaten a person's self-perception (Hull, Petrides, Allison, Smith, Baron-Cohen, Lai, & Mandy, 2017). I believe that persons can be high and low functioning in different areas at the same time, and that the labels of functioning have a hidden role of stigmatizing autism.

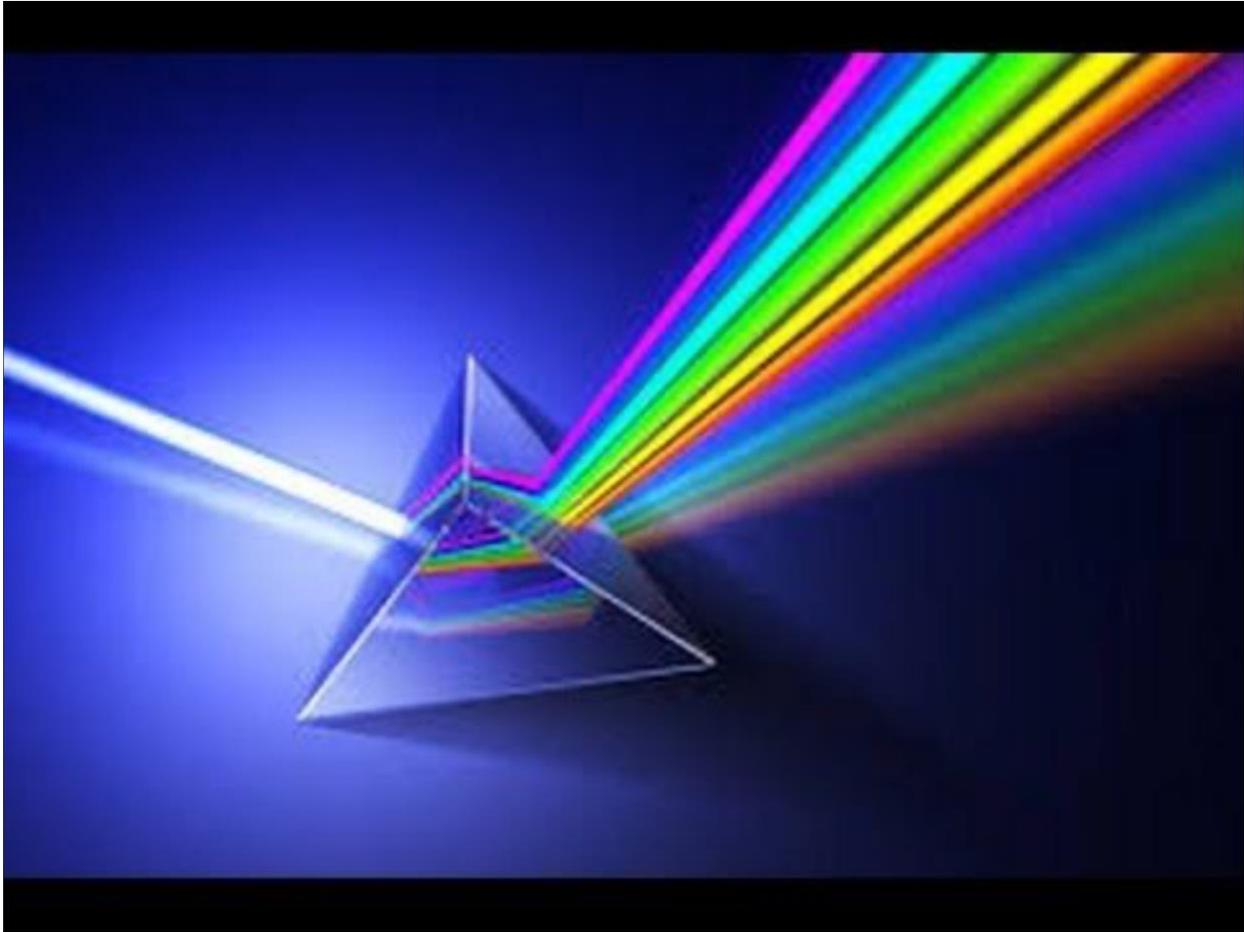


Illustration 1

In summation, similar to most research pertaining to impairment and disability, biomedical definitions of autism have informed dominated research surrounding autism. McGuire (2011a) argues that these medical understandings have created a deficit-based model that seek to cure and prevent autism. In response to biomedical definitions of autism, self-advocates and allies have begun to “re-story” autism (Douglas, Rice, Runswick-Cole, Easton, Gibson, Gruson-Wood, Klar, & Shields, 2019, p. 2). This movement promotes autistic people defining autism, and sharing understandings of autism that reflect their lived experiences.

### ***Autistic Definitions of Autism***

Service provision in Ontario for autistic people is contingent on a diagnosis of autism based on the DSM criteria stated above. Haney (2018), though, identifies that there are many different definitions of autism that are of relevance to social workers. These definitions do not only categorize autism under diagnosis. Rather, autism can be identified as a socially-constructed concept and as a neurological condition (Haney, 2018). A social model defines disability as constructed by societies and environments that do not consider the disabled body and mind (Hanes, 2016). A social definition of autism would argue autism is socially constructed through environments being constructed without consideration of an autistic person's needs. This is an important thought with respect to disabilities generally. To remove pathology from definitions of autism, and to integrate a structural approach, I am committed to avoiding defining autism at the individual level, as I believe that autistic persons individually create their own definition of autism.

Milton (2014a) observes that many different professionals claim expertise in autism studies. This expertise, Milton (2014a) argues is only attainable through the direct experience of living the "culture and practices" of autistic people (p. 796). Milton (2014a) questions whether this is tenable for those who are not autistic. Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman (2017) concur with this point, arguing that the lived experience of autism is necessary in defining autism.

Verhoeff (2012) argues that because autism is heterogeneous, biomedical definitions are insufficient. Biomedical understandings of autism stem from outsiders defining autism, and therefore include stereotypes of autistic people as "machine-like"

and as impaired in the acquisition of “tacit knowledge.” (Milton, 2014a, p. 795) It is argued that these outsider, medically scientific perspectives have caused autistic people to become distrustful of researchers (Milton, 2014a). Autistic people are said to generally question non-autistic peoples’ true understanding of autism. Milton (2014a) argues that popular and scientific misunderstandings can be attributed to the rules related to social skills and behaviour that are taught to autistic persons, and that autistic traits including repetitive body movements, sensory atypicality, and self-regulation strategies are often oversimplifications by non-autistic researchers.

Gillespie-Lynch et al. (2017) determined in an online survey of 636 adults that autistic survey participants had a tendency to refrain from biomedical, pathological views of autism. While they were more aware of the diagnostic changes around autism, their perspectives were that autism reflects a positive or neutral biological difference which does not require cure or normalization (Gillespie-Lynch et al., 2017). In line with this research, McGuire (2011b) concluded that the medicalized views of autism pathologize autism, and make autism an issue of moral deviance.

Labelling and deviance are often associated with autism. Moral deviance, for example, refers to publicizing autism as not only a pathology, but as a deviation from the norm. It represents autistic people as “non-valuable” and even “non-viable” in society (McGuire, 2011b, p. 66). In this respect, a common counter-assertion by autistics against labelling and deviance is to identify with their autism, as it cannot be separated from themselves (Sinclair, 1993 in McGuire, 2011a). Autism is therefore reframed as a social identity category, and validated as a valuable way of living in this world (McGuire, 2011b).

Autistic definitions of autism differ from those definitions of autism posed in the biomedical field. I acknowledge that there are a multiplicity of definitions of autism, and as a non-autistic researcher, I do not have the capacity to define autism myself. Because I have the overall goal of working in collaboration with autistic people to advocate for political change, in this literature it became clear to me that I didn't need to truly define autism to investigate autistics' views of autism policy in Ontario. This was integral to acknowledge, as my research required interview participants to 'self-identify' as 'autistic people' or 'people with autism', rather than using diagnosis to verify eligibility. Through engaging in this literature, I came to acknowledge the types of research I want to do and do not want to do – research 'with' rather than research 'on.' Overall, the definitions of autism have indicated to me that autistic people have the right to determine their own identity and to indicate what autism means to them.

### **Applied Behaviour Analysis (ABA)**

Applied Behaviour Analysis (ABA) is defined as “the science in which tactics derived from the principles of behavior are applied to improve socially significant behavior and experimentation is used to identify the variables responsible for the improvement in behavior.” (Cooper, Heron, & Heward, 2014, p. 2) ABA is based on Skinner's theories of behaviorism and operant conditioning (Morris, Smith, & Altus, 2005). As an applied theory, it is based on the philosophic principles of behaviourism and the experimental analysis of behaviour (Dillenburger & Keenan, 2009). Behaviourism looks at how behaviours can be understood by their environments through understanding stimulus-response and antecedent-behaviour-consequence relationships (Heward & Wood, 2003, pp. 293-310 in Cooper et al., 2014, p. 35). ABA

looks to “bring improvements and change in socially relevant behaviours within the context of an individual’s social environment” and has been used as a behaviour change therapy for autistic individuals along with other populations (Dillenburger & Keenan, 2009, pp. 193-194).

ABA is a popular therapy for autism because it is the only ‘evidence-based’ therapeutic practice for autism. This evidence is based on the UCLA Young Autism Program by Ole Ivar Lovaas (Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, Plavnick, Fleury, & Schultz, 2014). Lovaas (1987) constructed intensive learning environments in the homes of preschool-aged autistic children. The interventions used positive reinforcement to increase targeted behaviour, and decreased unwanted behaviour by using planned ignoring, time out, or aversive procedures (Reichow & Wolery, 2009; Turan, 2014). By providing over 40 hours per week of intensive one-to-one therapy, Lovaas (1987) sought to decrease aggression and self-stimulation and to build compliance, teach imitation, and establish appropriate toy play in the children. Their study concluded that 47% of children acquired “normal functioning”: the ability to pass first grade, achieving an IQ score typical of their peers after two years of therapy (Lovaas, 1987, pp. 6-7; Lovaas, 1987 in Rogers & Vismara, 2008).

Since Lovaas (1987), there has been a dearth of population-level experimental design studies about ABA with autistic children. The evidence for ABA as an effective intervention for autism, though, is based on 50 years of single-subject methodology (Dillenburger & Keenan, 2009). Single-subject methodology differs from a group research design by using a participant as their own control. Cooper et al., (2014). Johntson & Smith (2010) argue that single-subject methodologies are preferred in

research with autistic people because the population is not homogeneous, and the methodology can identify how rapidly an intervention creates behaviour change through graphing. Where randomized control trials require relatively stable populations, single-subject methodologies may allow researchers to study interventions with fewer participants (Johnston & Smith, 2010). Before implementing behaviour change, target behaviours must be identified.

Through the use of the Verbal Behaviour Milestones and Placement Program (VB-MAPP) and/or the Assessment of Basic Language and Learning Skills – Revised (ABLLS-R) preschool aged children can be assessed for gaps in their learning and to identify obstacles that may prevent the child from skill acquisition. Ideally, children are assessed every six months to determine what learning gaps and obstacles exist. The domains that are assessed include ability to request, learning in a group setting, reading, writing, feeding behaviour, grooming behaviour, toileting behaviour, playing alone, playing in groups, imitation, cooperation with and motivation by reinforcement, and their use language skills, among other things (Mathewson, 2018). The gaps and obstacles in learning become target behaviours to teach children in many ABA and IBI settings. These behaviours may be addressed using other therapeutic methods.

There are many different approaches to therapy that may be considered for autistic children. Francis (2005) in a survey of commonly used autism interventions, indicates that parents should consider the following when choosing an intervention:

(1) whether or not its rationale is in accordance with current understandings of ASD deficits; (2) its possible negative effects; (3) the training and experience of autism among professionals involved; (4) the impact of the proposed programme upon the family (concerning time, functioning, relations, and finances); and (5) the supporting evidence for its effectiveness. Based on the current findings, the

most effective elements for an intervention are behavioural techniques and structured teaching based on visual cues. (p. 498)

Other interventions that were surveyed by Francis (2005) included psychoeducational/behavioural approaches, social skills teaching, psychopharmaceutical interventions, and less traditional or complementary approaches. Francis (2005) commends behavioural techniques and structured teaching as a best practice in autism interventions. Further, Francis (2005) argues that an extensive individualized approach is necessary for comprehensive gains.

Many researchers have claimed that ABA can allow autistic individuals to enter “remission.” (Greschwind, 2009, p. 374; Lovaas, 1987, p. 8) Reichow & Wolery (2009) argue that ABA applied intensively, often called IBI, is the best chance at attaining skills for autistic preschool children. Not all autistic people agree that ABA is a preferred method or that ABA provides preferred outcomes.

In recent years, many self-advocates have begun to question the validity of ABA (A4A, 2018). The ethics of ABA techniques, behaviour change, and the intervention being used to ‘cure’ autism are amongst some of the critiques. Further, Lovaas’ (1987) initial intervention, which paved the evidence-base of ABA has been identified as representing a “denial of individual humanity.” (Haney, 2018, p. 64) ABA falls under the medical model of disability, as it seeks to address deficits in autistic individuals, viewing diversity “as flaws or imperfections that required fixing.” (Muskat, 2017, p. 81) Meyerding (2014) identifies that social pressures to conform can lead to feelings of alienation and conditioning for autistic persons to hide their autistic characteristics. This is often referred to as ‘camouflaging’ or ‘masking’ in an attempt to fit in and create social

bonds with others. Consequences of 'camouflaging' include exhaustion, challenging stereotypes, and threats to a person's self-perception (Hull et al., 2017). This can lead to internalized stigma, which is linked with negative effects on health and well-being (Waugh, Byrne, & Nicholas, 2014).

Baker (2006) argues that ABA is not a universally accepted therapy for autism, and that the emphasis of ABA in policy places responsibility on caregivers and autistic individuals to limit their autistic tendencies, rather than promoting an accepting and inclusive society. Further, Yergeau (2017) argues that ABA is violent towards autistic individuals. Yergeau (2017) problematizes ABA, recalling that ABA had also been used for the "UCLA Feminine Boy Project" as an intervention with boys seen to be at risk of "homosexuality, transsexualism, and transvestism." (p. 103) There are three issues that Yergeau (2017) identifies with applying ABA for autistic children. The first is that ABA reduces the need for society to accommodate individuals with disabilities. The second is that ABA promotes an ideology of recovery from autism. The third is that ABA promotes the surveilling of autistic persons' behaviour which leads to the reduction of one's autonomy (p. 105).

Gibson & Douglas (2018) also use the word "violent" in the description of ABA (p. 2). They argue that ABA is widely accepted for autistic children in an attempt to control the 'deviance' associated with autism and the abnormal mind and/or body. In promoting conformity between the mind and body, behavioural therapy has promises of 'correction' and 'treatment.' (Gibson & Douglas, 2018)

It is apparent that there are different perspectives about the use of ABA as an intervention for autistic children, and that there is a need for autistic peoples' opinions to

be further gathered about the usefulness of this intervention. Additionally, alternative interventions that are supported by autistic advocates must be better researched for their efficacy. These perspectives can lead to the development of more inclusive policy.

## **Policy Overview**

The purpose of this section is to provide an overview of autism policy development in Ontario. This section surveys parent and caregiver roles in policy development, and reviews the contemporary OAP and Childhood Budgets program in-depth.

### ***Parent and Caregiver Roles in Policy Development***

Shepherd & Waddell (2015) interviewed “three groups of knowledgeable participants who had been engaged in the public debates” of autism policy in Canada (p. 3552). These three groups included parents, policymakers, and researchers. In attempting to understand the conflicting narratives surrounding the improvement of autistic children’s services, they found that parents, policymakers, and researchers share commonalities of concerns around autism policies. The themes that emerged during their research interviews were (1) disappointment in political action; (2) inappropriate support; (3) hardships with balance by policy-makers; (4) policy does not consider research; and (5) services for autism were insufficient. First, participants were disappointed with litigation outcomes and reactive policy-making. Regardless of the government in power, the participants wanted funding for autism interventions to be guaranteed through policy (Shepherd & Waddell, 2015). Further, these participants felt that parents needed better support as they often become their autistic child’s “case manager.” (Shepherd & Waddell, 2015, p. 3555) It was identified that policy makers feel

a need to balance investments in autism with other priorities (Shepherd & Waddell, 2015). In this research, participants termed 'researchers' believed that policy could go further in reflecting available research evidence. Finally, Shepherd & Waddell (2015) found that participants believed that children and youth require expanded and more comprehensive services. Shepherd & Waddell (2015) contribute to knowledge surrounding autism advocacy and policy development in Ontario, and much of their conclusions promote the use of ABA/IBI services. The authors, though, did not ask autistic people to participate in their research.

While my research aims to fill the gap by investigating autistic adults' perspectives, it would be inconsiderate and naïve to dismiss parent and caregiver action in the realm of many autistic persons' wellbeing and autism policy in general. Despite persistent criticism and blame for the inadequacies of their autistic children, caregivers and parents of autistic children have played a vital role in the development of current autism policy, funding, and services. It would also be unfair to omit the struggles parents have faced.

Jack (2015) credits Bettelheim for constructing the rhetorical character of "the autism mother" as emotionally distant (p. 35). The term 'refrigerator mothers' was historically used in implying that mothers of autistic children had common traits of intellect and success, and by extension, were ostensibly selfish, prioritizing their own personal and professional development above their children (Douglas, 2014). While fathers were part of the equation, in Kanner's (1943) opinion, it was the mother who received a stigmatizing identification as non-caring, emotionally distant, cold, neglectful, and even abusive. These misogynist stereotypes outlined by mostly male psychologists

depicted mothers as a causal factor in the development of autism in children using a model of psychoanalysis rather than an understanding of autism as neurological difference. Sousa (2011) suggests that while much of contemporary literature, rooted in biomedical understandings, reflects the maternal responsibility and social burden of caring for a disabled child. Sousa (2011) acknowledges a cultural shift which has added an additional layer of complexity of maternal responsibility:

Whereas seemingly cold mothers and overbearing caregivers were once considered responsible for causing their children's intellectual disabilities, warrior-hero mothers are now responsible for curing the disability, or at least accessing the intervention that will mitigate the disability's impact on their children (p. 221)

The 'autism mother' remains a contemporary idea, referring to the additional responsibilities of mothers of autistic children. This concept directs the responsibility of service provision, care, and intimate knowledge of an autistic child on the mother. It remains a sexist and patriarchal idea, and relies on blaming a mother for the ostensibly 'poor' development of their child.

Douglas (2014) argues that "autism mothers" are a productive force in Ontario through resistance, advocacy, and activism (p. 8). When looking at the activist movements that have shaped Canada's and Ontario's autism policies, mothers are not credited. Rather it is the entire family unit, usually in coalition with other families, which strikes a force.

Actions made by families include *Auton v. British Columbia* (2004), which was a landmark case where parents advocated for therapies for autism to be included as a medical necessity under the *Canada Health Act* (R.S.C., 1985). They argued that a failure to do so is an infringement on Section 15 of the *Canadian Charter of Rights and*

*Freedoms* (1982). While autism services were not deemed 'core services' by the courts, most provinces, including Ontario, responded by creating an autism policy (Ontario Justice Education Network, 2006; Shepherd & Waddell, 2015).

In Ontario, the *Wynberg Deskin* case involved 28 families who brought the provincial government to federal court. While the Ontario Court of Appeal denied that the Ontario government had a responsibility to fund ABA/IBI when a child is six or older, this case created pressure which resulted in increased, yet still limited, funding for autism supports and funding intended to train teachers in the public-school system (Gabison & Kirby-McIntosh, 2016). Further, Turan (2014), through interviews with families to investigate perspectives on Ontario's Autism Intervention Program (the precursor to the OAP) found that mothers were constantly required to advocate for their autistic children to be included and to have appropriate supports within programs, services, and in school environments. A typical theme in parent and caregiver advocacy is ABA. Bowker et al. (2011), who explored parent choices for services of value to their autistic children, found that ABA was the most preferred service employed by parents and caregivers due to promising improvements in socially-significant behaviour and linguistic functioning. This preference is reflected in current policies in Ontario.

### ***The Ontario Autism Program (OAP)***

Early funding for autism services in Ontario began with the Early Intervention Program in 1999, which was replaced by the Autism Intervention Program in 2006 (Perry, 2002; Ministry of Children, Communities and Social Services, 2010). In March 2016, the age cut-off for children in Ontario's autism programs was six years old, and all children who were on the waitlist over that age were unable to receive services (Star

Editorial Board, June 8, 2017). Parents and caregivers had long struggled with the waitlist for the Autism Intervention Program, and this increased advocacy activity.

On June 28, 2016 the Ontario government announced that a new program, the OAP, would begin a year earlier than expected, and that “an advisory committee of parents, stakeholders, advocates, service providers and experts will begin meeting this summer to provide advice to the ministry on the design of the new program.” (Ministry of Children, Community and Social Services, 2016c, n.p.) The rebranded program was released in 2017 and updated in January 2018. The OAP introduced a family-centered program based on “evidence-based services delivered according to a relevant assessment of a child or youth’s needs, strengths and interests, and the family’s concerns and priorities.” (Ministry of Children and Youth Services, 2018, p. 9) The majority of the funding was earmarked for ‘evidence-based’ techniques (ABA) and little was allowed for alternatives (Ministry of Children and Youth Services, 2018).

Families accessed ABA by means of a direct-service option or a direct-funding option. The direct-service option placed families on a waitlist to work with a regional provider to develop a plan of service for their child. The direct-funding option gave caregivers the responsibility of choosing a provider for services, funding a maximum rate of \$55 per hour only for services that were found within the OAP behaviour plan (Ministry of Children and Youth Services, 2018). Families using the direct-funding option were responsible for submitting receipts for services and, if the receipts were found to be inappropriate, then steps were taken to recover the funds from the caregivers (Ministry of Children and Youth Services, 2018). The OAP provided qualifications for Clinical Supervisors and Frontline Therapists employed and funded under the OAP as

requiring training, supervision, and/or certification in ABA (Ministry of Children and Youth Services, 2018).

### ***Childhood Budgets Program***

The election of the Ontario Progressive Conservative Party in 2018 heralded new directions in government policies. On February 6, 2019, the Ministry of Children, Community and Social Services announced changes to how services for autistic children would be accessed and funded in the province of Ontario (Slaughter, June 7, 2018; Children's Treatment Network, Feb 13, 2019). These changes were built on some standards found in the 2017/2018 OAP but with some fundamental differences aimed at reducing costs for the province and "help more families" by working to move 23,000 children off an OAP service/funding waitlist (Ministry of Children, Community and Social Services, 2019e, n.p.; Rowland & Oger, Mar 21 2019). In this new funding option, the provincial government is now removed from the delivery of direct services of ABA. The direct-service option and direct-funding option are replaced with a yearly budget dependent on age.

The Childhood Budgets program provides parents of autistic children under age six with a yearly allotment of \$20,000, and caregivers of autistic children between six and 18 years old with a budget of \$5,000 (Ministry of Children, Community and Social Services, 2019e). The average cost for ABA programs, applied intensively – the effective 'evidence-based' method described by Lovaas (1987), can be \$26,000 to \$130,000 per year – or \$39 to \$100 per therapeutic hour (Sharatt, May 29, 2019; McLaughlin & Schneider, 2019). Notably, the new program follows age-based rather than needs-based criteria. On top of evidence-based behavioural services, the

Childhood Budgets program also covers expenses of “additional autism services and supports,” “other therapies and specialized services,” “respite services,” “family service planning and support,” “travel,” and “technology,” up to certain dollar amounts (Ministry of Children, Community and Social Services, 2019h, n.p.)

After pushback from parents and caregivers, the provincial government indicated that it was willing to receive feedback from stakeholders about the autism program. Throughout the summer of 2019 there was a “listening” phase, where the community was asked what additional supports may be needed for autistic children with higher needs (Ministry of Children, Community and Social Services, 2019e, n.p.) During this time the government press releases directed stakeholders to access supports and service listings through Autism Ontario, a community organization focused on advocacy, program and service provision, and promoting autism acceptance in Ontario (Autism Ontario, n.d.) At Autism Ontario, parents and caregivers would access services pertaining to support, workshops, and training, as well as navigation with the Childhood Budgets program (Ministry of Children, Community and Social Services, 2019d). By offloading responsibility to community organizations, the Ontario government was able to cut costs in autism policy and program development.

The Childhood Budgets program created changes in funding for three service-seekers in Ontario. When reviewing the literature in October 2019, the following information was made public about services provided through the OAP. Please note, that updates made to this program are covered in Chapter 3 in discussing a review of *The Ottawa Citizen* which inspired my investigation, under the sub-titles ‘Changes since *The Ottawa Citizen* Review.’

1. Those currently receiving services: those who were enrolled in the OAP through direct services would continue to access services until April 1, 2019, at which time the families were given the option of an additional six months of funding/services at current or lesser amounts of intensity. Service providers were expected to continue to deliver services as outlined in the 2017/2018 OAP guidelines (Ministry of Children, Community and Social Services, 2019d).
2. Those currently on the waitlist: after April 1, 2019, the caregivers of children currently on the OAP waitlist would expect to be contacted within 18 months via mail by the Ministry of Children, Community and Social Services to apply for a Childhood Budget. These families could refer to a list of service providers available through Autism Ontario to choose services that fit their needs (Ministry of Children, Community and Social Services, 2019d). There is no information about the waitlists for these services available.
3. Newly diagnosed/accessing services: for new children to register for the OAP, they must be 18 years old or under and have a written diagnosis of autism. There is no minimum age. Their next step was to contact the Central Intake and Registration Team to register to get on the waitlist. They would wait to then receive a letter from the Ministry of Children, Community and Social Services about how and when they should apply for a Childhood Budget (Ministry of Children, Community and Social Services, 2019d).

Other fundamental changes during this time that were introduced by this program included:

- Increasing funding for diagnostic hubs to have more children diagnosed at earlier ages (Ministry of Children, Community and Social Services, 2019e).
- Allowing more services and supports to be covered under the funding, including: evidence-based behavioural services (ABA) which must be delivered by qualified individuals as outlined in the 2017/2018 OAP guidelines; curriculum-based interventions; life-skills training; employment supports; skills development; parent and caregiver training; specialized independent school services; fees to access a certified service or guide dog; speech-language pathology; occupational therapy; physiotherapy; respite services; community recreation; interpretation and translation services for information sharing regarding the youth's support; individualized family service and supports; administrative employer costs; travel costs; technology; equipment and materials related to eligible services and supports. All costs must be accounted for, and funding may be terminated if the agreement is not complied with (Ministry of Children, Community and Social Services, 2019e).
- The removal of the behaviour plan, an accountability measure which details the services and supports the child will receive by a provider, as a necessity to receive funding through the Childhood Budgets program (Ministry of Children, Community and Social Services, 2019d).

When parents and caregivers request a Childhood Budget, they would receive a letter in the mail requesting them to apply for a Childhood Budget. They then would be expected to fill out an online form or request a paper copy with the information on their invitation letter within 90 days of receiving this letter. The form requires the parent or

caregiver to attach their original invitation *Childhood Budget Information Letter*, to include their own information and information about the child/youth, to complete a funding agreement, and to choose how they would like to receive funding. The parent or caregiver may choose to have part or all of the budget sent directly to a service provider, but must be aware that this does not guarantee that their child will receive services from this service provider – especially if there is a waitlist for services under that provider. When the parent or caregiver receives the cheque, they are not automatically allowed to spend the money on services. They must ensure that they have received an *Authorization to Spend* letter. Finally, the funding must be spent within the year. If not, the amount that was not reconciled will be taken out of the next year's funding (Ministry of Children, Community and Social Services, 2019e; Ministry of Children, Community and Social Services, 2019c).

The administrative burden is therefore taken from the government and placed on the individual caregiver. Accessing the program has likely become increasingly difficult for those of lower socio-economic status, those with low literacy, caregivers with English as a second language, newcomers, those diagnosed later in life, and those of other marginalized identities who remain without the privilege and/or education on how to navigate this system (McLauchlin & Schneider, 2019). The caregiver role has intensified as a case worker on top of the responsibility to care for their child.

Most policies that continue to affect autistic people are substandard in addressing social inequalities in a socio-economic, socio-political, socio-cultural, and psycho-social way (Graham, Shier, & Delaney, 2017). As a policy of public services, a complete autism policy would provide a public service that reflects equity and inclusion,

rather than creating obstacles and barriers. Inclusive methodology and methods may allow for more complete autism policy discussions.

### **Literature Review of Methodology and Methods:**

This section outlines five major studies which influenced my research methodology and methods. In an investigation of priorities for autism research, Pellicano, Dinsmore, & Charman (2014) used interviews and focus groups with autistic adults, parents of autistic children, practitioners, and researchers in the United Kingdom. They used a semi-structured interview method taking place face-to-face, over Skype, or over-the-phone. These interviews were audio recorded and transcribed and were analyzed using thematic analysis. The interviews progressed in order from participants' views on the current agenda of autism research in the United Kingdom and ending with a reflection on whether the current funding model matches up to the participants' research priorities.

Similarly, Shepherd & Waddell (2015) used a purposive sampling technique to investigate the disagreements in service provision debates surrounding autism services for children in Canada between 2007 and 2008. They interviewed parents, policymakers, and researchers in Canada in order to analyse data comparatively. The interviews were semi-structured and asked the participants how they came to be involved in autism debates, their understanding of policies and services, their beliefs of important unresolved issues, their experiences engaging with other people engaged in public debates (parents, policymakers, and researchers), and questions about how they can work together to improve outcomes for autistic children. These interviews took

place in-person or over-the-phone. Shepherd & Waddell (2015) are cognisant that they left out the voice of those impacted by the policies that they are studying, stating,

One important limitation needs highlighting. We did not include young people with autism, whose perspectives may differ from those of parents, policy makers and researchers... children with autism have been largely excluded from this process - indeed, children are often excluded from decision-making about the very services that are intended to help them. To the fullest extent possible, young people with autism should therefore be included in future policy deliberations to better understand how we many collectively meet their needs. (p. 3562)

With the recent increase of autistic self-advocates insisting on a space in policy development, this current research will employ a similar open-ended interview technique that fills a gap by including autistic perspectives that may have been impacted by provincial autism services and supports (Ne'eman, 2010).

Harrington, Foster, Rodger, & Ashburner (2013) used open-ended interview techniques to explore the schooling experiences of young autistic people. In their investigation, they highlighted that researchers must be aware of the following things: the consent process, preparing the participant for interviews, and supporting the participant throughout the interview. Their research points out that the voices of autistic people are often left out of research, based on assumptions that communication impairments restrict a person's ability to participate. These researchers also required participants to be diagnosed with autism in order to participate in the 30 to 70-minute semi-structured interviews. Harrington et al. (2013) provide recommendations which influenced my own research. In highlighting the difficulties of obtaining informed consent, they provided their participants with two different formats, making sure participants were aware of their right to decline any questions throughout the interview. In preparation for the interview, the paper discusses the importance of developing

rapport with the participant prior to the interview by getting to know them and by having the interview in a place where the participant would feel comfortable. Further, suggestions of using simple language and concrete examples were provided, as well as providing a schedule of topics that would be covered during the interview for the participant to refer to, and allowing for breaks. Finally, this research informed my thesis research by giving advice on how to redirect interview questions if conversations unconstructively digress.

Tager-Flushberg, Plesa Skwerer, Joseph, Brukilacchio, Decker, Eggleston, Meyer, & Yoder (2017) provide guidelines on how to include autistic people in research. They outline that there are barriers that prevent researchers from collecting data from minimally verbal autistic individuals, which risk homogeneity in many samples. Based on ABA, they suggest that researchers allow individuals to prepare for research visits by providing detailed information about what might happen during research. They suggest the use of social praise and positive feedback to keep participants on-track and warn researchers to be prepared for a participant needing a break in case of distress from the research. Further, it is suggested that participants are given a schedule of what to expect during research. Finally, they warn researchers to be wary around consent, and to honour any initial expression of refusal in a research setting. This influenced my choice to share interview questions with participants well in advance and to make consent an ongoing process throughout the interview.

Johnson (2014) produced a Master's thesis which used one-to-one interviews with adults who self-identified as autistic. This thesis influenced my own approach. The participants were recruited using non-probability sampling method through non-profit

organizations in Ottawa and posters advertising the research contact. Moreover, some participants were potentially recruited through “snowball” sampling: individuals were referred to the study by other individuals who took part (p. 36). The open-ended interviews only had two questions, and Johnson (2014) notes that during these interviews, participants would often ask whether they were providing correct answers,

This researcher always tried to reassure respondents that any answer they were willing to provide was helpful – even telling the researcher they did not know the answer to a specific question provided useful data (Johnson, 2014, p. 77)

This information is informative as it provides a basis for understanding that reinforcement and encouragement may be required during the interview process for gathering opinions. This also indicated that I needed to seek simplicity in my interview topics.

Online tools have also been effective in conducting interviews with autistic adults. McEvenue (2013) conducted interviews with autistic adults to investigate the impact of social work on autistic peoples’ lives. They used an online interview tool which was confidential and asynchronous resembling a chat forum. In this major research paper, McEvenue (2013) states that this tool allowed for participants to be engaged in the online interview process over a longer period of time, ranging from three hours to 15 days.

A literature review of methodological challenges and interview techniques that pertain to autism has provided this research with the following information:

1. Thematic analysis was used for analyzing the majority of surveyed research in this methodological literature review.

2. Autistic adults have not been interviewed about their own opinions of autism policy in Canada, and thus there is a gap in the literature.
3. Researchers must be aware there may be accommodations necessary for engaging autistic adults in the research and interview process. These will vary, depending on the needs of, and requests from, the participants.
4. Less structured interviews may cause an autistic adult to question their answers and promote off-topic discussion. If veering too far off-topic, discussions can be re-directed by having a visual of the topics to be covered during an interview. Verbal validation can assist a participant to feel that they are making a contribution to the research.
5. There are a variety of formats that interviews can take for collecting data in addition to the traditional one-to-one in-person interviews, including using online tools.

## **Conclusion**

This literature review has provided me with a framework to inform and situate the analysis of interview data discussed in subsequent chapters. By looking at how autism has been painted in Canada historically and presently, exploring the academic debate about ABA, reviewing Ontario's autism policy, and examining how previous researchers have approached similar studies, I had a basis for developing an exploratory research study which asks what autistic adults would like to see funded by the government and their opinions of ABA.

## Chapter 3: Methodology and Methods

### Introduction

Yergeau (2016) opines that stories told about disability are told too often from non-disabled perspectives. In response, the slogan ‘nothing about us without us’ has been a central mantra to promote disability rights for several decades. In the spirit of this mantra, my research uses an inclusive research technique which gathers opinions of autistic individuals as they pertain to autism and autism policy. This comes from my own acknowledgement that autistic people are experts in autism, and is in line with my personal values that seek to promote autistic self-determination. My experiences working with autistic adults in community settings have indicated to me that they have knowledge about autism policy and Applied Behaviour Analysis (ABA) and have valuable and unexplored opinions. Thus, I sought inclusivity in the research technique to investigate the opinions of autistic adults about autism funding, services, and policy in Ontario, and to collect their thoughts around what should be funded by the Ontario government. As research with an aim to promote action, the methodology and methods were chosen to center the experiences of autistic adults.

### ***Inspiration for Data Collection and Analysis***

In order to provide context for this thesis prior to conducting interviews with self-advocates in Ottawa, a cursory content analysis of *The Ottawa Citizen* was conducted with articles pertaining to the changes in the OAP between February 6 and March 13, 2019. This review allowed me to answer the question: were the perspectives of autistic adults included in public discourse around autism funding in Ottawa in the weeks following the announcement of the Childhood Budgets program?

The content drawn for the analysis was systematically drawn from online news articles from *The Ottawa Citizen* between February 1 and March 13, 2019. The search was conducted using Google News. The articles included were purposively selected based on the keyword 'autism Ottawa Citizen' and refining the date between February 1 and March 10, 2019. These dates were chosen because this was the period immediately following announcement of the change to the OAP, and *The Ottawa Citizen* is a popular news outlet in the capital region that covers local and provincial politics without a paywall. Eleven articles were selected based on this search.

I began the analysis by reading articles twice, hand coding themes with preliminary codes 'Family,' 'Financial Concerns,' 'Politics,' 'Economy,' 'Protests,' 'Speaking Out,' 'Services,' and 'Other.' These codes were further distilled to create the broader themes detailed below. This is how I also conducted the analysis of interview transcripts, inspired by Grounded Theory methodology. I recognize that this review was cursory and not rigorous. It was done purely to begin an investigation of perceptions on autism funding in Ontario, to develop sensitizing concepts for the research interviews, and to investigate if autistics' perspectives were present in local news.

In the eleven articles pertaining to the changes in policies surrounding autism funding I found three dominant perspectives: those of (1) caregivers, (2) politicians, and (3) professionals (educators and service providers). There was only one mention of autistic adults within this review. This occurred when *The Ottawa Citizen* recounts Joel Harden, NDP MPP who called on the provincial government to "invite parents, service providers, and adults with autism to join a 'real conversation' about what services are needed." (Gillis, Feb 22, 2019, n.p.) This analysis helped me to better understand some

stakeholders' perspectives about autism funding and provided sensitizing concepts to inform the interviews with autistic adults. The stakeholder opinions identified in this review included caregivers, service providers, and policy makers. Upon investigation, the following themes were prevalent:

### **Personal Stories**

Personal stories of children and families waiting for services provided under the OAP appeared in the majority of the articles reviewed. Many families recalled paying out-of-pocket for services while waiting for the direct-service option or direct-funding option under the OAP (Payne, Feb 6 2019; Laucius; Feb 8, 2019; Crawford; Feb 15, 2019; Laucius, Feb 25, 2019; Payne, Feb 25, 2019; Adam, Feb 26, 2019). The costs of paying for services were reported to have caused some families to remortgage their homes. Furthermore, families feared financial difficulties arising out of the implementation of the Childhood Budgets program (Crawford, Feb 15, 2019; Laucius, Feb 8, 2019). These stories further provided evidence that there is a need for service provision for autistic children, as the needs of the children can outweigh the resources of families. An example is given about the story of Joanne Small-Greenail who was reported to have two children with “a lot of challenges, not just autism, but developmental delays.” (Laucius, Feb 8, 2019, n.p.) Their family was receiving provincially provided services through the Children's Hospital of Eastern Ontario (CHEO), but Joanne feared this program would become unaffordable with the introduction of the Childhood Budgets program (Laucius, Feb 8, 2019).

## **Politicians' Reactions**

Many articles featured the reactions of politicians to the proposed autism funding changes. Government officials were framed as emphasizing the difficulty of creating an effective autism policy for governments, as “treatment [is] ridiculously expensive and the need of each child is different” (Mofatt in Payne, Feb 6, 2019, n.p.) *The Ottawa Citizen* also recalled the politician Bruce McIntosh, former legislative assistant to Kitchener Area, resigning due to McIntosh being unable to support the program changes (Payne, Feb 6, 2019). Lisa MacLeod, who was at the time Minister of Children, Community, and Social Services, attracted the most scrutiny. In the articles, politicians were portrayed as supporting the Childhood Budgets program, as they believed that the OAP was insufficient because the majority of children who required services remained on waitlists (Laucius & Payne, Mar 13, 2019). The articles recount that in February 2019 it was announced that the Progressive Conservative government might have frozen OAP waitlists in order to artificially inflate the need for a new program through creating an apparent service issue (Laucius, Feb 25, 2019; Payne, Feb 25, 2019). An article on February 25 recounts NDP MPP Monique Taylor’s reaction as “accusing the government of lying to parents” because of this artificial inflation, resulting in their ejection from the Legislature (Laucius, Feb 25, 2019, n.p.)

## **Parent Advocacy**

Parent and caregiver advocacy was reflected in the majority of the articles reviewed. Three forms of parent advocacy appeared: (1) Parents recounting their stories to the press as a call to action; (2) Parents collectively organizing to protest and rally; and (3) Parents being resourceful in researching and finding out more about the

motivations behind the new Childhood Budgets program. By telling their stories, vocal parents were given a medium through the press to give idealized perspectives on how a new policy should be developed (Laucius, Feb 8, 2019; Crawford, Feb 15, 2019). Parents in these stories were portrayed as collectively organizing to show disapproval with the proposed changes to programs (Laucius, Feb 8, 2019; Laucius, Feb 15 2019; Laucius, Feb 20, 2019; Payne, Feb 25, 2019; Adam, Feb 26, 2019; The Canadian Press, Mar 6, 2019). More moderate perspectives of parent reactions were not portrayed. The parents that were represented in these stories protested across Ontario, including outside of Lisa MacLeod's Barrhaven constituency office, located in suburban southwest Ottawa (Gillis, Feb 22, 2019). Protests called for consultation with parents in the creation of the new policies and for Lisa MacLeod to step down (Gillis, Feb 22, 2019; Payne, Feb 25, 2019). An article published on February 20, 2019 reviewed an analysis by an economist and father of two autistic children. This economist and father predicted in an analysis that the program would cost 50 to 100 million dollars less than the OAP services costed (Laucius, Feb 20, 2019). In review, parent advocacy appeared to build on the strengths of parents to seek out information and promote institutional change.

### **Information about Applied Behaviour Analysis (ABA)**

The articles in *The Ottawa Citizen* supported the augmentation of current policies and to standardize ABA-based programming for autistic children. This was reflected through testimonials and in a specific interview with a service provider/university professor. The testimonials recounted how many families had seen improvements in their autistic children's language, academic, and social skills, and/or seeing a decrease

in problem behaviours (Laucius, Feb 8, 2019). An interview with Dr. Kendra Thompson, president-elect of the Ontario Association of Behaviour Analysis and Associate Professor from the Applied Disability Studies Program at Brock University spoke about the need for ABA programming for autistic children. Thompson's opinion was that ABA helps autistic people increase on-task or social behaviours, teaches new life skills, communication skills and social skills, and that the interventions help them to maintain, transfer, and generalize these behaviours. An example given by Thompson of a behaviour that can be taught through ABA was self-control (Laucius, Feb 15, 2019).

### **Costs: government or parent responsibility?**

The costs of the OAP and the Childhood Budgets program are debated in the media. The past Liberal government had been required to defend its spending on the program (The Canadian Press, Mar 6, 2019), and the Childhood Budgets program had been scrutinized as attempting to reduce costs for the government while increasing costs for parents through benefit "claw backs." (Laucius, Feb 20, 2019, n.p.) In news, it is reported that ABA therapy, applied intensively, could cost families as much as \$80,000 per year (Laucius, Feb 8, 2019; Laucius, Feb 20, 2019; Gillis, Feb 22, 2019; Adam, Feb 26, 2019; The Canadian Press, Mar 6, 2019). As previously discussed, the amount announced that would be given directly to parents through the Childhood Budgets program was up to \$20,000 a year for children under 6 years of age, \$5,000 thereafter with a limit of \$140,000 total for autistic children who begin treatment before age six (Payne, Feb 6, 2019). Further, other programs, including the inclusive summer camp "Camp Kaleidoscope" and the Ottawa Carleton District School Board saw these changes as having negative consequences (Payne, Mar 13, 2019, n.p.) The negative

consequences indicated are that these children would be integrated into public schools and camps that have no additional supports for autistic children.

### **Changes since The Ottawa Citizen Review Update 1 (September 21, 2019)**

Protests and rallies continued after this cursory review was completed. Further, articles continued to argue that the number of children on the current waitlist (23,000) may have been a false number, higher than it should have been. The Progressive Conservative government continued to be accused of freezing the waitlist in order to artificially increase the number of children waiting for services. This was seen as a tactic used by the provincial government in order to make the OAP appear inefficient and inadequate (Laucius, Feb 25, 2019). There were additional scandals around the funding amounts that were offered for the new program, which may have been less than what was additionally provided in the OAP (Laucius, Feb 20, 2019). One result of this was the demotion of Lisa MacLeod, who currently (in April 2020) acts as Minister of Tourism, Culture and Sport. Todd Smith is now the Minister of Children, Community and Social Services (Alphonso & Stone, July 1 2019). The government also responded by bringing together a committee of 20 people, including “parents with lived experience, autistic adults, educators and experts.” (Ministry of Children, Community and Social Services, 2019e, n.p.) Together they were to examine results from data gathered from the community and submit a report with advice to guide a new program. This report was to ostensibly serve as a map for a new program to be developed for April 1, 2020 (Ministry of Children, Community and Social Services, 2019e).

### **Changes since The Ottawa Citizen Review Update 2 (December 23, 2019)**

In October 2019 the Ontario Autism Advisory Panel Report (2019) was released which made recommendations based on findings from community consultations and expert opinions about best practices for a new program. The panel (discussed in Update 1) made some key recommendations, including how to increase access to the program, including mental health supports, and developing partnerships with the Ministry of Education and the Ministry of Health. In a News Release on December 17, 2019 the Ministry of Children, Community and Social Services, announced that the adoption of key recommendations for a needs-based program would be done in more than one stage. The first stage of implementation would begin in April 2020 (Ministry of Children, Community and Social Services, 2019f). Changes to the program would be overseen by a newly implemented 'Working Group' comprised of research and clinical experts, an autistic self-advocate and a parent of three autistic children, a parent of an autistic child, and a representative from Ontario's Indigenous communities. This working group is mandated to provide input on the continued development of the program (Ministry of Children, Community and Social Services, 2019h). The result is that much of the full program will be delayed until April 2021 (Payne, Dec 18, 2019).

### **Changes since The Ottawa Citizen Review Update 3 (Final, February 1, 2020)**

The December 17 decision to delay the introduction of a new needs-based program until 2021 was reported to have caused great distress among parents of autistic children who remain without services. The result was protests arising from parents from across Ontario who demonstrated along Bell Boulevard and North Front

Street in Belleville: his MPP riding (Quinte), chanting “Todd Smith is a Liar!” (Baldwin, Dec 27, 2019, n.p.) Rallies took place December 27 and January 19 due to frustration over the insufficient funding provided for ABA offered through the Childhood Budgets program (Durkin, Jan 16, 2020; Mahar, Jan 19, 2020). Another protest, organized by the Ontario Autism Coalition, was planned at Queen’s Park for February 18 when the Ontario Legislature resumed following winter break (Stone, Jan 24, 2020). Todd Smith has been quoted explaining that the reason for the delay in the new autism program is due to ensuring the new program is viable. The new program will be implemented through the working group (See Update 2), will not be comprised of Childhood Budgets, and that “this is going to be a great, great program and the people in the autism field support the plan 100% but it can’t be rushed and put in place all at once.” (Todd Smith, reported in Splitters, Jan 8, 2020, n.p.) On January 24, 2020 the Ontario government announced that they would be offering to extend current direct-services to those receiving services under the OAP, and offer “interim one-time funding” to those who receive Childhood Budgets for 2020-2021 (Stone, Jan 24, 2020, n.p.) The result of the delayed establishment of a new program until April 2021 is that many families will receive a Childhood Budget for at least one year (Monsebraaten & Rushowy, Jan 24, 2020).

### **Methodology and Chosen Method**

The research question is intertwined into the methodologies chosen for this thesis. Methodology can be defined as a set of rules and procedures for collecting and analyzing data (Miner, Jayaratne, Pesonen, & Zubrugg, 2012; Solomon & Draine, 2010). Methodology has also been defined as a theory which justifies the method from

which information is gathered and analyzed in research (Carter & Little, 2007). Because the research question is exploratory and comparative, looking to see what the opinions of autistic people are with regard to funding and policies for autism services and supports, this study is qualitative and inductive. Qualitative research is a way to capture the everyday opinions and experiences of, in this case, autistic people, and reduces hierarchies between the participant and the researcher (Spalter-Roth & Hartmann, 1996 in Miner et al., 2012). Inductive research looks to move from specific to general in order to build theory and generate hypotheses (Solomon & Draine, 2010).

The methodological approaches used in creating the study design were influenced by Grounded Theory and aimed to be Participatory Action Research. This research is an example of Grounded Theory and Participatory Action Research because it sought to create a small-scale theory that promotes social change, including and working with participants. Grounded Theory uses in-depth interviewing for inductive analyses, and employs coding using constant comparative analysis (Padgett, 2017). Grounded Theory rejects grande narratives and hypotheses testing and seeks to create a smaller micro-theory through the analysis of interview data.

Because Structural Social Work challenges oppressive narratives in society, and Critical Autism Studies opposes normative approaches to autism, my aim was to create a small-scale theory which was action-oriented. This small-scale theory could demonstrate that the dominant theoretical approaches to autism have thus far been insufficient. Through conducting inductive research, I aimed to demonstrate that autism research must be person-centered, arising from the wants and needs of autistic persons

and their communities of care, rather than oppressive ableist societal notions that identify autism as something to be cured.

90-minute semi-structured interviews were completed using an interview guide (Figure 4) as a starting place for conversations. At times, the conversation veered from the topics, and additional questions were asked for elaboration and clarification. This allowed for a deeper understanding of participants' perspectives.

Aspiring to conduct Participatory Action Research, I was dependent on a level of community involvement and had a broader goal of instigating action towards social and political change (Padgett, 2017). This research has depended on my partnerships with people engaged in autism advocacy in Ontario and the partners took on the roles of supervision, third-party recruiting, consultation, and participation. With an overall goal of developing a micro-theory that describes autistic people as central in contributing to conversations about autism and policy, advocating for them to be consulted during times of change, the research has potential to be action-oriented. This is because in conducting this research I aimed to display a broader commitment to solving real-world problems as identified by autistic adults. In combining Grounded Theory and Participatory Action Research, I created a research protocol with the aim to understand autistics' perspectives of autism services, policies, and funding in Ontario.

To improve my ability to participate in Participatory Action Research, I engaged in critical self-reflection. Critical reflection is reflecting on action. After conducting interviews, I reflected on my own role as a researcher in an attempt to identify how my identity, social location, and contextual background played a role in the interview data. Through this, I sought to understand how power imbalances between myself and

participants may have influenced the interview data. I attempted to address these imbalances in subsequent interviews and to consider them during analysis (Daley, 2010). These notes, with no participant identifying information, allowed me to critically reflect on the research process and the interviews with the agenda of identifying potential power disparities and times when I thought I may have influenced the participants wording or discussions with an aim to identify better practices for interviewing autistic adults and minimizing my own voice within the results and analysis (Chapter 4) of the study.

### **Population and Sample**

I sampled purposively, selecting the population to be restricted to self-identified autistic adults located in Ottawa, Canada. By employing a convenience sampling technique, participants were identified through third-party recruiters attained through my own student and professional network.

The participants being interviewed were self-identified autistic adults over the age of 18, fluent in the English language, and located in the Ottawa region. Participants were required to self-identify as autistic due to the fact that there are a number of barriers that can get in the way of an individual accessing a formal diagnosis of autism (Campbell, 2018). This includes the fact that women, persons with mental health histories, and other marginalized and diverse identities often go without diagnosis. Additionally, obtaining a diagnosis of autism in Ontario has been demonstrated to be as difficult, evidenced by the fact that many publicly-funded diagnostic hubs in Ontario have waitlists, and by my own knowledge that many adults seeking diagnostic assessments must seek out private assessments (Children's Treatment Network, n.d.)

The population of the research was over the age of 18 for two reasons. First, this was an age where consent could be more easily obtained. Secondly, as the participants had aged out of children's services in Ontario, while they may be impacted by Ontario policies, I could not foresee them being directly implicated financially by the outcomes of the current Ontario Autism Program (OAP). This is because the current OAP only serves children up to age 18. This decreased the social and economic risks of participation. The population was drawn from the Ottawa region due to convenience factors. Additionally, there was a strong likelihood that adults living in the national capital area, where a lot of activity around autism policies takes place, would have a sense of the issues around the OAP. Further they may have an idea of what university research entails due to the proximity to post-secondary institutions in the area.

Four autistic adults were interviewed. Due to the qualitative nature of this study, the restriction of participant numbers allowed for thick description: a deeper description of opinions, events, and impacts of each participant individually, rather than a surface description of common traits of an average population (Denzin, 2001). Additionally, restriction of the number of participants was due to the fact that the research population (autistic adults who are able to and interested in participating in research, and who have opinions about autism funding in Ontario) could be considered "difficult to locate." (Babbie & Benaquisto, 2014, p. 164) Therefore, while this research may not be purely "representative" of all autistic adults in Ontario (Carter & Little, 2007), it provides suggestive evidence that autistic adults are capable and willing to contribute to discussions pertaining to autism funding and policies in Ontario. Specifically, the

participants reflect experiences of four autistic people in Ottawa, but maybe not more broadly.

The recruitment process began with convenience sampling. Convenience sampling is a non-probability sampling technique which relies on the available subjects who meet the criteria for the study to be participants (Etikan, Musa, & Alkassim, 2016). There was also potential for the sample to be informed of the study through snowball sampling, where people who may or may not have been part of the research informed participants about the research (Lopez & Whitehead, 2013). By engaging in Participatory Action Research, I am involved in the development of an adult autism hub in Ottawa, named the Ottawa Adult Autism Initiative and asked autistic adults through this group if they would like to be interviewed. Other networks developed were through my own engagement at the Canadian Disability Studies Association with a co-founder of Autistics 4 Autistics (A4A) and Autistiqueers – two autistic self-advocacy groups, and through my own Research Assistant work at Carleton University assisting with the screening of *Seeing the Unseen*, a film about autistic women in Iceland in November 2019.

Recruitment took place via email following an ethics-approved scripted email and flyer. Third-party recruiters included: A Manager at Carleton University's Paul Menton Centre for Students with disabilities, a faculty member with knowledge of potential participants in Ottawa, an experienced counsellor of autistic adults in Ottawa, and a well-connected leader in autistic communities and co-founder of Autistics 4 Autistics (A4A) and Autistiqueers. All third-parties communicated with the potential participants through email, except one who used Facebook Posts. Each third-party was emailed

explaining their duties as a third-party recruiter, giving them a script of an email or post and a flyer to share with potential participants. All potential participants were required to email me directly to become involved in the study. Due to time restrictions, each participant was booked for their first meeting on a first-come-first-serve basis.

## **Process Design**

Contact with participants took place in six phases. After a phase of general recruitment, the first phase, 'Initial Contact,' required the participant to reach out to me through an email. During this time, the participant was made aware of the interview options available and accommodations that could be provided. Often a thread of emails (more than one email and response) took place to clarify the research and organize dates, times, and mediums for the first meeting if the participant was interested.

The second phase of contact was 'the first meeting.' The first meeting took place in-person in a booked private room at Carleton University. While potential participants had the option of completing the first meeting over-the-phone or online through WhatsApp Messenger, none chose this option. The participant was given the opportunity to choose the medium through which the first meeting and interview took place to ensure comfort and to accommodate for need-based restrictions or preferences of alternative forms of communication (Harrington et al., 2013; Meyerding, 2014). During this interaction, I explained my social location; the purpose of the study; what the research would ask for in the consent process, for example, questions to ensure participants understood consent, confidentiality, and anonymity in the context of research. These questions were intended to screen for participants who may need a third-party for research consent and to ensure that participants understood any and all

limits of confidentiality and accommodations available to them. This process ensured that all participants had the full capacity and willingness to participate in the research. The first meeting allowed me the opportunity to develop rapport with the participant (Harrington et al., 2013), and for the participant to have greater autonomy in determining whether they would like to take part in the study. During this meeting the participant was given documents with the interview formats available, the interview questions that would be asked of them, and potential accommodations that were available to the participant during the interview. The first meeting was intended to ensure rigor in the research and allowed for prolonged engagement so that the participant would have a better sense of what to expect in subsequent meetings. Through developing rapport there was a reduction in likelihood of reactivity and respondent bias (Padgett, 2017).

Prior to the interview, I sent an email to the participant to remind them of their interview time and location via email (phase three). Phase four of the research was the interview. The interview was a maximum of 90 minutes, which included 15 minutes reserved for myself and participant to debrief about the research process. I offered to conduct the research in-person in a private room at Carleton University or at the Ottawa Public Library (Sunnyside Branch) Public Library, over-the-phone (using Zoom Communications), or online (using WhatsApp Messenger) depending on the choice of the participant. All interviews ended up taking place in private rooms at Carleton University and, no participants chose to use over-the-phone or online methods for first meetings or interviews. The interview questions were developed in collaboration with my supervisors, as well as in consultation with an autistic diversity consultant.

Questions were open-ended and acted as a guide (See Figure 4 which shows all interview questions). Consent was obtained either orally or written prior to conducting interviews (See Figure 5 Consent Form). Often, I found myself asking the participant to elaborate on topics that they had brought up. Certain questions were re-worded and re-phrased, skipped if the content was already covered or if the participant displayed that they had little knowledge about the subject in question. During de-briefing I asked the participant how they felt generally and in relation to the interview process. Additionally, I offered an optional list of resources aimed at well-being to the participant at this time.

Within one-week of the interview, I followed-up with the participant to thank them for their participation and for sharing their expertise (phase five). In this email, I encouraged the participant to email me if they would like a copy of their transcripts and/or their audio-recorded interview, as they were allowed to retract or add any information and are the owners of that data. The sharing of the transcripts showed my commitment to transparency and Participatory Action Research. This also allowed for member checking. By allowing the participant to verify the findings, it helped to guard against researcher bias (Padgett, 2017). Phase six has begun to take place. In February 2020, I followed-up with the participants to share results in an accessible summary format of thesis findings, and have given participants the option of obtaining the full thesis when it has been completed. If there are any further publications based on this research, I will again reach out and offer to share those with them.

### **Methodological Ethical Considerations**

The following ethical concerns were considered during this research:

1. Date of withdrawal

2. Paying honoraria and travel expenses
3. Potential harm to participant
4. Consent and Anonymity
5. Incidental Findings
6. Data Breach

The participant was able to withdraw from the study at any time. Their data was to be destroyed upon request for up to eight weeks after the interview date. The participant was encouraged to review the interview transcripts and/or interview audio, and to retract or add any information they felt necessary as an added measure to ensure their comfort. The participant received compensation whether or not the interview took place during the interview meeting. The following compensation was given to participants:

- \$40 for participation
- Travel expenses (typically \$7.00 for public transit covering \$3.50 fare each way. If the participant drove, parking was covered up to \$10, and if the participant used a taxi, Uber, or Lyft, the ride was reimbursed up to \$20).

Compensation was provided due to my own ethical considerations, as I am aware that autistic people are often not compensated for their time, especially during research, and I felt that to address this status quo I should provide a small stipend to all research subjects. Further, my personal experience being a participant in clinical research informed me that this amount was appropriate and equivalent to, and appropriate as an honorarium. Providing compensation was in line with equitable research practices and the inclusion and recognition of marginalized community

members. By not giving compensation, I risked indicating to the participant that I did not recognize and value their contribution to the research (Cheff, 2018).

Potential research risks that participants were made aware of included emotional, social, and economic risks. Emotional risks included unpleasant memories, deriving from interview questions. Further there was a risk that participants would feel inadequacy, as was observed in Johnson's Masters' Thesis (2014), that indicated that participants often questioned the usefulness of their responses. Emotional risks were mitigated by promoting participant choice in the interview medium. I also built rapport with the participant during the first meeting prior to the interview, telling the participant my own interest in the topic and social location and learning more about them. I made the participant aware of their ability to refuse or come back to any questions. It was also important to allow for accommodations during the interview. Accommodations included being prepared participants to be accompanied by a third-party support person provided that the third-party sign a Confidentiality Agreement/NDA. Finally, I provided an optional resource list at the end of the interview. No interviewees asked for accommodations or requested to have a support person present at the interviews.

Prior to conducting interviews and audio-recording interviews, informed consent was obtained from the participant. Three methods of obtaining consent from the participant were provided and the method chosen depended on the participant preference and needs. Written and oral consent forms were completed by participants. Copies were kept by the participant and myself. I stored the consent form as a PDF and the original was destroyed. I was also prepared for circumstances in which a third-party could consent. This is due to my awareness that some autistic adults may have

caregivers who hold legal guardianship, restricting their ability to consent. In this case a legally authorized representative in the form of a third-party who was able to protect the rights and welfare of the participant could have consented on the participant's behalf. Participation using third-party consent was contingent on participant assent, as consistent with TCPS 2: Article 3.2. No interviewees required third-party consent in this research.

During the first meeting with the participant, I used a script to ensure the participant understood consent, anonymity, and confidentiality. During this time, I explained the consent process in plain language. When the consent form was being completed prior to the interview, I reviewed the form in detail with the participant to ensure they understood what they were consenting to. No audio recording took place without consent and additional assent prior to beginning the audio recording.

Confidentiality was agreed-upon between myself and the participant using either oral or written consent (Figure 5) which included the pseudonym chosen and preferred pronouns of the participant. Each participant chose their pseudonym. I also used descriptions in square parenthesis to anonymize any service providers, people mentioned, or other identifiable information pertaining to the participant. I did not de-identify names of commonly known politicians (such as Doug Ford, Lisa McLeod) in Ontario during transcription, unless there was a direct link between this person and the participant disclosed that could make the participant identifiable. Even where pseudonyms were used, there was a likelihood that other participants or members of this community could guess the identities of participants because the sample size is so small. Participants were made aware of the social risk of being identified when social

identifiers of preferred pseudonym, preferred pronoun, willingness to participate in a study, and autistic identity are being collected. Risks of social exclusions from individuals or groups who provide support to the participant or exclusion from potential employers were warned of and reasonably prevented by allowing each participant to review their transcript and add or retract any information, providing optional support resources, obscuring names of organizations, and de-identifying individuals on a case-by-case basis.

I was prepared during research in case there was a time in which I had a legal obligation to break confidentiality. All participants and all third-parties were informed prior to participation of reasons in which I may have a duty to break confidentiality. Termed 'incidental findings' I had the following duties to report. First, I had a duty to report to others if there were disclosures of imminent harm to self (participant, third-party) and imminent harm to others. Under the Ontario *Child, Youth and Family Services Act* (2017) I had a duty to report any disclosures of active harm to a child (Ontario, 2010). Further, I included a duty to report if any participant shared incidences of active harm between a third-party and the participant and any incidences of ongoing abuse to autistic people. This is consistent with the CASW (2005) *Code of Ethics*, and in such disclosures I was prepared to inform the Carleton University Campus Safety Services or a Regional Police Service, workplaces/governing bodies/colleges, the Children's Aid Society, or to ask my supervisor for assistance. All participants were made aware that if they disclosed historic harm, self-harm, or illegal activities, that confidentiality would not be broken, as these are not necessary measures for pursuing

further action. No confidentiality was broken during interactions between myself and participants.

While no contact with participants for formal interviews took place remotely, it is necessary to indicate that I did relay to the participants that I could not guarantee data security for remote methods of data collection. Ensuring that there were private methods of collecting interview data online and over-the-phone was necessary because of the economic or social risks associated with interview topics. To mitigate risks of data security in the incidence of remote interviews, I chose two methods of contact that could be deemed as more secure than other counterparts: Zoom Video Communications Inc. and WhatsApp Messenger.

Zoom Video Communications Inc. was selected for phone interviews because I would need to successfully record phone interviews. Zoom would have allowed me to call the participant or to have the participant call me on the platform using a public switched telephone network: “Zoom Phone delivers a secure and reliable alternative to traditional on-premise PBX solutions. Call setup and in-call features are delivered via Session Initiation Protocol (SIP).” This method is encrypted and protected using Secure Real-time Transport Protocol (Zoom Video Communications Inc, 2019, p. 6). The recording could be downloaded from Zoom’s cloud and stored on password-protected USBs (Zoom Video Communications Inc, 2019). I then planned to delete the recording from Zoom’s cloud. Zoom Video Communications offers special security features of API integration key credentials, and Zoom Phone offers encryption, authentication, and a private network (Zoom Video Communications Inc, 2019). Zoom Video Communications uses a third-party assessment (TrustArc) in order to ensure compliance with the

*Personal Information Protection and Electronic Documents Act (PIPEDA) (2019)* which ensures that personal information is only used for the reason it is collected and restricts the disclosure of personal information (Office of the Privacy Commissioner of Canada, 2019; Zoom Video Communications Inc, 2018).

WhatsApp Messenger was the online medium which could have been used for interviews because it is a widely used messaging application which encrypts messages between two participants, ensuring that myself and the participant were the only ones able to read the messages (WhatsApp, 2017). At the time of the research, WhatsApp Messenger was compliant with PIPEDA. WhatsApp Messenger has been investigated by PIPEDA (2013) and has resolved any issues with regards to privacy found in the past (Office of the Privacy Commissioner of Canada, 2013).

While I did my very best to ensure that all remote methods of data collection were secure, in today's high-tech world I recognized that I could not totally guarantee this security. I was prepared to proceed the over-the-phone and online interviews with a disclaimer that I could not guarantee data security with Zoom Video Communications and WhatsApp Messenger. The participant was able to decline participation if they did not wish to use these networks for communication. No participants chose this method of interview, and thus I did not need to consider these risks after preparation.

### **Data Collection**

Written or oral consent forms with participant pseudonym and preferred pronouns, and consent to audio recording (Figure 5) were collected from participants. Audio recordings of the interview were collected using my personal password-protected cell phone. After being transferred onto a password-protected and encrypted USB the

original recording was deleted. The audio recordings were subsequently transcribed within one-week of the interview taking place by myself. These transcriptions were anonymized: with personal identification information, such as service providers or school names, removed. Finally, I kept an anonymized and confidential journal handwritten for critical self-reflection purposes, writing entries after the interview had taken place to investigate potential biases and influences they have on the interview data and eventual analysis of this information. Pages from this journal were scanned and saved, and the pages destroyed.

### **Data Storage**

All data pertaining to participants was kept on a password-protected and encrypted USB key, with one back-up. Anonymized files were kept with the following information: audio recordings of the interviews, anonymized transcripts, and scanned versions of the consent forms. USB keys were and are kept in a locked drawer. No paper documentation was kept directly about the interviews, except for a field-note journal of my own which refrained from identifying participants and focused on critical self-reflection. Pages from the field-note journal were scanned and saved onto the USB keys, and the pages destroyed.

It was a huge learning curve for me to learn how to password-protect and encrypt USB keys. Using the “Appletoolbox” webpage, I was required to learn how to use Disk Utility on my laptop to erase, format, encrypt, and password-protect two USB keys (Peterson, 2019, n.p.) The USBs were kept in a locked drawer within my apartment.

There were only a few incidents where data was not stored on password-protected and encrypted USB keys. These included email correspondence, calendar

entries, and files sent to the participants using Outlook or Microsoft OneDrive. Emails and files sent between myself and the participant were generally encrypted, kept in anonymized folders on my Microsoft Outlook using my institutional email. All calendar entries were saved on my Microsoft Outlook through my institutional email.

## **Data Analysis**

Collected interview transcripts were coded through establishing preliminary themes based on frequently comparing the transcripts to one another, as well as to the pre-established themes based on the cursory content analysis of *The Ottawa Citizen*. After initial preliminary themes were identified, the most salient themes were selected based on their relevance to the research question: what are the opinions of autistic adults in Ottawa about autism funding, services, and related policies in Ontario?

Prior to analyzing transcripts, I reviewed my critical self-reflection notes to become aware of any biases or presuppositions I may bring to the research. This heightened my awareness of my own identity, social location, and contextual background that may have influenced the transcript data and helped me to identify times when my power and privilege influenced participant responses. Transcripts were analyzed together using a constant comparative method, through reading each transcripts twice and hand coding themes with preliminary codes 'Behaviour Therapy,' 'Alternative Therapy,' 'Other Supports and Services,' 'Funding Experiences,' 'Funding of Adults,' 'Funding ideas,' 'Role of the family,' 'Others identifying autism,' 'Role of diagnosis,' 'The spectrum,' 'Prevalence of autism,' 'How the self identifies,' 'Experiences in School,' 'Opportunities for Schools,' 'Medicalization of Autism,' 'Apologetic,' and 'Capitalism.' These themes were further distilled into broader themes by comparing

each transcript's preliminary themes and comparing quotes with one another. Broader themes are outlined and discussed in Chapters 4 and 5. The micro-theory that I developed during this research was that autistic people have meaningful opinions about autism funding in Ontario, and thus should be consulted during times of change.

### **Ethics Approval**

On September 6, 2019 I received an email from Carleton's Research Ethics Board-A (CUREB-A) which asked me to consider some changes to the research protocol in order to gain approval. After three months of researching, writing, editing, and finally submitting my ethics application this was a welcome email. My application was 100 pages, including 33 attachments. The email stated that my proposal had been deemed minimal risk. Notable revisions I made after receiving this email included ensuring that participants knew that they would get their honourarium for showing up to the interview, whether they completed the interview or not. I also included a withdrawal of information date of eight weeks upon suggestion and changed some of the wording on consent and recruitment forms. I did push back on two recommendations. First, the ethics board questioned my \$40 honourarium. They asked "Would autistic adults likely face greater economic inequality? If so, does making completion of the interview a requirement for the \$40 compensation make it so that participants may feel compelled to continue participating even if they would rather withdraw?" I responded by saying: "Too often are autistic people researched and uncompensated for their time. Providing compensation is in line with equitable research practices and the inclusion and recognition of marginalized community members. Not paying an autistic person for their valued time would indicate that the researcher does not recognize the participants

contribution to their research (Cheff, 2018).” I did however clarify in my recruitment paperwork that the \$40 compensation would be given to participants for attending the interview, and not contingent on interview completion.

This, though, did come up as an ethical obstacle. It appeared I needed to think through the delivery of the honorarium. In one interview I forgot to give the honorarium and needed to e-transfer it to a participant. After two interviews I learned in my Research Methods course, to my horror, that it is a best practice to deliver the honorarium prior to conducting the interview. One participant made a comment about the ‘self-identification’ criteria of my study, saying that they told their friends to participate to get the \$40. There was no reason to believe that this happened in reality. Another participant made a comment towards the end of their interview about their own financial need. This indicated to me that providing the honourarium may have drawn particular participants to the interview rather than the topic of the interview itself. At the same time, I believe it would be unethical and unjust to not provide compensation for the time, energy, and opinions shared, especially because the topic had potential to cause emotional and social risk.

The Research Ethics Board also questioned the wording “accommodations available” as confusing, as participants may “presume that it means there will be a place to sleep for the night.” While I changed one poster to read, “Please let the researcher know if you have any accessibility concerns,” I did keep the wording accommodations for other documents and educated CUREB-A that I use the term accommodations to refer to United Nations Convention on the Rights of People with Disabilities (2006), Article 2 which references accommodation in terms of “reasonable accommodations”

and is a commonly understood term in the disability community (n.p.) After revision and re-submission my ethics was approved by CUREB-A (Project number 111389) on September 6, 2019 (See Figure 1 for Ethics Clearance Certificate).

Ethical challenges did arise during research with respect to confidentiality. I ran into one participant in an outside setting and did not acknowledge the participant as to maintain confidentiality. The participant, however, did acknowledge me. I refrained from speaking about the research with them. I had another instance where I found it difficult to keep confidentiality. After an initial meeting with a (potential) participant within the School of Social Work, I was walking with them to the elevator. This participant made a racist comment in front of a racialized professor. I didn't react in the moment, but internally felt disgusted. After the participant had left, I went to debrief with that professor. The professor was kind and willing to talk with me about allyship, but also identified that there was space for me to identify this participant so that there could be some education. At this time, I had to put participant confidentiality above my own social justice morals.

## **Conclusion**

By employing the methods of Grounded Theory and Participatory Action Research, it is apparent that the method of interviewing is an appropriate tool for better understanding autistic persons' perspectives of autism funding in Ontario. The recruitment process, stages of participation, and variety of ways in which participants could participate, were employed in order to minimally influence a participant's autonomy while keeping with my own capacities as a student researcher. Ethical

concerns were considered throughout the creation of the research protocol to ensure rigorous data collection and analysis.

## Chapter 4: Results and Analysis

### Introduction

A structural approach to social work, complemented by Grounded Theory, starts where the individual is, remaining non-judgemental of opinions and supporting the individual's goals (Carniol, 1992; Padgett, 2017). My own positionality, as a non-autistic student with previous experience working in Applied Behaviour Analysis (Intensive Behaviour Intervention – IBI) and in the community left me with knowledge about autism, but this knowledge did not include the lived experiences of autistic persons. Structural Social Work and Critical Autism Studies allowed the research approach to center the lived experiences of participants and created space for autistics to identify areas for change. How participants identified autism in the context of self and others framed our discussions surrounding autism services, funding, and policies. The participants used their experiences to identify their preferred supports and services, identified the importance of medication as an autism support, and how the education system plays a role in supporting autistic children. Finally, the participants used their knowledge of society and autism to make recommendations on how autism programs should be funded. Through engaging four autistic adults in qualitative interviews related to recent changes to the Ontario Autism Program (OAP), this research sought to raise awareness about autistics' perspectives of autism funding in Ontario, advocating that autistic adults have meaningful recommendations for supports and services based on their own experiences and expertise in autism, highlighting the importance of inclusionary policy development.

## About the Participants

I met individually with each of the four participants between September and October of 2019. Interviews lasted anywhere from 25 to 72 minutes, depending on the comfort of the participant and the amount of information they felt they could and wanted to share with me in response to questions.

Rather than using real names, all participants chose their pseudonym, some finding it more fun than others. Each interview was very individual. First, I met with Rudy (pseudonym). Rudy was eager to participate in my study and to share her past experiences in with various therapies. Rudy used her autism advocacy activities to frame her responses. Rudy was the only participant who used the pronouns she/her. Next, I met with Tom (pseudonym; he/him), whose interview surrounded the experiences of both child and adult services for autism, as well as adult funding through the Ontario Disability Support Program (ODSP). Third, I met with James (pseudonym; he/him), who spoke about his opinions surrounding autism and he shared stories about addressing challenges in his past. Finally, I met with Philip (pseudonym; he/him), who, after checking in with him, instructed me to ask him more direct questions. As a student from outside of Ontario, Philip shared his experiences being funded and receiving services in British Columbia, and about his transition to Ontario.

All interviews, being semi-structured, deviated from the scripted interview questions for many reasons. Often, I found that there were interesting things that I wanted the participant to expand on and asked these questions directly. Other times, I asked follow-up questions when a participant said something that contradicted something I had read during my literature review. I also clarified questions and

responses, and used prompts when participants did not know what something was and when answers were abrupt and non-specific. I tried to be as friendly as possible, offering support and empathy throughout, and this may have taken away from my researcher 'neutrality.' Instead, I maintained an attitude of open curiosity. As I am actively involved in the local autism community, involving autistic persons, professionals, people who support and work with autistic persons, parents, and caregivers, I did not aim to be neutral in interviews. My research subjectivity is understood as part of anti-oppressive practice principles, which promotes researcher reflexivity and identifies that truth and knowledge are fluid, individual, and guided through interpretation (Moosa-Mitha, 2005). In the end, the transcript data were rich with expert experiences and recommendations. While writing this chapter, I recognized that it is only representative of a fraction of the wealth of data collected.

### **Identifying Autism**

The way that participants identified as autistic differed. Each participant's lived experiences validated their expertise in defining autism for themselves (Gillespie-Lynch et al., 2017; Milton, 2014a). Further, the way that the participants self-identified located many of their conversations about autism services, funding, and policies, and the specific recommendations they made.

In describing autism, many participants highlight the importance of diagnosis. Rudy described, "for me... when I describe myself and when it comes to diagnoses, I say specifically diagnosed with Asperger's Syndrome because I think that that is more accurate about the nature of where I would get such a label."

Rudy also noted that she preferred person-first and strengths-based language in self-identification,

I also self-identify myself as an Aspergirl, because it sounds [like a] much more person-centered label, and I also got inspired by another self-advocate named Rudy Simone, who was diagnosed later in life with Asperger's Syndrome, and she has written many books about what it's like to be a female diagnosed on the autism spectrum.

The influence of a book in selecting identifiers is significant. Much research and literature surrounding autism is male-dominated, only 20% of diagnoses being comprised of women in Canada (Ofner, Coles, Decou, Do, Bienek, Snider, & Ugnat, 2018). There is no consensus on whether the prevalence is really higher in men, or if the diagnostic categorizations and signs of autism are different in women so that women and girls are less likely to receive diagnosis, despite similar rates (Haney, 2016).

James identified his autistic identity using the DSM criteria. He also compared himself to other autistic people in sharing his identity. James recalled, "from my diagnosis I know that I am a lot more high-functioning than most people on the autism spectrum. I was originally diagnosed with Asperger's, but that was... back when the DSM-IV was still in control of those things."

Tom recalled that he was diagnosed at an early age but did not know about the diagnosis until he was older,

They got me patted down as autistic when I was like two... My mom took me to some people... and then they're like 'yeah, your kid is borderline autistic.' But I didn't find out about that until I was 11 or so.

In Chapter 2, I described the autism 'spectrum' using a prism image as a visual (Illustration 1). Autistic advocates have called for a re-evaluation of the 'spectrum.' This

re-evaluation seeks for the spectrum to be viewed as multi-faceted rather than linear, recognizing that individuals have strengths and deficits in many different areas (Burgess, 2019). Tate (2019) writing for the Autistic Women & Nonbinary Network argues that linear spectrum labels of functioning level can hold insulting assumptions about the life trajectory of an individual. Rudy's opinion of the spectrum was multi-faceted and non-linear,

Autism has been described as a spectrum and each person, and this... has been made more clear to me through life experience and through recent studies... each person is made up of several things, not just their individual traits, but their socioeconomic status, hard events and positive events that happened to them, and so that's very person centered and a very organic look at someone.

I found that of the participants described a linear spectrum based on severity, rather than a spectrum which is multifaceted. James described where he currently feels he falls on the spectrum, saying "autism is a spectrum, so everything here is going to be dependent on how high or low they are on the spectrum. It's a very wide variety of people... if they are high-functioning like myself."

James, though, described having different lived experiences with the spectrum, and how working with services and supports have helped him to achieve this different functioning level,

I know what it's like being the low-functioning area of the spectrum to now being on the high-functioning part of the spectrum. Because I have done a ton of work on myself, and have pushed through to where people would never guess that I have autism.

Tom did not identify as "fully autistic." Tom shared, "how do I best word this? There is a level of disconnect between me and an actual autistic person, because I am actually on the borderline... like literally on the border of normal and autistic."

Identity may be impacted by stigmatization surrounding autism. McGuire (2011a) argues that the stigmatization of autistic individuals is rooted in historical perspectives of autism, the language that surrounds autism, and public images of autism. Philip identified that stigma can prevent people from disclosing their autism, saying “I find for many people they want to keep their autism a secret.” When speaking about the employment context, James also noted that he refrained from disclosing his autism to his employers, “Every time I have been employed by someone I have not disclosed it.”

Philip stated, “many of us are kinda normal,” a point which introduces the increasing awareness of autism prevalence. The prevalence of autism played an important role in forming participants’ identities. The Public Health Agency of Canada released “Autism Spectrum Disorder Among Children and Youth in Canada 2018: A Report of the National Autism Spectrum Disorder Surveillance System.” (2018) The national results, which omitted Ontario in its data collection, identified that one in 66 children and youth age five to 17 years of age were diagnosed with autism in 2015 (Ofner, et al., 2018). The perception of this rate varied among participants. Rudy described this report during her interview, recalling that “the prevalence of autism, which is one in 59 here in Canada.” Tom estimated that “more than 10%” of the population is autistic, and James estimated “just over 1% now.” James used the prevalence of autism to justify the importance of autism services, while Rudy used prevalence rates to support arguments around autism policy, saying, “having at least one family member diagnosed with autism... is becoming more a norm because of increases in diagnosis rates...It has become a sizable minority population that their voice has to be considered.”

Critical Autism Studies advocates that autistic voices are critical in creating narratives of autism (Douglas et al., 2019). By not involving autistic people in policy creation, there remains an imbalance in power and continued repression and discrimination against autistic people (Woods et al. 2018). Tom described autistic people as fundamental in Canadian society, saying “like it or not, autistic people are a body, a body of people. They are consumers, they are basically part of the lifeblood of Ontario. Without them, things wouldn’t chug as easily.”

Many self-advocacy movements have expanded out of campaigns against the societal portrayal of autistic individuals as child-like and unable to make their own decisions (Bertilsson Rosqvist, Brownlow & O’Dell, 2014). This child-like depiction of autistic adults and persons with other developmental disabilities may appear prevalent due to ‘mental age theory.’ Mental age theory postulates that people with developmental disabilities’ bodies age quicker than their minds, and thus, will never have the capacity to have the adult rights of independence and autonomy (Smith, 2017). Tom addressed this in his impressions of how society treats autistic people. Tom stated, “they think that autistic people are still kids.” To combat issues of stigmatization, Rudy would like to see a change in the language used to describe all disabled people, preferring “to say the term differently abled.”

Finally, Tom called for a societal changes in perceptions of autism,

We need to demystify the autistic people, to de-monstrify... cus [sic (because)] for too long we have associated autistic people with like clowns or like people to laugh at... they need to unveil the misconceptions and show that autistic people have potential to be people like us, or people like you in this case.

Dr. Stephen Shore famously said, “If you’ve met one person with autism, you’ve met one person with autism” (Lime Connect, 2018, n.p.) In identifying themselves,

participants displayed that autism is highly individual and is a part of humanity. As James said, “just like anybody else, autistic people are individuals.” Participants commonly identified with their diagnosis, used comparison to others to identify themselves, referred to prevalence rates to support the normality of autism, and identified areas where public awareness can grow with respect to autism. Unfortunately, as mentioned in previous chapters, many of the supports and services centre on a medical model of autism. Participants shared their experiences of these supports and services, and identified a variety of ways in which these approaches could change.

### **Supports and Services**

In the cursory content analysis of *The Ottawa Citizen* after the announcement of the Childhood Budgets program (Chapter 3) Applied Behaviour Analysis (ABA) was framed as standard care and necessary for autistic children to thrive in society. While the inclusion criteria for this research required participants to have knowledge and/or opinions about ABA or autism funding, a plethora of supports and services were discussed. Surrounding discussions of supports and services, participants brought up many therapies, including ABA, complementary approaches, counselling, being part of research, CBT, and adult services. Further, participants identified where services could improve.

Philip had no knowledge of what ABA was, stating “what is applied...?” And, while James had heard of ABA, he had no experience with it directly,

I am not entirely up to date on the ABA... I know I have heard of it and I know that I may have read a few things here or there, um, but I couldn't think of it off the top of my head.

Tom did not name any therapies directly in his interview, and disclosed to me after the interview that he wanted to better answer the questions around ABA. I assured Tom in that moment, that the point of the interview was to hear his opinions around his experiences, whether or not they included ABA.

Rudy was the only participant who recounted direct experience in ABA-based programming as both a learner in ABA-based programs, and through current employment within an ABA/IBI service. Reflecting on her and her sister's experience in ABA-based programming, Rudy took a "pragmatic" approach when describing ABA therapy:

I don't attribute it as the end-all-be-all for autism therapy... I think some of the biggest benefits that I got from ABA and IBI was about taking turns and also about being respectful about people's personal space, and... knowing that doing certain actions might result in a little bit of fun time after.

Rudy also accessed alternative therapies, and describes that ABA is one of a plethora of therapies that she attributed to her own growth and well-being.

So ABA and IBI... sensory-integration therapy, Montessori-based therapy, I mean all the way down to wearing weighted vests to have us sleep better. I mean, what kind of therapy did we not try... Oh, and also speech therapy... They all benefitted us to varying degrees....

This experience echoes many recorded accounts of parents and caregivers. Trying a multitude of therapies is not an uncommon experience for families. And while there are warnings against alternative approaches to autism therapy, as they may be pseudoscientific (Ip, Zwaigenbaum & Brian, 2019; Maich & Hall, 2016), Rudy defended the therapies that she was enrolled in as a child, saying "they're not pseudo-therapies."

She appreciated the variety of approaches that she had, and identified that they have given her benefits.

I have really been thinking about all the various kinds of therapy that I have done and the benefits they have given me, because when they would have been initially presented to me and my sister, it was in the form of fun activities to engage us.

This is similar to reported preferred therapeutic approaches identified by The Autistic Self Advocacy Network (2017). In a study, they found that therapies that focused on skills that helped the individuals understand their disabilities, cope with sensory overload, and encouraged self-determination and self-care, were preferred by autistic people and people with developmental disabilities (Gardiner, 2017).

Tom identified that he participated in several short-term studies and therapies that he participated in as a child.

The best I can sum up is like my Mom would take me to therapy... and then the doctor or whatever would be like, so here's some different things I want you to do, let's see how you do them, something like playing with dolls, pretending, re-enacting...

When asked if he found the assessments fun, Tom responded, "Oh, yeah, like very great. Like these were, uh, basically like how like the fact that I remember them fondly basically shows they – just shows how good they were." Tom's positive reviews, are similar to those of Rudy, show identifying that the therapies which are targeted for autistic children can be fun and engaging for children.

James attributed a different form of behavioural therapy to his well-being today. In recounting a story of how he transformed his confidence, his looks, and his health, James associated Cognitive Behaviour Therapy (CBT), a short-term therapy rooted in behaviourism and cognitive theory (Payne, 2016), with major milestones in his life. CBT

focuses on cognition and behaviour change through changing core beliefs, maladaptive thoughts, and maladaptive behaviours. It is more commonly used with adolescents and adults. CBT is an evidence-based therapy, and has and has some support for use with autistic children (Wood, Drahota, Sze, Har, Chui & Langer, 2009), but has more research evidence in use with teenagers and adults (Gaus, 2007; Gaus, 2011; Laugeson & Park, 2014; Spain, Sin, Chalder, Murphy, & Happé, 2015; Spain, Blainey, & Vaillancourts, 2017; Wood, Ehrenreich-May, Alessandri, Fujii, Renno, Laugeson, Piacentini, De Nadia, Arnold, Lewin, Murphy, & Storch, 2015).

CBT helped negate that social awkwardness... CBT was a huge, huge, part of that. Had it not been for CBT I don't know if I would have been able to follow through on the diet or the fitness plan or anything else. So I owe a lot of that to CBT and highly recommend it.

Philip described the primary services he accessed for autism in British Columbia as "counselling," but could not identify any benefits gained from these counselling sessions,

Like for me, I never liked counselling, I didn't find it ever worked. I would have preferred more one-on-one, cus [sic (because)] for counselling, when I went for counselling they would talk to me and they would say 'oh you need to improve on this'... well, why do that when I can just do the compulsion, I didn't find counselling really worked.

Philip described a deficit-based model of counselling in which behaviour reduction was targeted without sufficient benefits or rewards to outweighed the undesirable behaviour. Because there seemed to be insufficient reasons for changing that behaviour, Philip had a hard time motivating himself to conform to the expectations of society. Thus, counselling potentially alienated him rather than assisted him (Meyerding, 2014). Philip recounted that a physical therapeutic object was assistive for him:

We did purchase a weighted blanket to kind of help... We thought that it could be used with the autism funding, cus [sic (because)] it says your allowed, um, physical things to help with autism... so we thought it would be part of that because a weighted blanket is used for people who are autistic... the blanket was pretty expensive.

Philip stated that there were issues in accessing funding for the blanket. A common idea brought up by participants was that supports and services should not only focus on ABA, but on a variety of supports and services. As Rudy expressed, "I think that more people need to realize that there is not only ABA and IBI but there is [sic] various forms of therapy." James put it simply, "Listen... every person needs different supports."

Both Tom and Rudy spoke about support for autistic adults in Ontario. Tom spoke about his personal experiences and the importance of adult services for autism.

I take part in a thing called [organization name omitted] ... every so often you are given a whole bunch of options for how to do your next couple weeks, like for instance... one of the plans for this Friday fell through... basically the overhead of the Friday nights was like – 'so what do you want to do instead?' And I was like, 'I don't know give me some options.' And she actually lists four... and it also has a bunch of wide-reaching areas... they always have like a wide variety of things to do.

Rudy also argued that, "what is becoming more apparent in the past few years is the almost complete lack of services for adults who are diagnosed with autism." Further, Philip expressed that there is not only a lack of services, but a lack of funding to access appropriate services for autistic adults, saying "I didn't get much time to get support, cus [sic (because)] I was diagnosed at 16... when you turn 18 the funding stops. It cuts. So paying for that with your own funds is like paying for your autism."

The few options available for autistic adults are echoed in Autism Ontario's (2008) "Forgotten: Ontario Adults with Autism and Adults with Asperger's," and by the

Ontario Adult Autism Research and Support Network (n.d.), who indicate that few autistic adults in Ontario are properly supported. The report by Autism Ontario (2008) made several recommendations including a need for sufficient and regulated services for autistic adults, that a provincially-based needs-assessment be conducted, that eligibility criteria for services be based on functional needs rather than intellectual functioning in policies, and that access can be facilitated to establish best practices in education and research specific to autistic adults (Autism Ontario, 2008). Tom recalled being denied passport funding, an Ontario program for adults with developmental disabilities which provides reimbursement for approved recreation and respite services (Ministry of Children, Community and Social Services, 2018). Tom's experience being denied passport funding, showed that even though 13 years has passed since the publication of this report, the Ontario government has not implemented standard eligibility criteria outside of intellectual functioning, "to get passport funding... I was too high of an IQ, like of function, to qualify, so to speak, like, I was too normal." Similar to English Poor Laws, a notion of deserving and undeserving of social services still exists in contemporary Ontario policy decisions.

Recommendations for services for autistic individuals of all ages made by participants included Rudy's identification of the need for autistic children to be taught self-advocacy skills,

If there was not so much emphasis on persons with autism being good, respectful people, or at least having it balanced with how to politely stand up for yourself... I don't think there would be such high rates of bullying or sad consequences on mental health that could happen.

Tom identified that there is a need for job assistance programs for autistic people,

They should set up programs for autistic people... to learn how to work... because sometimes people have, like, barriers set up for themselves, that are like, 'I don't think I can work'... so I think that what should happen is something like that.

Tom also identified that autistic people would benefit from social gatherings, saying "I've never seen any huge organized weekly hangouts – especially ones catered towards autistic people. And I think that if there's anything to take away from this interview, there should be more of those kinds of organized hangouts."

Overall, the participants had a variety of experiences in services targeted for autism, and have identified constructive areas for growth in current services. This section provided an overview of what kind of services can be expanded for autistic children and adults, and potentially funded by the Ontario government. Something that is better funded than supports and services by the Ontario government is the medical system, which was brought up by many participants in relation to supports and services.

### **The Role of Medicine**

Medication was referred to as a support for autism in many interviews. The Canadian Pediatric Society's Position Statement, written by Ip et al., (2019) speaks to the use of pharmacological management of autism, saying the following:

Medication use should only be considered when nonpharmacological strategies have been exhausted, and they should always be used in combination with behavioural interventions for children with ASD. Sometimes, starting a medication while awaiting access to services may be necessary, but such decisions must be considered carefully on a case-by-case basis. Because children with ASD can experience more medication side effects than those without ASD, dosing should "start low (often lower than published recommendations), and go slow" [sic] (no reference provided) (Ip et al., 2019, n.p.)

Autism Canada (n.d.) reports that "no drugs can correct the underlying neurological problems in ASDs, drugs used for other conditions are sometimes used to

treat autism symptoms or behaviours associated with autism.” (n.p.) Similarly, the Food and Drug Administration (2019) of the United States has only approved risperidone (Risperdal) and aripiprazole (Abilify) for ‘irritability’ that can be associated with autism. It is not uncommon for ‘off-label’ pharmacological medications to be used as an autism therapy (Williamson & Martin, 2010). Medications “used for co-occurring behavioural symptoms and mental health disorders” that are effective in non-autistic children do not always work the same in autistic children – the side effects, often negative, can be more prominent and pronounced, and the positive effects can be less pronounced (Ip et al., 2019, n.p.) Off-label medications (not inclusive of risperidone and aripiprazole) often used for behaviour management include anti-psychotics and mood stabilizers for aggression, self-injury, severe tantrums, and social withdrawal; ADHD medications for inattention, hyperactivity, and impulsivity; and SSRIs and mood stabilizers for repetitive behaviours. Most of the off-label medications have not been extensively studied in autistic children (Accordino, Kidd, Politte, Henry, & McDougale, 2016; Williamson & Martin, 2010).

Philip referred to his use of medication as something he does not necessarily recognize the effects of, saying, “If I switch pills I won’t see a difference, but my parents can.” Similarly, Tom referred to his experiences with his mother administering his ADHD medication to him as a child “drinking pills... in Jell-O form.” He advocated that these medications are not a quick-fix for autism,

You can’t really solve a problem by giving them medicine... When I was a kid, I was given Ritalin... I was well aware. And one day my mom realised that the Ritalin was making me more zombie like, so then we switched to Concerta, until I just stopped.

James referred to being misdiagnosed many times before attaining his autism diagnosis. While some research supports that misdiagnosis and missed diagnosis can be quite common for those who ‘pass’ as higher-functioning (Luciano, Keller, Politi, Aguglia, Magnano, Burti, Murano, Aresi, Damiani, & Berardi, 2014), these cases are more represented in girls and women (Baudino, 2010; Gould & Ashton-Smith, 2011). The case of James runs counter to current Canadian research which generally finds that autism is being over-diagnosed in the United States and Canada (Prizant, 2012; Rødgaard, Jensen, Vergens, Soulières, & Mottron, 2019). James also shared his experiences on common ADHD medications. “I was misdiagnosed many times,” he stated, “not just was I denied to be put on a waitlist, but I was misdiagnosed many times...”

...I was a really little kid, and so my parents would talk to him [the doctor] and do most of the talking for me... At the end of every session it would be the same thing: ADHD with OCD tendencies, and so what did he do, he tried me on every single ADHD med under the sun. And, if you know anything about autism, ADHD meds and autism really don’t mix well. Especially because he tried me on relatively high doses at the time... I was in the worst place that I have probably ever been in my entire life.

The high doses he recalls differs from the “start low go slow” current recommendations of the Canadian Pediatric Society (Ip et al., 2019, n.p.)

James and Tom both positively reviewed medications at older ages. When referring to a story in which James successfully transformed his confidence, his looks, and his health, he identified how changing medication assisted with increasing his self-confidence,

So in grade nine I was really fat. I was on this medication called Abilify, I was socially awkward, I had a very small amount of interests... I got a blood test... they said to me, you have to lose X [sic] amount of weight and you gotta lower your cholesterol and lower your weight or we’re going to have to medicate you for

the rest of your life... So my parents freaked out too and they immediately got me a fitness trainer, I got into a nutritionist, they took me off of Abilify and put me onto ADHD meds, Concerta to be specific, and they took me off a medication that was keeping the weight on and put me onto a medication that suppresses appetite.

Tom identified that he would have liked the medication that he is currently on to be offered at an earlier age, rather than a “calming room” (seclusion room) which was used in his school environment as a means to control his emotional responses of anger,

I am still taking medication today, but it is probably for more appropriate measures. And I think that what I should have been doing back then, if I decided to go back, is recommend Cipralex to prevent overstress, and if I get too stressed, don't put me in the calming room, just have me take Lorazepam, which, if you don't know what that is, it is this sort-of tranquilizing pill. It brings your energy levels to a complete low.

It is interesting that medication was identified by three of the participants in discussing autism policy and services with me. It thus is evident that medication is seen as a support for autism by these participants. This may be due to the relative ease of accessing and attaining medication in Canada, whereas attaining social services often require waitlists, time, and financial commitments. Another publicly-funded system that autistic children are impacted by is the education system.

### **The Education System**

Along with therapeutic and pharmaceutical supports and services, education and the supports provided through the education system, was a topic introduced by many participants. Participants spoke about previous experiences growing up in the education system, identified that education should be a priority when considering provincial funding supporting autistic people, and offered suggestions about how to improve the education system.

Tom spoke about his experiences in a Catholic primary-junior school with mixed reviews, saying, “really good place. But, uh, I remember, there was a bit of a segregation with the less functioning people. There’s always been that kind of segregation. Like where the autistic people, they get put into like a little room.”

Tom is not alone in feeling the experiences of special education were exclusionary. Jordan (2008) alleges that the segregation of autistic individuals from the mainstream classroom began with Lovaas’ (1987) promotion of ABA for preschool-aged autistic children. Jordan (2008) argues that when a child is unsupported in the classroom, “failure” is pinned on the child rather than on the capacities of the classroom (n.p.) In a call for schools to increase capacities for diversity, Jordan (2008) states that segregated schooling may lead a person to a segregated life. While Ontario’s Ministry of Education (2013) has committed to the use of the Universal Design for Learning, “to assist educators in designing products and environments to make them accessible to everyone, regardless of age, skills, or situation” (Ministry of Education, 2013, p. 14), the Ontario public school system does not always follow those principles. This is because the Ministry of Education (n.d.) states that the special education program services are defined by each school board in Ontario.

James brought up concerns about presumptions made by his school, which may have delayed his initial diagnosis. “I tested gifted in grade school, and, because of that testing they refused to put me on the waitlist to be tested for autism.”

This premise that James could not be autistic and gifted might show an ill-prepared school environment for autism. Often autism is stereotyped with savant skills, and while these generalizations can be misleading, they have also been deemed to

“offer a fair and reliable reflection of the autistic condition.” (Draaisma, 2009, p. 1479)

Knowledge of some stereotypical features may have proven helpful in the moment to speed up James’ diagnosis, and the funding and supports that come with having a diagnosis. Philip also brought up the fact that his school was ill-prepared to meet his needs. Speaking in the context of British Columbia, he also reflected discontent with his school,

I didn’t get any help from the school until grade 12 and the only help I got from the school was just being able to have extra time. So they didn’t actually do my IEP until Grade 12, which is pretty late.

In Ontario, the Individualized Education Plan (IEP) process is required for Special Education programs. The IEP is implemented, reviewed, and updated every reporting period, especially with respect to “annual program goals, learning expectations, teaching strategies, individualized equipment, and levels of human support” with the student (Ministry of Education, 2004, p. 48). There may be issues with keeping schools accountable to the IEP process, as the Ontario Autism Advisory Panel Report (2019) has called for the introduction of an education advisory committee on autism, to “conduct a review of school board adherence to Individual Education Plan (IEP) Standards.” (p. 35) The fact that Philip has no recollection of his IEP being continuously updated would be inconsistent with the requirements in Ontario, but may not be atypical of the experiences of an autistic student in Ontario.

Philip also spoke about mistrust of his school’s use of his diagnosis and identity.

For my high school, what was so funny was that they hadn’t helped me for years upon years upon years, but then, the second they found out that I had autism, they wanted the papers, they wanted the papers, the second they got the papers they didn’t help me... By getting the papers the school actually gets paid for having an autistic student. So for me it kind of felt like they wanted the papers to get money for the school, but they didn’t really care about helping me.

In Ontario, the Ministry of Education uses the “Special Education Grant” which allocates a per-pupil amount of money for students who use special education services. These are allocated to the schoolboards with “benchmarks” of “\$1,015.60 per JK to Grade 3 student, \$780.12 per Grade 4 to 8 student, and \$515.04 per Grade 9 to 12 student.” (Ministry of Education, 2019a, p. 2) There are additional funds that are allocated for special equipment purchases based on a grant of \$10,000 per school board and an ability to claim purchase amounts. Further, there is a Behaviour Expertise Amount allocation comprised of the “ABA Expertise Professionals Amount” of \$176,642 per school board and the “ABA Training Amount” of \$1,500 per school board (Ministry of Education, 2019b, p. 15). In an education system framed by neoliberal capitalism, the autistic child is monetized. It is disturbing to think that Philip reflects that his job as a student was to procure a monetary contribution, and was not given the resources he required as compensation (Ben-Moshe, Hill, Nocella, & Templer, 2009; Monture, 2010).

Tom spoke about a common ABA technique, the “Premack principle,” “a principle that states that making the opportunity to engage in a high-probability behavior contingent on the occurrence of a low-frequency behavior will function as reinforcement for the low-frequency behavior” (Cooper et al., 2014, p. 13), colloquially referred to as ‘first [target behaviour], then [reinforcement]’ being used in his school environment. This didn’t always work out so well for Tom.

Work, and then you get to play. Work, and then you get to play. And then, sometimes I would not be able to work, and then I wanted to play, but unfortunately, if I can’t do work, I can’t play, if you get the drift. And if I become, especially, if I become in-co-operable, if, once they had created the room they would put me into, a sort of ‘calming room.’

While ABA techniques seemed to work for Tom some of the time, his inability to participate in contingent learning did not only lead to the absence of reinforcement, but to the introduction of punishment for his expression of dissatisfaction in the form of seclusion.

It's like a, think this room – without any furniture, not padded walls, you know those like giant pads you see in gyms, like, like plastered all over the walls... very rough carpet flooring, and it was like literally half the size of this room [Interview room, 512 Dunton Tower is approximately 5 meters by 4 meters, see Illustration 2 for floorplan]. And imagine that the door was locked from the outside. Technically not locked, but shut, by a teacher, and you couldn't get out until you had properly calmed... I remember like multiple occasions where I was stuck in there for like hours, or as I perceived them to be hours, they're probably more like 30 minutes to an hour, but... I think for the purpose of keeping you calm, but the entire situation of keeping you in a literally solitary confinement, with a locked door, that is not 'calming' at all, that's the opposite of calming.

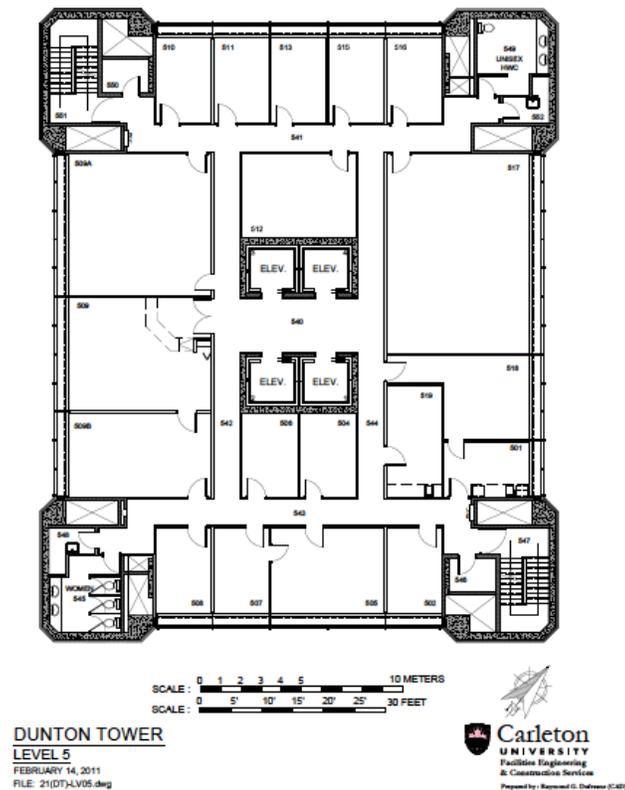


Illustration 2

Tom's experience in a seclusion room is not atypical. Autistics 4 Autistics (2018), an autistic self-advocacy group, wrote in a blog post about the use of restraint and isolation rooms in Ontario which remain underregulated and unreported (A4A, 2018). Further, Pat Mirenda, an expert in special education at University of British Columbia, echoes Tom in his identification that these rooms do anything but calm, mentioning the irony of them being referred to as calming rooms (Mirenda in Clibbon, Oct 12, 2015). Tom, introspectively identified that these rooms may have caused him long-lasting harm,

Who knows, maybe it did leave scars in me. About how I, feel towards emotions, like, like I always have to believe that I'm never allowed to feel angry even though anger is a very natural part of your life.

As part of the Ontario Autism Advisory Panel Report (2019) one of the recommendations to the Ministry of Education is to create an education advisory committee who can "phase out the practice of using seclusion rooms." (p. 35) Rudy also shared her own thoughts about the use of restraint in classroom environments as a starting place for recommending improvements to Ontario's education program,

Cases of having students who might be runners being pinioned down in front of their peers and then ending up in jail, and the parent needs to be called out of work because of what's happened. I mean, that, that's not OK. I know that right now in Ontario the education services are strapped as it is, but it should not have to come to that, it really shouldn't.

Autistic students may have a different trajectory than their non-autistic peers.

James reflected how important he thought that autistic students' educational path should be accommodated based on their strengths,

I think it's definitely important for kids in high school... even if they are savants in particular areas, to take English, or math, or science, that are going to be used in

everyday life, regardless or not whether they are designated interest. However...let them have, choose more courses specifically designed for that area.

This being said, in reflecting on accommodations of memory aids, extra time on tests, and replacement courses, James also stressed the importance of autistic students learning to adapt to expectations of society, as “It is important that despite having those advantages going to high school to university, you need to learn how to work in the real world just as everybody else.”

Rudy identified that autism, among other disabilities, could be demystified in Ontario classrooms to decrease overall stigma and to address inclusion.

I think that something that does need to occur in order to increase overall societal empathy and awareness, and I think that this needs to occur earlier in schools... I mean start in elementary school by asking, ‘when you hear the word disability, what do you automatically think?’ And have it go from there, and maybe in high school have certain teaching sessions of certain disability stereotypes.

She believed that the introduction of conversation around disability acceptance has the capacity to “increase overall societal empathy, because you will have students who are at least somewhat aware.” While the Ministry of Education (2017) states it is guided by a purpose to support delivery of programs and services to all children, it is clear that there are improvements that can be made to the education system in Ontario to better support autistic children. By seeking out autistic experiences and feedback, perhaps schools can better support autistic children in the future.

### **Provincial Funding**

Participants shared their own experiences with funding of supports and services, identified their perceptions on how policy is created and how funding works. They also pointed out areas of concern and areas of improvement in the current funding of autism

services and support. Philip shared his experiences with a budget-type system in British Columbia, which seems similar to the Childhood Budgets program. “I think we got about \$500 a month or \$1,000 a month for autism funding. So that’s to be spent on counselling and things like that...” Philip expressed irritation with the system’s inability to roll-over funds to the next fiscal year, which is also a distinguished part of the Childhood Budgets program,

It was put into a special fund, so it would be like two bank accounts... Even though the money adds up and even after months on months you have a few thousand dollars, if I don’t use all the funding it goes back to the government. Which for me, coming out here it’s \$20,000 for university per year, so I could go use that money...

Philip continued, saying, “it would be very beneficial... for the money to be saved up and to be used on that person for beneficial reasons... such as post-secondary education or just continual services in their life.”

Tom expressed that he felt “like the funding could be better done.” Referring to ODSP, Tom expressed gratitude for some of the supports he got from ODSP but also identified that is hard to make ODSP funding go very far, “they’re doing good, they’re doing good for like, if you have the ODSP you get discounts on the OCTranspo Monthly Pass, that’s how I’m able to afford it...” Tom continued,

...They give you like, a good chunk of money to pay for rent and just a little bit of spending money for your own volition... Here is the big problem with like ODSP. It’s being used in a society where the housing market is steadily on the climb and going through the roof, and ODSP is not rising to meet that... If the ODSP doesn’t rise to meet those things, and you don’t have a job, you could very well end up having to scrounge, scrimp, and salvage your money any way you can.

Tom’s concerns reflect research findings on this topic that of Tiessen (2016), for example, who identifies that “as it stands today, total benefit income for those who qualify for OW and ODSP is locking nearly 895,000 Ontarians into deep poverty.” (p.

10) Similarly, Withers (2012) claims that ODSP is in line with poverty rates. Tom's description is similar to Withers (2012), who says "a basic ODSP cheque amounts to roughly \$100 more than the average rent of a one-bedroom apartment in Toronto." (Withers, 2012, p. 2, in Blower, 2016) Further, Withers (2012) notes that there are difficulties in attaining ODSP, with approximately half of all those who apply being initially denied (Withers, 2012, in Blower, 2016).

Affordability was also a topic of discussion when speaking about the provision of supports and services. Rudy identified how difficult it can be to afford ABA-based services when there is a lack of provincial funding,

Families who are already so hard put in order to make ends meet for themselves, and for their families, and ABA/IBI especially, if it is privately run, where there is not necessarily regulations as to how much the cost is, it per year is tens of thousands of dollars. That, that is a chunk of change, right there, which is hard put, which is very hard for the average Canadian family.

Evidence-based behavioural services in Ontario which are purchased through the OAP under the 2018 direct-funding option covers a maximum of \$55 per hour (Ministry of Children and Youth Services, 2018). The Children's Hospital of Eastern Ontario (CHEO), a major children's and pediatric hospital in Ottawa lists prices for services which are eligible for funding under the Childhood Budgets program starting January 2020. Prices range for weekly programming from \$1,824 per week to \$456 per week depending on hours spent in programming. Individual intervention for one to two hours weekly across 12 weeks costs \$1,680 for 20 hours or \$3,360 for 40 hours. Groups, two hours per week for 11 weeks, cost \$850 (CHEO, n.d.) The cost of ABA was a large concern reflected by parents and caregivers in the cursory content analysis of *The Ottawa Citizen* (Chapter 3).

James stated that he was unsure of whether the CBT he received was covered privately through insurance or through government funding, CBT, Cognitive Behaviour Therapy is a short-term therapy that focuses on cognition and behaviour change through changing core beliefs, maladaptive thoughts, and maladaptive behaviours. While CBT has some support for use with autistic children (Wood, Drahota, Sze, Har, Chui & Langer, 2009), it is more commonly used in teenagers and adults (Gaus, 2007; Gaus, 2011; Laugeson & Park, 2014; Spain, Sin, Chalder, Murphy, & Happé, 2015; Spain, Blainey, & Vaillancourts, 2017; Wood, Ehrenreich-May, Alessandri, Fujii, Renno, Laugeson, Piacentini, De Nadia, Arnold, Lewin, Murphy, & Storch, 2015). The current guidelines for the Childhood Budgets program indicate that CBT is not an approved service, rather ABA/IBI is the only evidence-based behaviour service covered (Ministry of Children, Community and Social Services, 2019h). James' indication that CBT was integral for his success compliments the recommendation from the Ontario Autism Panel Report that indicates CBT should be provided for families of children registered under the OAP. Whether CBT will be included in the April 2021 program is uncertain. This uncertainty was also found in the fact that participants did not think that autistic persons' opinions were on the agenda of the Ontario government in developing programs and policies

Tom and Philip identified that autistic people were not being consulted when policies were being created. Tom stated, "they need opinions from autistic people. Even if they don't really have any kind of ideas of what they want. Ask them what they need and they'll say what they need." Philip also identified that there is more of a focus on people who 'deal' with autistic people when creating policies, "I think that one thing that

they're doing is they're taking more the opinions of people who deal with autistic people, so they're taking the counsellors, of the parents, instead of the actual autistic people."

Participants did not think that autistic people should be the only people defining autism policies, as Tom believed, "at least have autistic children, to understand the struggles... because having an autistic children [sic] means you kind of understand how it is going on, how the children acts, how the children reacts [sic]."

Philip also stated, "I think they should be like half and half... you need another perspective of someone who's not autistic... for balance if that makes sense... like both points of view." Rudy, in direct reference to the recent protests in Ottawa surrounding the changes to the OAP, stated, "I do think there needs to be more inclusion with persons diagnosed with autism on serious issues such as this..." Rudy continued,

...I think the advisory panel is the most that has been done by the Ontario government in years for including persons diagnosed with autism in actually making policies come about... I think that the ASD advisory panel is actually filled with persons actually diagnosed on the autism spectrum themselves, which is a good thing.

Participants also connected autism funding to the state of the economy. Believing that provincial funding is just, they also recognized, as James put it, "there are a lot of social services that we can't continue to afford as a province." James stated,

I think that the amount that we have right now, well, pre-Doug Ford, right before Kathleen Wynne left, I think that we had a proper amount right then and there. I'm kind of confused about the cutting to autism services by Doug Ford. I get that he wants to reduce the debt in Ontario, because the debt in Ontario is absurd, we have a ridiculous amount of debt.

Tom also referred to Doug Ford when identifying cuts in autism funding and supports,

I can't really get into the mind of Doug Ford... he's prioritizing other things, and then when told that, autistic funding is gone away [sic], he's like, we really don't

need that right now, let's cut funding for that and see how that works. Again, like, without consulting the people who benefit from it, or even the people who need that to survive.

Rudy, though, identified that the Canadian economy validates the need for autism services and supports,

Given currently Canada's economy... I think that families being put in a position to be able to pay for services without doing some serious considerations such as taking out a loan or mortgaging their home, I think that [being able to pay for services] is all but possible right now.

Philip supported this. He identified that stigmatization of autism increases if families are required to fund their own services and supports,

The government should cover them. Just because it's an extra cost. I think a family shouldn't have to pay for having an autistic child because that can sometimes make it look like the autistic child's a burden. So I think the government should pay...

I don't know, even though you can afford it, even if you're a millionaire or billionaire, um, I still think it would be kind of like a burden. Like it can be viewed [as a burden] to some parents, like this is a downside of having an autistic child.

James' opinion clashed with Rudy and Philip. While Rudy identified that services should be covered due to the unaffordability of services, and Philip identified that needing to pay for services may increase stigmatization, James took the perspective that paying for services may incentivise service provider quality and meaningful service use by clients. When asked if people can afford to pay for services, should they pay for them themselves? James answered,

Well now listen, they absolutely should have to pay for it themselves. If they can. It's not on the government to pay for things that can already [be] paid for by that person... I also think that gives me more of an incentive to use those services.

Tom took a more pragmatic view, saying “in an idealized world the government should be paying for that. So I would have to say, half-and-half... you put in half, the government puts in half, and then it’s like basically so your supported by both sides.”

Rudy believed that the new OAP should be “doing it based by needs,” similar to the calls by parent and service provider advocates found in the cursory content analysis of *The Ottawa Citizen* (Chapter 3) and to the Ontario Autism Advisory Panel Report (2019)’s recommendations. It is not transparent how needs would be determined.

James identified that he would like to see “an OSAP type of system where the service is specifically provided to those who need it and cannot afford it.” James’ idea is consistent with a neoliberal ideal. Lightman & Lightman (2017) identify that in a neoliberal society, services are constructed narrowly, are minimalistic, assistance is offered in cash, services may be coercive, and that the goal intervention maximizes individual autonomy (Lightman & Lightman, 2017). Consistent with neoliberalism and the aim to downregulate, James also displayed fear in having the government in charge of all service provision. He warned,

Government funded doesn’t always mean better. And as bad as I feel for people who can’t get there, you gotta be really careful with these kinds of things, because the more people who have it, the lower quality it usually is.

The participants displayed understanding when discussing autism funding. While there were a variety of opinions about how supports and services should be funded, based on personal experience and ideology, having autistic perspectives included in developing funding strategies could increase access to supports and services and success of funding policies for autism.

## Conclusion

A strength of interview methods in social work practice include the fact that they can gather a deeper understanding of social issues. Each participant can be situated contextually, and this provides a greater understanding of the complexity of issues. In my interviews with four autistic adults, each participant self-located differently, and this self-location, along with their lived experiences, influenced their opinions about supports, services, policies, and funding. Further, the positionality of the participant influenced their contributions to a body of knowledge which aims to identify how autistic people can be better supported in Ontario. By acknowledging that autistic people are the true experts of autism during interviews, space was created to collect opinions that have the potential to influence future policy development. Participants indicated the importance of their autistic identity in forming opinions about policies and funding, often referring to diagnosis, the idea of the 'spectrum,' and prevalence rates. In discussing important supports and services in their opinion, they indicated preference for services that were enjoyable and individualized, that there is a lack in adult services and funding, and argued that ABA is not the only option for individuals and families looking for autism supports and services. In reference to supports and services, many participants recalled the role of medicine through seeing physicians and having been prescribed medications. They indicated that in childhood this may have been neutral or not helpful, but that at older ages medication had more positive impacts on their lives. Additionally, while recalling supports and services, participants spoke about the responsibility of schools and the school system in identifying autism in children, providing adequate support, fostering inclusion, and educating other students about disability to lower

stigma and bullying. How services were to be funded was not consistent amongst participants. Overall, many participants felt frustrated that autism support was inadequate and did not meet the needs of autistic persons, and that autistic people and their families should be involved in creating policies surrounding autism funding. In the next chapter the themes will be discussed further, attempting to tell a research story.

## **Chapter 5: Discussion and Conclusion**

### **Introduction**

Writing a Master of Social Work thesis provided me an opportunity to explore how I could become involved in promoting autistic self-determination during a time of autism policy change. Research interviews with autistic adults demonstrated that better services, policies, and funding could be created through actively involving and engaging autistic adults in policy and service creation.

Structural Social Work and Critical Autism Studies provided me an avenue to describe autism broader than a personal problem. This is in line with an anti-oppressive perspective of disability, which recognizes that “broader structures of society restrict, confine, and oppress” people with impairments (Carter, Hanes, & MacDonald, 2016, p. 157). By becoming an ally, an integral role of a Structural Social Worker and in line with Critical Autism Studies, I sought to use this research to center autistic persons as

experts in autism, working with autistic persons to fight the broader structures that define autism as a personal tragedy, “re-storying” autism (Douglas et al., 2019, p. 2) as a social construct and a normative difference (Carter, Hanes, & MacDonald, 2016; Moreau & Leonard, 1989; Woods et al., 2018). In line with Grounded Theory methodology, which seeks to develop a micro-theory based on interviews, and Participatory Action Research methods, a research method which seeks to raise collective consciousness and instigate social change, I interviewed four self-identified autistic adults in Ottawa, Ontario in 2019. I looked to answer the question: what are the opinions of autistic adults in Ottawa about autism funding, services, and related policies in Ontario?

The research question stemmed from my own personal experiences working in the Ontario Autism Program (OAP) and in conversations surrounding changes to the OAP with others. I began research with a cursory review of *The Ottawa Citizen*. This cursory review overviewed parent advocacy after changes to the OAP, and did not center the perspectives of autistic persons. The parent advocacy covered during the time of the research resulted in the demotion of a Minister, the development of provincially-initiated community consultations, an advisory committee developing a report, and a commitment to create a new program by April 2021. During interviews with autistic adults, themes included identifying autism, supports and services, the role of medicine, the education system, and provincial funding. I aimed to use an inclusive methodology and methods in order to demonstrate that autistic persons can be included in policy discussions. Incorporating autistic persons perspectives can create for more holistic autism policy discussions.

## Discussion of Themes

In order to understand the opinions of autistic adults in Ottawa with respect to autism funding, services, and related policies in Ontario, it was necessary to analyze dissect how autistic adult participants defined autism, their experiences with services, and supports through education and medicine, and what their opinions were surrounding funding and policy creation.

During this research I learned the importance of my own social location as a non-autistic scholar. This is stressed in the fact that participants needed to identify autism and how it fit into their life during the interviews. In line with Critical Autism Studies I knew that my lack of autistic identity may have created barriers in understanding autism (Milton, 2014a). This may have allowed, though, for participants to define their autism in more depth.

While my inclusion criteria were inclusive of those who may not have been formally diagnosed, all participants recalled diagnosis during interviews. The participants shared the impact of their diagnoses on how they chose to identify with autism. Rudy expressed that it was due to accuracy that she preferred to use the term “Asperger’s Syndrome” and Tom preferred to use the term “borderline autistic.” Many participants expressed the importance of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) labels and the spectrum in creating an identity surrounding autism. These assigned labels were insufficient in creating identity, though. Rudy preferred to self-identify as an “Aspergirl,” and James explained that, while autism is not a bad thing, he is proud when people cannot guess that he is autistic. Philip also

brought up the fact that stigma surrounds an autistic identity. He commented that many people do not want to disclose their autism.

Identification of autism, in relation to the self, played an important role in forming opinions about autism funding and services in Ontario. During interviews participants identified the need for autism awareness due to high prevalence rates. In discussion around autism services and policy, participants argued that autism is highly prevalent and gave estimates on how many people are autistic. The prevalence rates were a starting point for advocating that autistic persons must be included in policy development, and in arguing the importance of services and supports. Prevalence rates also allowed participants to advocate for increased awareness of autism, in order to, as Tom said, “demystify” and “de-monstrify” autism. This conceptualization of autism as a normative human difference echoes Critical Autism Studies research that aims to “re-story” autism as “relational, generative, and desirable” in humanity (Douglas et al., 2019, p. 14).

Defining autism for oneself played a significant role in influencing each interview with the participant. Understanding how each participant perceived autism informed the themes of supports and services, the support they received through the medical and educational systems, and their opinions of provincial funding and policies. The interviews did not, however, produce enough information to understand what may have influenced a participant’s definition of autism. This theme makes it apparent that there are a multiplicity of opinions surrounding how autistic people may identify, recognizing that autism may or may not play a central role in an autistic person’s life. Therefore, I conclude that autistic persons must have the ability to self-determine their identity,

especially when contributing to important discussions surrounding supports and services.

Often autistic persons do not have the privilege to self-determine the supports and services they interact with, due to age, availability, finances available, or geographic location, among other reasons. My past experiences working in Applied Behaviour Analysis (ABA) and preparing for research, including reviewing articles pertaining to the OAP in *The Ottawa Citizen* (Chapter 3), led me to assume that many of the participants would have had direct experience in ABA services and supports.

The OAP promotes and funds ABA for children. ABA focus on behavioural change through modifying environments, giving contingent reinforcement, and sometimes includes mild forms of punishment. In my experience providing Intensive Behaviour Intervention (IBI: the intensive application of ABA) under the OAP, I recall that we would promote behaviour changes including teaching social skills, like requesting, and life skills, like toileting. With these added behaviours, there are also target behaviours to reduce, such as ‘meltdowns’ or ‘accidents’ caused by the inability to communicate these needs.

My assumption that many participants would have had experience in ABA-based services were incorrect. In fact, only one participant recalled direct experience in ABA/IBI. Other participants may have had experiences in ABA, but did not specifically name or have knowledge of ABA. Supports and services that were not ABA were understood as useful to participants. Rudy spoke of her experiences in ABA as one of many services she and her sister had enjoyed, including speech therapy, sensory-integration therapy, Montessori-based therapy, and wearing a weighted vest as all

valued services and supports. She was appreciative of a combination of services and supports, saying that they accumulated to have positive impacts on her life. Tom had participated in many short-term studies and therapies as a child. Both Rudy and Tom expressed that their memories of these services were positive, as they revolved around play and activities. James positively reviewed Cognitive Behaviour Therapy (CBT) services as a teenager, saying “I owe a lot... to CBT and highly recommend it.” James’ identification of CBT as an appreciated method is in line with the Ontario Autism Advisory Panel Report (2019), which recommends that CBT be included in a new needs-based program. Philip also expressed an appreciation for a weighted blanket as a teenager to alleviate his anxiety.

While there was discussion of useful supports and services, other supports were identified as non-preferred. Philip identified that he did not enjoy counselling, as it was often deficit-focused and concentrated on behaviour reduction strategies. Participants also expressed that there were areas for services and supports to be extended. In identifying areas for growth, participants spoke about a gap in service provision for adults in Ontario. Participants acknowledged that the needs of autistic adults and children could be better met through the provision of employment assistance services, organized social activities, and self-advocacy promotion. It appeared that the underfunded services of non-behavioural therapies, CBT, and adult-based therapies were all valued by participants, and would benefit from funding on the provincial level.

A form of support that was brought up in interviews focused on accessing services through provincial healthcare and taking prescription medication. Three out of four participants, all using the pronouns he/him, spoke about their relationship to the

medical system and to medication as an accessed support used by themselves and their families with respect to autism. The *Canada Health Act* (1984) provides reasonable access to health care for all Canadians and is funded through provincial and federal tax dollars (Government of Canada, n.d.) Through accessing provincial medical services, participants would have attained prescriptions. While prescription drugs are not covered under the *Canada Health Act* (1984), some people in Ontario get prescription medication covered through employment/private insurance plans. While medication is regarded as complementary to social services in supporting autism therapy (Ip et al., 2019), there are few medications which are specific for autism in itself (Accordino et al., 2016; Williamson & Martin, 2010).

Philip could not directly identify how medication impacted him, but he acknowledged others could recognize when he switched medications. While Philip appeared indifferent, Tom expressed, “you can’t really solve a problem by giving them medicine.” It appears that earlier in life, medication use may be associated with negative experiences. Both Tom and James identified that they were prescribed medications, usually used for ADHD (stimulants), and that these medications had negative impacts on them as children. The negative experiences may have derived because prescribing medication for behaviours associated with autism frames autism as a biomedical problem that can be fixed or altered by medication. This has the potential to oppress, as it fails to recognize autism as presenting neutral or positive differences (McGuire, 2011a). At the same time, medication was expressed as a tool of empowering a person to live their best life. James identified that ADHD medication was appropriate as a young adult in negating the weight gain side-effect of taking Abilify (aripiprazole), an

atypical antipsychotic drug. Tom also spoke positively about using the antidepressant Cipralex (escitalopram) and the PRN ('as needed') use of the benzodiazepine Lorazepam (common name: Ativan) as an adult.

The lack of adequate funding, services, and supports for autism in Ontario may increase a person's drive to try medications in order to cope with some of the behaviours associated with autism, rather than understanding the function of those behaviours. ABA explores the relationship between the antecedents, behaviours, and consequences of behaviour in order to better understand why maladaptive behaviours are occurring. These behaviours are then changed through offering alternative behaviours that meet similar functions (Cooper et al., 2014). A biomedical resolution for maladaptive behaviours comes from the belief that there is a chemical imbalance in the brain which can be fixed through medication, and thus we can change the maladaptive behaviour without understanding the function (Lacasse & Leo, 2015). The relative ease of access to prescription medication in comparison to attaining other supports for autism in Canada may have influenced the reason that medication was commonly sought out by participants and their families as a support for autism. So, while medication was valuable and not valuable at times, it seems that participants indicated an acknowledgement that autism service, support, policy, and funding should acknowledge the use of medicine.

Participants also understood that supports and services were offered through educational institutions that they had interacted with. In the school environment, autistic children may face barriers in accessing appropriate supports and services. Tom indicated that there were barriers to inclusion, speaking about segregation in the school

environment. James indicated that his school was inadequately prepared to identify autism. Barriers led participants to mistrust their schools. Philip, reflecting on the inability to provide supportive education, said, “it kind of felt like they wanted the papers (proof of diagnosis) to get money for the school, but they didn’t really care about helping me.”

Tom, in describing his experiences in the “calming room,” expressed a call for the use of seclusion rooms to end. This experience is echoed by the Ontario Autism Advisory Panel Report (2019) and Autistics 4 Autistics (A4A, 2018). Tom indicated that seclusion rooms may have had long-lasting consequences, and suggested that PRN (‘as needed’) medication could be an alternative to use of seclusion rooms.

While participants appreciated supports and services offered through the education system, such as accommodations, James stated that autistic people need to “learn how to work in the real world just as everybody else.” Like other students, autistic students are, as Philip acknowledged, “kinda normal.” In balancing adequate and non-stigmatizing education for autistic children, Rudy expressed that a support for autism should be offered to all children. This support would implement more conversations around disability acceptance. As a result, long term “societal empathy” would increase and ableism would diminish. Therefore a more global identification of autism policy and funding would incorporate a systems level change, not only providing educational opportunities for autistic students, but also their peers and in educating those who interacting with autistic students.

Autistic children often receive supports and services outside of the medical and education system. The supports and services that an autistic person receives may be

limited due to financial constraints. Participants reflected inadequacies of provincial funding due to the economy. Three of four participants spoke directly about the OAP funding cuts, identifying that the changes were misguided. Provincial funding currently offers short-term resolutions, offering time-limited therapy to some families enrolled in the OAP, and to others a cash-benefit for accessing services themselves. Living in a neoliberal and capitalist society, we witness the under-funding of provincial supports and services for autistic persons. These services are seen as an individual and family concern. This was highlighted by the participants' descriptions of the many shortcomings of funding that placed the cost of autism on individuals and families as an unfair disadvantage. At the same time, participants were apologetic of the needs of autistic persons, expressing that they could see autism funding as economically difficult to sustain by the province.

Participants had different thoughts about how autism services and supports should be funded. Moreover, participants were all aware of the current economy and how it impacts the state of autism funding. In speaking about the economy, Rudy identified that being able to pay for services and supports often requires families to make "serious considerations such as taking out a loan or mortgaging their home." She thought that services should be needs-based. This concern for affordability mirrors a concern found in the 'Personal Stories' theme during the review of *The Ottawa Citizen* (Chapter 3). The needs of children can outweigh the resources available. In advocating for full provincial funding, Philip advised that requiring families to pay for autism services has the potential to increase the stigma of autism. On the other hand, James identified that if families can pay for services, they should, as paying for oneself may incentivize a

person to use the services and for the services to be better offered. He spoke about an “OSAP”-type program, which is means tested. Tom was on neither extreme, and identified that services should be partially covered by the government, and partially self-funded.

Participants agreed that policies surrounding autism funding should be inclusive of autistic voices and their parents. Stigma and fear are barriers that prohibit autistic people from becoming advocates. Stigma and fear do not appear to be barriers for parents and caregivers in the review of *The Ottawa Citizen* (Chapter 3). Many parents did not hesitate to recount their stories, collectively organize, and investigate the motivations behind changes in the OAP. Participants all agreed that autistic people should be considered and consulted when creating policies surrounding autism. It is therefore evident that institutional change must be inclusive of a diversity of voices, centering autistic people as experts.

Current theories surrounding autism services and policies were not regarded as inclusive by participants. Further, in the cursory content analysis of *The Ottawa Citizen*, it was evident that autistic perspectives were not centered. The micro-theory developed through this research is that autistic persons’ opinions are central in developing autism policies and funding, which shape the services and support they can receive during their lifetime, and thus autistic adults should be consulted during times of change.

### **Implications for Future Research**

As my internet search history constantly contains the term ‘autism,’ ads, news, and media targeted towards me, especially through Google and other customized feeds, often update me on recent research. I still find myself shocked when seeing

biomedical research being reported, such as “Media Advisory: National Institute of Health (NIH) funded study suggests acetaminophen exposure in pregnancy linked to higher risk of ADHD, autism.” (2019, n.p.) (Ji, Azuine, Zhang, Hou, Hong, Wang, Riley, Pearson, Zuckerman & Wang, 2019) I think to myself, ‘what the heck are they doing at the Johns Hopkins Bloomberg School of Public Health?’ People have been seeking a cause of autism for many years, from parental blame to Measles Mumps and Rubella (MMR) vaccines (Douglas, 2014; Rao, 2011). A critical perspective of disability, framed by Critical Autism Studies, dismisses the search for a cause, and accepts autism as a normative difference, as Tom said, without autism “things wouldn’t chug as easily.” Future research ‘on autism’ therefore should be for autistic people, with autistic people, not seeking cause, but seeking a society which creates equity for autistic persons.

This research demonstrated that some autistic people will share their opinions about autism funding in Ontario if asked. Understanding this, future services, supports, policies, and funding surrounding autism must attempt to ask autistic adults to contribute their knowledge. Future research on specific autism services should similarly attempt to engage with past service-users in order to best understand how the service can improve. Why certain people go undiagnosed, misdiagnosed, or have delayed diagnoses must be investigated to improve diagnoses of all autistic people. For example, what socioeconomic factors play into misdiagnosis? How can practitioners be better informed of the various ways that autism presents?

The role of the medical field should be better investigated. Can medical practitioners work towards destigmatizing autism? Further, medication can be deconstructed seeking to understand the off-label use of prescription medications in

autistic people, if it is with or without concurrent therapies, if they are prescribed mainly because of comorbid diagnoses or for autism alone. The general success of these specific medications also must be reported. These investigations should make public the positive and negative impacts of medications in the opinions of autistic individuals and their families, rather than the prescribing or observing expert.

In education, future research can examine 'best practices' of special education based on past experiences of educators. Is segregation ever appreciated by individuals in segregated special education classrooms? Have inclusionary efforts in schools proven successful for disabled children? Trials can be conducted to identify new educational methods to improve education for all students, creating structured teaching sessions to normalize and destigmatize disability, as Rudy identified, to "increase overall societal empathy and awareness."

Finally, research should be conducted regarding iterative policy development. An iterative process to creating policy could be proactively inclusive, requiring community consultations, feedback, and ongoing cooperation with contextual and societal changes. I question whether proactive iterative, inclusive policy development strategies could prevent pushback to policies that are perceived as inadequate, much like the backlash seen with the release of the Childhood Budgets program. This research could determine whether transparency during policy development can prevent the negative consequences that result from dissatisfaction with policy changes.

## **Limitations**

It is important to recognize the limitations that this research had. Limitations began during with the recruitment of four subjects, which were restricted to convenience

sampling methods. Through choosing the initial participants by means of convenience, I acknowledge the risk that the interviewees may not be representative of the adult autistic population in Ottawa, let alone autistic persons elsewhere in the world (Lopez & Whitehead, 2013). Moreover, I recognize that the small sample size of four participants makes it difficult to make extensive assertions about the findings and how these findings relate to broader lived experiences of autistics. But, as indicated in this research, not all autistics' perspectives are consistent or homogeneous, and thus qualitative research being 'representative' was not a key concern. Limiting the research to Ottawa additionally leaves questions about the validity of this research outside of the national capital of Canada, as persons who are outside of Ottawa may not have the same identity factors which produced these study results.

Furthermore, research was limited in inclusivity and accessibility. Tozer, Atkin, & Wenham (2013) identify that research often overlooks adults with "severe learning disabilities" and "severe autism," because researchers and practitioners can lack both confidence and resources to engage with people with severe communication difficulties (p. 480). While I attempted to accommodate participants by offering over-the-phone and online options of data collection, autistic adults who participated were all able to speak and meet with me in person. I also want to recognize, although I did not collect this information formally outside of the collection of preferred pronouns, that all of the participants presented as white and cisgender. While the Autism Spectrum Disorder among Children and Youth in Canada (2018) reports that males are four times more likely to be diagnosed with autism than females (Ofner, et al., 2018), it is a limitation that only one person who identified with the pronouns she/her contributed to this research.

This made it impossible to make assertions about gender influencing perspectives, which withdrew my ability for feminist analysis. In retrospect, collecting some quantitative data about the participant in the form of a questionnaire about their identity would have improved results to better understand how identity factors and privilege impacted the participants answers.

During research, there were restrictions based on the protocol I had submitted to the Research Ethics Board about how I could carry out research. This posed limits on how I could support my participants, some of whom, I felt, may have needed more contact from me in the future than I could provide. As a student in social work, this was difficult, and in my future research I hope to make research more community-based and participatory, asking my participants to be co-researchers.

There were restrictions on my time, energy, money, and capacity which limited the number of participants who were interviewed and my ability to prepare for the research. I recognize that this is a limitation and also identify that this is a broader structural issue within institutions and Carleton's School of Social Work, which, at times left me feeling unprepared to carry out the research that I had proposed. The demands of a full course load, while conducting research, while holding three jobs, without having peers who were on the same 'thesis' pathway as me, coupled by my own competitive drive, in some instances left me feeling mentally unwell. I am very grateful to my supervisors who supported me through this process, to faculty and staff who never doubted me, to my family who set a great an example, and to my community at Carleton Athletics who gave me a social outlet for stress.

As this research was participatory and I am involved in a community affected by autism funding, it is impossible for research to be impartial or divided from emotion and bias. Recognizing this bias allows this research to be used for advocacy, rather than to simply stating facts. The research presented in this thesis was only bits and pieces of information gathered from interviews with participants which I thought were relevant to the topic. I thus only presented imperative information for advocacy purposes. This identifies a limitation in presenting a complete view of the participants' histories and opinions. Finally, the information shared is incomplete as I am not autistic, and have only shared the information that participants were willing and able to share with me. I also want to recognize that my own social location as a non-autistic person, a student, as a white, cisgender woman, may have changed the interview dynamic and the interview results. Therefore, it seems that it is impossible to present a full picture of what 'autistics' think about autism funding in Ontario.

## **Conclusions**

What are autistics' perspectives of autism services, policies, and funding in Ontario? They are diverse, as diverse as the spectrum with which autism is associated. The research question asked the opinions of autistic adults about funding and policies for autism services. This research question was addressed briefly by participants sharing their personal experiences of services, education, and medication; overviewing their perspectives of valued services and supports, and sharing how funding and policy creation should be carried out.

In chapter one, I shared my experiences working in the field of autism and conversations that constituted the development of the research question. I believed that

through engaging with autistic adults in interviews, I could make up for my lack autistic identity, and somehow form my own opinion about the Ontario Autism Program (OAP). Further the research question developed in an attempt to promote inclusive policy development while painting a more complete picture of what services and supports are needed by autistic persons in Ontario.

Next, I reviewed literature (chapter two) which helped inform me prior to conducting one-to-one interviews with participants. This literature scoped from asking how literature defines autism, determining what supports and services are available for autistic persons in Ontario, parent and caregiver roles in policy development, and an overview of the OAP and the Childhood Budget's program. I also reviewed five major studies influencing my methodology and methods. Chapter three delves more into my methodology and methods, beginning with an overview of a cursory content analysis of *The Ottawa Citizen's* coverage of the changes in the OAP between February 1 and March 13, 2019 with subsequent updates. Next, I overviewed how my inductive interview methodology was appropriate to inform me of autistics' perspectives of autism funding in Ontario.

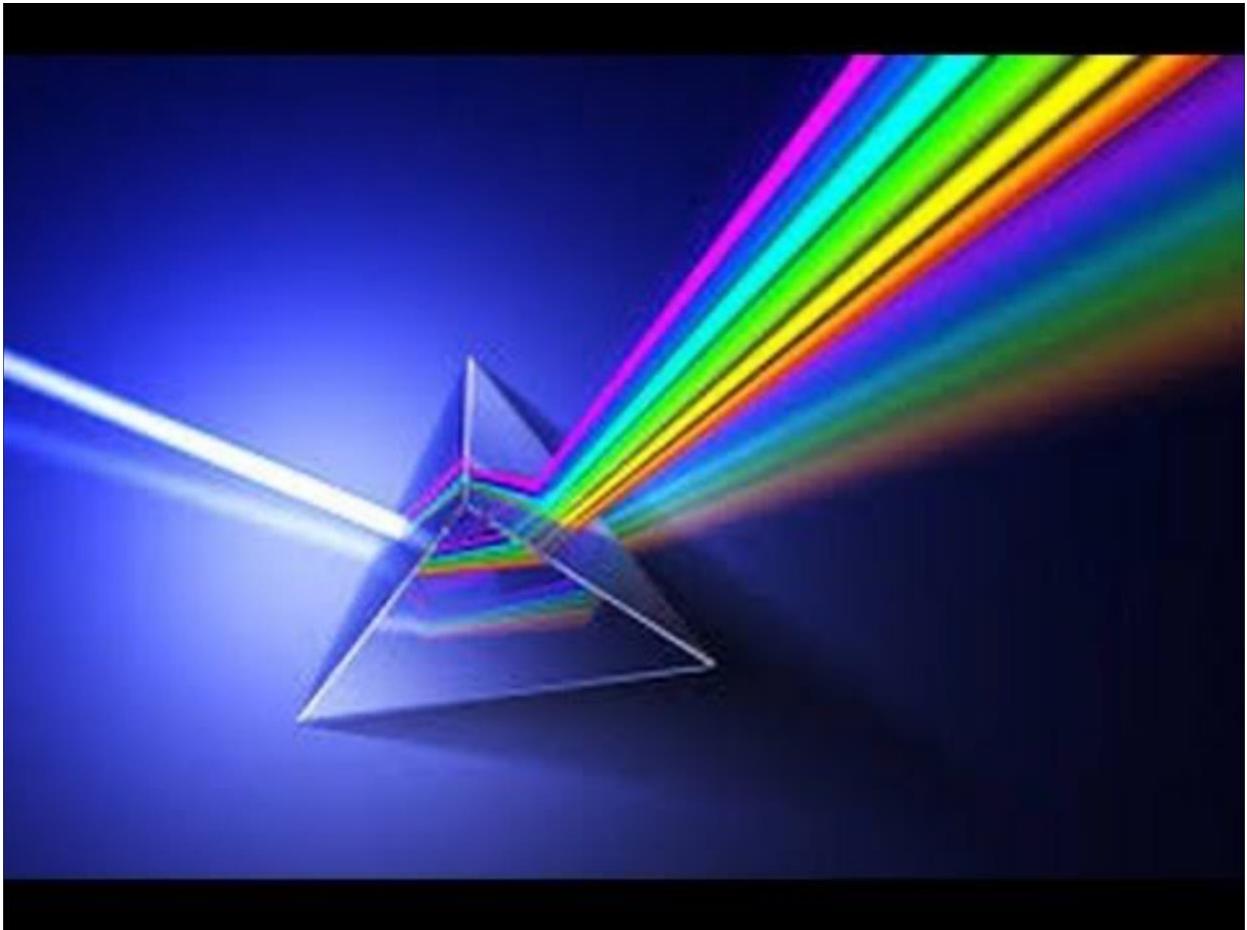
In aspiring to be Participatory Action Research and Grounded Theory research, I interviewed four autistic adults. These participants graciously shared their experiences with autism services and funding, and identified what changes they would like to see. In chapter four, I overview these themes. It became apparent that participants' opinions of autism funding depended on identifying their autistic self-location. Using their experiences with services and supports, medication, and the education system, they identified where things had gone right and wrong, and how a variety of services can be

improved for a future generation. Finally, the participants identified a variety of constructive ways in which autism services could be funded, ranging from needs-based funding, to partial-funding options, to individuals paying for services if they can. Restrictions on funding, such as age and services covered were also challenged by participants.

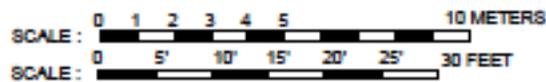
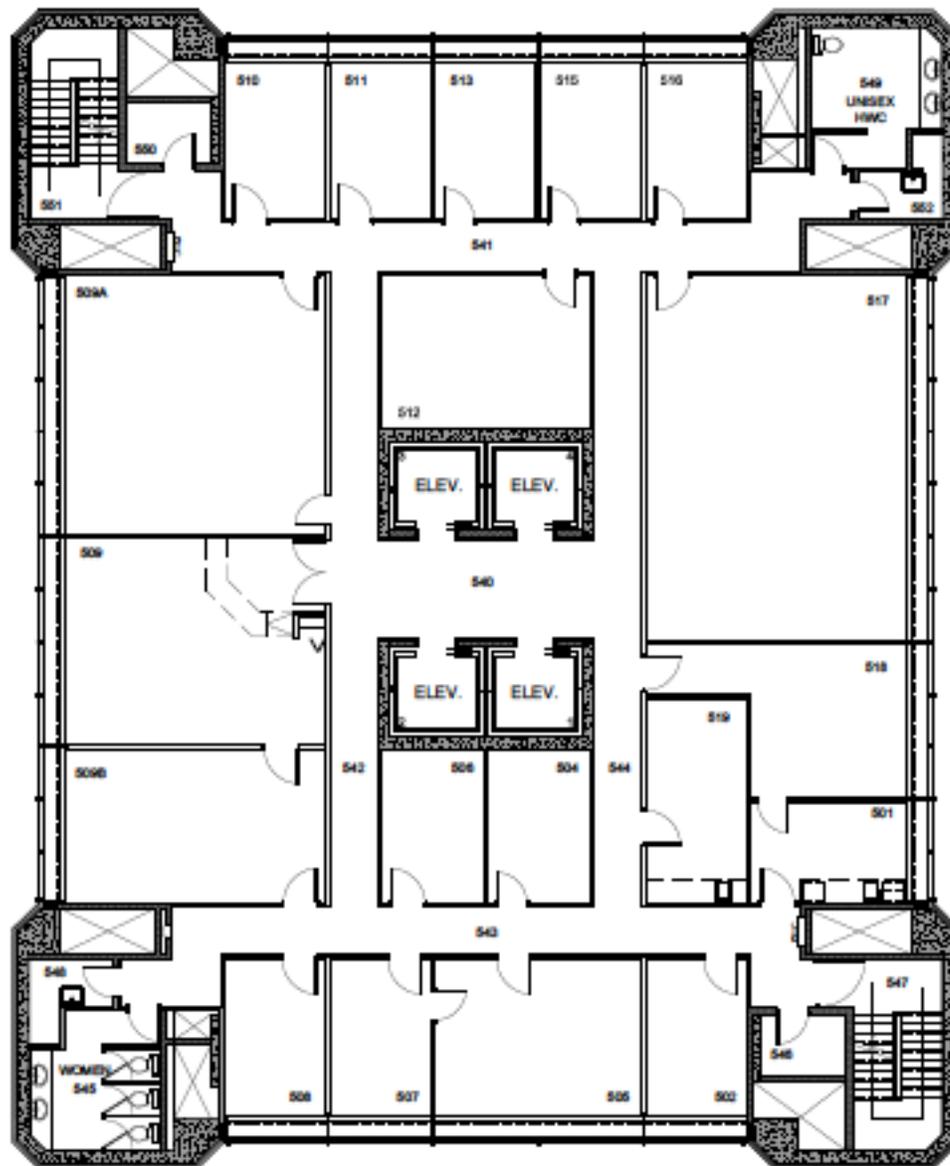
Chapter five concludes this research, attempting to tell the research story. In this chapter, I acknowledge were limits to this research, and that there are many further questions which can be explored in the future. As a starting point for advocacy, this research informs my future work with the Ottawa Adult Autism Initiative, which aims to ensure better supports and services for autistic adults by centering the voices of autistic adults. Current and future services and supports for autistic children and adults must reflect the expressed wants and needs of autistic people, looking at past intervention experiences and how autistic people identify that they can improve.

## List of Illustrations

### 'Illustration' 1



'Illustration' 2



**DUNTON TOWER**

**LEVEL 5**

FEBRUARY 14, 2011  
FILE: 21(DT)-LV05.dwg



# Appendices

## Figure 1



Office of Research Ethics  
503 Robertson Hall | 1125 Colonel By Drive  
Ottawa, Ontario K1S 5B6  
613-520-2500 Ext. 2517  
[ethics@carleton.ca](mailto:ethics@carleton.ca)

### CERTIFICATION OF INSTITUTIONAL ETHICS CLEARANCE

The Carleton University Research Ethics Board-A (CUREB-A) has granted ethics clearance for the research project described below and research may now proceed. CUREB-A is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2).

Ethics Protocol Clearance ID: Project # 111389

**Project Team Members:** Margaret James Van Rensburg (Primary Investigator)  
Roy Richard Hanes (ACVS Staff)  
Dr. Miranda Brady (Research Supervisor)

**Project Title:** Autistics' Perspectives of Autism Funding in Ontario

**Funding Source** (If applicable):

Effective: **September 06, 2019**

Expires: **September 30, 2020.**

**Please ensure the study clearance number is prominently placed in all recruitment and consent materials: CUREB-A Clearance # 111389.**

### Restrictions.

This certification is subject to the following conditions:

1. Clearance is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to CUREB-A via a Change to Protocol Form. All changes must be cleared prior to the continuance of the research.
3. An Annual Status Report for the renewal of ethics clearance must be submitted and cleared by the renewal date listed above. Failure to submit the Annual Status Report will result in the closure of the file. If funding is associated, funds will be frozen.
4. A closure request must be sent to CUREB-A when the research is complete or terminated.
5. During the course of the study, if you encounter an adverse event, material incidental finding, protocol deviation or other unanticipated problem, you must complete and submit a Report of Adverse Events and Unanticipated Problems Form, found here: <https://carleton.ca/researchethics/forms-and-templates/>

Failure to conduct the research in accordance with the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2nd edition* and the *Carleton University Policies and*

*Procedures for the Ethical Conduct of Research* may result in the suspension or termination of the research project.

Upon reasonable request, it is the policy of CUREB, for cleared protocols, to release the name of the PI, the title of the project, and the date of clearance and any renewal(s).

Please contact the Research Compliance Coordinators, at [ethics@carleton.ca](mailto:ethics@carleton.ca), if you have any questions.

CLEARED BY:

Date: **September 06, 2019**

Natasha Artemeva, PhD, Chair, CUREB-A

Janet Mantler, PhD, Vice-Chair, CUREB-A

Figure 2

### MSW THESIS PROPOSAL DEFENCE FORM

STUDENT: Margaret Janse van Rensburg Student # 100881603

EMAIL CONTACT: margaretjansevanrens@cmail.carleton.ca

THESIS SUPERVISOR: Roy Hanes

PROPOSED THESES TITLE: AUTISTIC PERSPECTIVES AND AUTISM FUNDING IN ONTARIO

PROPOSAL DATE: June 26, 2019

PROPOSAL APPROVED

Approved with Minor Revisions

Approved with Major Revisions  
(see attached)

NOT Approved

COMMENTS: Excellent, comprehensive proposal -  
Margaret will continue to work with her committee  
and incorporate the members' suggestions going forward with  
her thesis. Notes from committee members will be shared  
with her.

Signatures of Thesis Committee:

Miranda Brady

Miranda Brady, Committee Member

Roy Hanes

Roy Hanes, Thesis Supervisor

Hugh Shewell

Hugh Shewell, Chair of Defense

Please submit the completed form to the Graduate Administrator

---

### Figure 3

#### Initial Contact Email: Explanation of the Study

**Subject line:** What being a participant in my research means

Dear Participant Name,

My name is Margaret Janse van Rensburg from the School of Social Work at Carleton University under the supervision of Dr. Roy Hanes and Dr. Miranda Brady. Thank you for emailing me about participating in my thesis.

I am a non-autistic student who wants to address issues in Ontario's autism services model and who is looking to support autistic self-determination. I want to find out autistic peoples' opinions of autism services and funding in Ontario. This is because I believe that autistic people have valuable lived experiences that need to be used in media publications and policy development. My research is titled 'Autistics' Perspectives of Autism Funding in Ontario.'

I am looking to interview four to six adults located in the Ottawa region who self-identify as autistic (no diagnosis required) about their opinions about government funded autism services in Ontario and in particular the funding of ABA. The data collected in the interviews will be compared to news articles about autism funding to see whether perspectives are similar or dissimilar to those presented in news media.

**The next step to secure your participation is scheduling your first meeting with myself.**

- 1. What is your availability in the next week?**
- 2. What is your preferred method of contact for the first meeting? (in-person, over-the-phone, or online)**

What happens in the study?

The following things will take place in this study:

1. First Meeting
2. 90-minute interview
3. One-week follow-up
4. Additional follow-ups by email

In the first meeting I will give you the consent form, a list of available accommodations, and the interview questions that will be asked at the 90-minute interview. We will schedule your interview at this time. You can ask me questions about the study at this time. We can do this first meeting in-person at a Sunnyside Public Library or Carleton University in a booked room, over-the-phone using Zoom Phone, or online through WhatsApp Messenger.

Each interview will be up to 90-minutes. You choose if it takes place in-person, over-the-phone using Zoom Phone, or online through WhatsApp messenger. This interview will be audio-recorded or the conversations copied and pasted. Interviews are confidential and anonymous. If you choose for the interview to take place over-the-phone or online, I cannot guarantee data security using these methods.

I will follow-up with you one week after the interview to check-in. You will be asked if you would like to review your transcripts or audio files at this point, take away or add any information to the interview.

Additional follow-ups will take place over email. I will share results, follow-up about further publications or incidental findings, and offer to return your data.

## **What else should you know?**

### **1. Risks and benefits**

#### Risks

- Feeling like you have to participate
- Emotional or psychological discomfort
- Social exclusion

#### Benefits

- Participate in and influence policy
- Know your experiences and opinions are valuable
- Help society be more inclusive of autistic voices
- Advocate for autistic self-determination

### **2. Confidentiality**

The research project will allow you to choose a pseudonym (fake name) or assign you a pseudonym (fake name).

- I will only use you for your first name or to use a chosen pseudonym when signing the confidentiality agreement
- If you tell me your last name or contact information I will not share that with anyone, and will refrain from collecting that data
- You have the opportunity to take back any information that you think should not be included in the study
- To protect you, confidentiality will be respected by the researcher

I will break confidentiality if:

- You tell me that you are going to harm yourself
- You tell me that someone is going to be harmed
- You tell me about active harm happening to a child
- You tell me that there is active abuse between a third-party and yourself
- You tell me about ongoing abuse to autistic people
- In such instances, the researcher will contact their supervisors and/or appropriate relevant authorities (campus/regional police services, Children's Aid Society, other governing and regulatory bodies). You will be told if this is going to happen.

### **3. Support**

- You can bring a person to support you to the interview.
- You have the right to refuse any questions throughout the interview.
- Accommodations are available for you upon request.
- At the end of each interview there will be 15 minutes scheduled for debriefing
- You can have a third-party consent on your behalf, if you assent at the same time

### **4. Data collection and Storage**

Data collected about you will consist of the following:

- Copies of consent forms
- Interview recordings and/or transcripts for research purposes
- Informal notes regarding contact
- Your contact information

All information in this study will only be accessible to the researcher. All of the information that you give the researcher will be kept on an encrypted and password-protected USB key. There will be one encrypted and password-protected back-up USB of this data. These USBs will be kept in a locked drawer and the researcher will have the only key. This data will be returned to you if you would like after the study is complete. Data will be destroyed one-year after the study has completed. De-identified transcripts and a copy of your contact information will be kept for 5 years after the research study.

### **5. Compensation**

Compensation for this study include the following:

- \$40.00 honourarium for completing the interview
- Travel expenses
  - Up to \$7.00 for public transit
  - Up to \$10.00 for parking
  - Up to \$20.00 for taxi, Uber, or Lyft
- If mailing a consent form
  - Up to \$2.15

If you withdraw from the study after the interview has taken place, you will receive full compensation for your time.

Please contact me if you have any questions or concerns about being a participant.

**Margaret Janse van Rensburg**

[margaretjansevanrens@cmail.carleton.ca](mailto:margaretjansevanrens@cmail.carleton.ca)

If you have any ethical concerns with the study, please contact the Carleton University Research Ethics Board-A (by phone at 613-520-2600 ext. 2517 or via email at [ethics@carleton.ca](mailto:ethics@carleton.ca)). You may also contact the supervisors of this project Dr. Roy Hanes ([RoyHanes@cunet.carleton.ca](mailto:RoyHanes@cunet.carleton.ca)) and Dr. Miranda Brady ([Miranda.Brady@carleton.ca](mailto:Miranda.Brady@carleton.ca))

**Figure 4**

### **Interview Questions**

1. Much of Ontario's funding for autism services are rooted in Applied Behaviour Analysis (ABA), what are your thoughts about Applied Behaviour Analysis (ABA)?
2. What do you think about programs rooted in ABA for children? Do you have different thoughts about ABA programs for adults?
3. What do you think about government funding for autism services?
4. Are there differences between services that are currently funded and what autistic people desire?
  - a. What are your thoughts about services that are favoured by parents and service providers?
5. Do you think that the Ontario government should fund supports and services for autistic people?
  - a. If so, what kinds of supports and services should be funded?
  - b. Should autistic people or families who can afford it have to pay for these services themselves?
6. Do you think the government of Ontario is including the opinions of autistic people when making policies and services for autistic people?
  - a. Should there be greater inclusion of autistic persons and/or advocates in the development of policies and services?
  - b. In recent debates and media coverage regarding autism program funding, do you feel the perspective of autistic persons have been adequately included? If they were not adequately included, what are some proposed changes in media coverage you could suggest?
7. Is there anything else you want the public to know about the funding of provincial government programs for autistic people? Is there anything else you want the public to know about autism?
8. We are not wrapping up the interview. How are you feeling about the interview process? Is there anything else you would like to add at this time?

If you have any ethical concerns with the study, please contact the Carleton University Research Ethics Board-A (by phone at 613-520-2600 ext. 2517 or via email at [ethics@carleton.ca](mailto:ethics@carleton.ca)). You may also contact the supervisors of this project Dr. Roy Hanes ([RoyHanes@cunet.carleton.ca](mailto:RoyHanes@cunet.carleton.ca)) and Dr. Miranda Brady ([Miranda.Brady@carleton.ca](mailto:Miranda.Brady@carleton.ca))

## **Figure 5**

### **Research Consent Form Script for Oral Consent**

My name is Margaret Janse van Rensburg and I am a Master of Social Work Student in the School of Social Work at Carleton University. I am working under the supervision of Dr. Roy Hanes and Dr. Miranda Brady. My research study is called 'Autistics' Perspectives of Autism in Ontario.'

#### **Invitation:**

The reason I have invited you to participate is because you self-identify as autistic, you are over 18, you can correspond in English, you live in the Ottawa Region, and because you have opinions about autism funding in Ontario or applied behaviour analysis.

I want to make sure that you completely understand the consent form to decide whether you agree to participate in the study.

You have free choice to participate in this study and withdraw if you want within 2 months of completing the interview. Please ask as many questions and take whatever time you need to fully understand what I am asking of you in participation.

#### **What is the purpose of this study?**

I am a non-autistic scholar who is committed to autistic self-determination. I want to see whether autistics' have different opinions about autism funding in Ontario than the opinions in the media. I hope that this study will promote autistic leadership in media and policy development.

#### **What will you be asked to do?**

The study involves an interview exploring what you think should be funded by the Ontario government in terms of autism services. The interview will take about 90-minutes and will be wrapped up in the last 15-minutes with debriefing. The interview can take place in-person, over-the-phone, or online.

With your consent the interview will be audio-recorded [copied-and-pasted], and once transcribed, the recording will be retained for 1 year. You can choose not to be audio-recorded.

I will use a pseudonym to identify you in the study. You can choose a pseudonym or I will assign one. Have you thought whether you would like to choose a pseudonym or have one assigned?

I will contact you for follow-ups after the interview: one-week after to check-in, as well as offering the results, the return of your data, and any additional publications that result from this study. This study is part of my MSW thesis requirements, by being interviewed you are agreeing to have your data used for this project and any publications that are based off of this thesis.

### **Risks and Inconveniences:**

There are four main risks and inconveniences I would like to review with you:

1. Feeling obligated to participate: I want to ensure you know that this study is voluntary and optional, and that being part of it will not affect any personal or professional relationships you have with anyone who has recruited you. You can decide to leave the study at any time.
2. Social risks: While this study is confidential and anonymous, there is a risk that people may guess your identity within the study. The result may be exclusion or conflict with groups or community members who provide support to you due to them disagreeing with statements made in this study.
3. Emotional risks: Talking about autism services may bring up memories or emotions. Please ask for breaks and reach out if you need support. If the way that I interact with you at any time makes you feel unequal, please give me feedback on how I can address you in a way that is respectful and empowering.
4. Data breach. All the information that you give me will be kept on an encrypted and password-protected USB key. Over-the-phone and online interviews cannot guarantee data security, but I will do my best to ensure confidentiality using encryption methods. Risk of data breach increases if the data is returned to you at any point during the study.

### **Benefits of Participation:**

Your participation will help to promote literature about autistic self-determination. I hope that this information will help researchers, policy-makers, and the media understand that consulting autistic adults provides valuable insight into this and many other topics.

Do you have any questions about the risks and benefits?

### **Compensation:**

You will be given \$40.00 for participation in the interview. Other expenses that may be covered include:

- Public transit expenses up to \$7.00
- Parking expenses up to \$10.00
- Taxi, Uber, or Lyft up to \$20.00
- Mail expenses up to \$2.15

**No waiver of your rights:**

In orally agreeing to participate, you are not waiving any rights or releasing myself as a researcher from any liability.

**Withdrawing from the study:**

If you withdraw your consent during the course of the study, all information collected from you before your withdrawal will still be used, unless you request that it be removed from the study data. You may withdraw within 8 weeks of the interview.

After the interview you may request that any of your data be retracted from the study and deleted by notice given to me within 8 weeks of the interview.

If you withdraw before the interview you will not receive the honourarium. If you withdraw during or after the interview you will receive full compensation for your time.

**Confidentiality:**

This study is confidential and anonymous. Over-the-phone and online interviews cannot guarantee data security, but I will do my best to ensure confidentiality using the available encryption methods.

All measures will be taken to respect your confidentiality with respect to raw data, with contact information and last names (if disclosed) being a priority. You can retract (take back) information from the study within 8 weeks after the interview was completed. You do not need to disclose your real first name or any last name.

The only times I will breach confidentiality are:

1. If you disclose that you are actively going to hurt yourself
2. If you disclose that someone is in immediate danger
3. If you disclose that a child is actively being harmed
4. If you disclose that there is ongoing abuse between yourself and a third-party
5. If you disclose active violence against autistic people

In such instances, the researcher will contact their supervisors or a regulating authority (such as associated colleges, the Children's Aid Society, or a Regional Police Service) as part of a duty to report. You will be told about this.

The information that is used for this thesis or is published will use a pseudonym.

Research records may be accessed by the Carleton University Research Ethics Board in order to ensure continuing ethics compliance.

## **Data Retention**

Your information is being collected for research purposes pertaining to this project only. If you feel uncomfortable about information being collected at any point, accommodations are available. During the research the following information will be collected:

1. Informal notes taken outside the interview to ensure I can be prepared for the interview and follow-up with you (re. compensation, results, etc.)
2. Dates, times, and location of meetings on the researchers Microsoft Outlook calendar
3. Consent forms
4. Your contact information in the form of an email
5. Email correspondence through Microsoft Outlook
6. Interview recordings
7. Interview transcripts

Your information will be stored on a password-protected and encrypted USB key with one back-up. These will be kept in a locked drawer. No hard copies of notes or consent forms will be kept. All information will be retained for a period of one-year after the study has completed. I will keep a copy of de-identified transcripts and contact information for a maximum of five-years after the study has completed for corresponding publications. All other data will be destroyed one-year after the study has completed. Data can be returned to you after the study has completed.

## **New information during the study**

If there are any changes that could affect your decision to continue participating, you will be informed promptly.

Have you seen/heard this before:

If you have any ethical concerns with the study, please contact the Carleton University Research Ethics Board-A (by phone at 613-520-2600 ext. 2517 or via email at [ethics@carleton.ca](mailto:ethics@carleton.ca)).

If you at any time feel that I am being unethical in my research this is who you can contact. You can also reach me by email me at [margaretjansevanrensburg@cmail.carleton.ca](mailto:margaretjansevanrensburg@cmail.carleton.ca). You can contact one of my supervisors if you wish at: [royhanes@cunet.carleton.ca](mailto:royhanes@cunet.carleton.ca) or [mirandabradley@cunet.carleton.ca](mailto:mirandabradley@cunet.carleton.ca).

**Statement of consent**

Do you have any questions about this study or need any clarification?

Would you like to choose a pseudonym or have one assigned?

\_\_\_\_\_

Do you voluntarily agree to participate in the study?

Yes \_\_\_\_\_ No \_\_\_\_\_

Do you agree to be audio recorded or have your conversation copy and pasted?

Yes \_\_\_\_\_ No \_\_\_\_\_

(Note: Please explain if recordings are optional to participation)

Date: \_\_\_\_\_

Participant's Name/Pseudonym: \_\_\_\_\_

Participant's Preferred pronouns: \_\_\_\_\_

**Research team member who interacted with the subject**

I have explained the study to the participant and answered any and all of their questions. The participant appeared to understand and agree. I provided a copy of the consent information to the participant for their reference.

\_\_\_\_\_  
Signature of researcher

\_\_\_\_\_  
Date

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