A CRITICAL REVIEW OF THE AUTISM SUPPORT MECHANISM IN ONTARIO

MOHAMMAD MOKTADIR KABIR

Supervisor's Name: Dr. Marina Morrow

Advisor's Name: Dr. Farah Ahmad

Supervisor's Signature: ___________________________

Date Approved: _________________________________

Advisor's Signature: _____________________________

Date Approved: _________________________________

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ABSTRACT

In a scenario of increasing prevalence of autism in Canada, as well as in the world, this Major Research Paper (MRP) makes an attempt to critically review Ontario Autism Program which is the provincial autism support mechanism in Ontario. Using a critical disability lens this paper explores the challenges of autistic people including their families to receive services while the program is influenced by neoliberal ideology and a dominant biomedical model that aims to rectify and cure autism instead of creating a supportive environment by acknowledging their neurodiversive identity. The Ontario Autism Program mostly supports Applied Behavioural Analysis (ABA) based therapy for children but fails to accommodate many of them and put them in a gradually increasing waitlist. Autistic people are abused, stigmatized and often denied from their rights to have proper education, employment and social inclusion. Moreover, there is very limited support for autistic adults from the government which makes them live their lives in uncertainty. Recently, the Federal Government has taken initiative to develop a national autism framework. It is important to include the voices and concerns of the autistic community while developing the framework and ensure diversified services, social acceptance and inclusion.

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1. PROBLEM STATEMENT

In today's world, autism is being considered as one of the fastest growing conditions identified during children's developmental years (Randolph-Gips, 2011). There is more than one way of understanding autism and related experiences, and there are many structural forces influencing the policies and programs meant to support people with autism and their families. While exploring the biomedical and neurodiversive understandings of autism through critical disability lens, this paper will explore the Ontario Autism Program (OAP) and its funding trends, examine the challenges that affect autistic individuals throughout their lives including their families, and finally, conclude with a discussion on the importance of ensuring that the support mechanisms create an enabling environment to bring meaningful changes in the quality of lives of autistics.

2. BACKGROUND

Here, I present varying ways of understanding autism, specifically biomedical model, social disability model, and neurodiverse movements. Next, I would discuss human rights and neoliberalism as structural forces impacting policy formations. Finally, I will give an overview of current Canadian health and social support systems surrounding autism, leading towards the objective of this paper.

2.1 Varying Ways of Understanding Autism

Currently the dominant biomedical model describes autism as a brain developmental disorder with symptoms of behavioural problems which are typically exhibited by impaired social behaviour, repetitive or stereotypic movements, and difficulties in communicating with others (Randolph-Gips, 2011).This perspective historically attributed the etiology of autism to "cold" parenting and poor social circumstances, though genetic reasons have now taken precedence during the last few decades (Randolph-Gips, 2011). Autism has been biomedically explained as a disorder since its identification in the last century (Baron-Cohen, 2017). In medical science, 'disorder' is the term to explain the conditions where the causal mechanism is unknown as opposed to 'disease' where the etiology is known. While the term 'disorder' is intended to be simply descriptive, it actually implies that the person's "cognition and neurobiology is dysfunctional" because the natural order has gone wrong with that person – which denies the role of societal discriminatory attitudes, behaviours and practices towards a phenomenon which is not typical, or 'abnormal' in biomedical language (Baron-Cohen, 2017). And, thus, autism is perceived as a disability or dysfunction rather than viewing it as a neurological difference (Baron-Cohen, 2017). More recent clinical developments define autism as a spectrum disorder because the type and severity of the condition differ from person to person and, thus, it is experienced differently by different individuals (National Institute of Mental Health, n.d.). According to the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4th edition), there were separate diagnostic subcategories namely autistic disorder, Asperger's disorder, and pervasive developmental disorder. But there was lack of reliability among clinicians to categorise or distinguish these three conditions properly (Harker & Stone, 2014). Later in 2013, the 5th edition of the manual was released (DSM-V) where these conditions had been put together and referred to as Autism Spectrum Disorder or ASD (Harker & Stone, 2014).Currently, the American Psychiatric Association defines ASD as a "complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behaviour. While autism is considered a lifelong disorder, the degree of impairment in functioning because of these challenges varies between individuals with autism." (American Psychiatric Association, n.d.). A notable point is the rapid increase in prevalence of autism diagnosis since it was first recognised almost eighty years ago (Keenan & Dillenburger, 2018; Wolff, 2004). A public survey conducted by the Centres for Disease Control and Prevention (CDC) in 2011-12 reported an alarming figure of one in fifty children between age 6 and 17 years being affected by autism (Office of the Auditor General of Ontario, 2013). However, it is diagnosed four to five times more among boys than girls, but the reason for this difference remain unknown (Public Health Agency of Canada, 2018; Anagnostou et al., 2014). Children with milder or subtle symptoms are often undiagnosed during their early years of lives (Edelson et al, 2021). There is limited data regarding prevalence of autism in adulthood; although one study conducted in the United Kingdom suggested the prevalence to be less than 1%. However, there is a possibility of underestimation since people with less obvious symptoms often remain undiagnosed, or even misdiagnosed with another psychiatric condition (Edelson et al, 2021). Medical professionals believe that despite being a lifelong condition, autism can be improved with appropriate treatments and services (National Institute of Mental Health, n.d.), and because of its varying types and symptoms, the types of supports required for individuals on the spectrum vary as well (Autism Ontario, n.d. a). The focus on individuals through biomedical perspective, and a neglect of involved families and caring environments are some points worth mentioning here.

Another way of viewing disability emerged in 1980s is the social model of disability where disability is viewed as socially constructed phenomenon (Oliver 1983). The aim here is to shift the focus from the individual to the broader context of social, environmental, and systemic factors that create barriers for people with disabilities. The social model advocates for the rights of people with disabilities and calls for equal opportunities, participation, and inclusion in all aspects of life, including education, employment, healthcare, and social activities (Oliver 1983). Another tenet is viewing and empowering individuals with disabilities as agents of change. After a while, this model received criticism as being applied as a political tool with a ‘fundamentalist’ character - that is, it excludes biology altogether (Oliver, 2013). Such theoretical evolution contributes to today’s critical disability studies and is a function of the neurodiversity movement.

The neurodiversity movement believes that autism is a neurological difference or a natural variation among humans, and not a disease or a disorder (Runswick-Cole, 2014). It challenges the dominant biomedical narrative of ‘causation and cure’ and embraces autism as an aspect of identity inseparable from the individual. This narrative of neurodiversity does not pathologize autism as a brain defect that needs to be cured, but rather explains it as an aspect of inseparable identity that should be embraced without any stigmatisation (Kapp et al., 2013). Neurodiversity awareness encourages autistic people to proudly self-identify themselves as autistics who do not require any cure (Kapp et al., 2013). In this paper I chose to respect this perspective and, therefore, I used identity-first language, which put the disability first in the description, such as autistic people or autistic individual.

Neurodiversity activists argue that there is no single way that we can determine brain functions to be normal as there are many ways that the brain can be 'wired' (Baron-Cohen, 2017). Therefore, people who are different because of their varied brain functions should not be stigmatized. They also imply about the need for frameworks that do not pathologize autistic people but rather respect their different kinds of abilities by embracing the diversity, and focus on their varying needs using a human rights lens (Baron-Cohen, 2017).

Medical science has not established any specific cause for autism. The attempts to associate it as a result of the interaction between the genetics of the individual and the surrounding environment have not yet been clearly explained (Runswick-Cole, 2014). Genetic associations that have been identified as linked to autism are due to natural variants of nucleotides, and not due to any mutation (Baron-Cohen, 2017). The development of autistic brain also does not exhibit any direct evidence of neuropathology. Again, the variation in the neuronal connectivity suggests that the "brain is wired differently" among autistics, and there is no clear evidence of brain disorder (Baron-Cohen, 2017). MRI (Magnetic Resonance Imaging) studies have revealed some differences in brain activity but those are not conclusive of brain dysfunctionality. Therefore, autism cannot be conclusively labelled as a dysfunction or a disorder considering all these aspects (Baron-Cohen, 2017). But the polarising concepts of dominant biomedical tenet that frame autism as a "condition that requires intensive corrective intervention" influence and shape policy and practice accordingly (Orsini, 2012). Autistic people are also more marginalized from participating in policy discussions than people with physical disabilities (Orsini, 2012). Therefore, autistic voices and concerns are not reflected in the policies and programs designed for them. Nevertheless, some legal frameworks exist to protect their rights and promote inclusiveness through programs and policies.

2.2 Autism, Human Rights and Neoliberalism

The Ontario Human Rights Commission (OHRC) recognises disability as a complex and evolving phenomenon that encompasses a wide variety of conditions resulting from impairments of individuals or environmental barriers, or both (Ontario Human Rights Commission, 2023). The environmental barriers include adverse attitudes, inaccessible information and unfavourable environments that impact on a person's full participation in society (Ontario Human Rights Commission, 2023). This shift towards the social model of disability, which views disability as a result of societal organization rather than impairments or differences of the individuals, have been acknowledged by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) and the Supreme Court of Canada. The CRPD is based on the principles of non-discrimination, equal opportunity, full and effective participation, inclusion, accessibility, and overall respect towards the people with disabilities by accepting them as a part of human diversity (United Nations, 2006).

The Supreme Court of Canada has accepted the subjective components of disability in a landmark case of human rights considering that discrimination and human rights violations occur not only due to functional limitations, but also due to perceptions, stereotypes, and myths (Ontario Human Rights Commission, 2023). The Canada Health Act defines the principles of Canadian health care policy that promises protection, promotion and restoration of the physical and mental well-being of Canadian residents. It ensures that everyone, including people with disabilities have reasonable access to health services without any barriers including financial barriers (Canada Health Act, 1985).

However, viewing disability as an abnormality leads to rationalization of abuse, neglect, exclusion, and even exploitation of disabled people in various situations (Ontario Human Rights Commission, 2023). Some interrelated factors such as ignorance, negative stereotyping, stigma and prejudice leads to discrimination, and sometimes paternalistic and patronising behaviour. Disabled people are seen as burdens on society, and it is perceived that they are incapable of making decisions that serve their best interest and, thereby, excluded in policy development and decision making process (Ontario Human

Rights Commission, 2023). The stigma surrounding autism also impacts family members and caregivers – termed as affiliated stigma – which puts them into further stress (Werner & Shulman, 2015). In this paper I will further discuss in subsequent sections how this ableist belief system marginalizes autistic people, creates barriers, and inaccurately assesses their potentials and needs. But first, I will discuss neoliberalism which is recognized as having a growing influence on policymaking and program offerings.

"Neoliberalism", although difficult to define purely theoretically, is a dominant concept or paradigm of policy making and economy, which is characterised by eliminating price control and allowing free trade through increasing privatisation, austerity, and reducing the state's control over economy – and this shapes today's modern world (Thorsen, 2010). Neoliberal principals such as individualism, privatisation, deregulation and decentralisation have resulted in reforming healthcare systems in countries like Canada, the United States, the United Kingdom, Australia, and New Zealand (McGregor, 2001). In a neoliberal society every individual is held responsible for his/her own health and wellbeing (McGregor, 2001). The state cuts down its social welfare budgets and promotes privatisation while decentralising services (McGregor, 2001). We can see that the decentralisation has taken place in case of autism services in Canada as the responsibility lies on the provincial government, as discussed later.

The neoliberal countries in the western world have been dominating mental health literacy with the biomedical model of mental health (Watters, 2010). Mental health problems have been described as some form of "chemical imbalances" or "brain diseases" or "genetic/inherited factors", and thus western mental health professionals have been convincing the world to think and talk about mental illnesses in "biomedical" terms (Watters, 2010). The fact that biopsychiatry aims to understand mental disorders in terms of the biological functions of the nervous system has an ideological tie to neoliberalism, this promotes individualistic understandings of complex social problems rather than thinking holistically (Morrow, 2013). Hence it leads to the conceptualisation of the recovery process as a personal journey while neglecting social and structural relations of power in influencing wellbeing (Morrow, 2013).

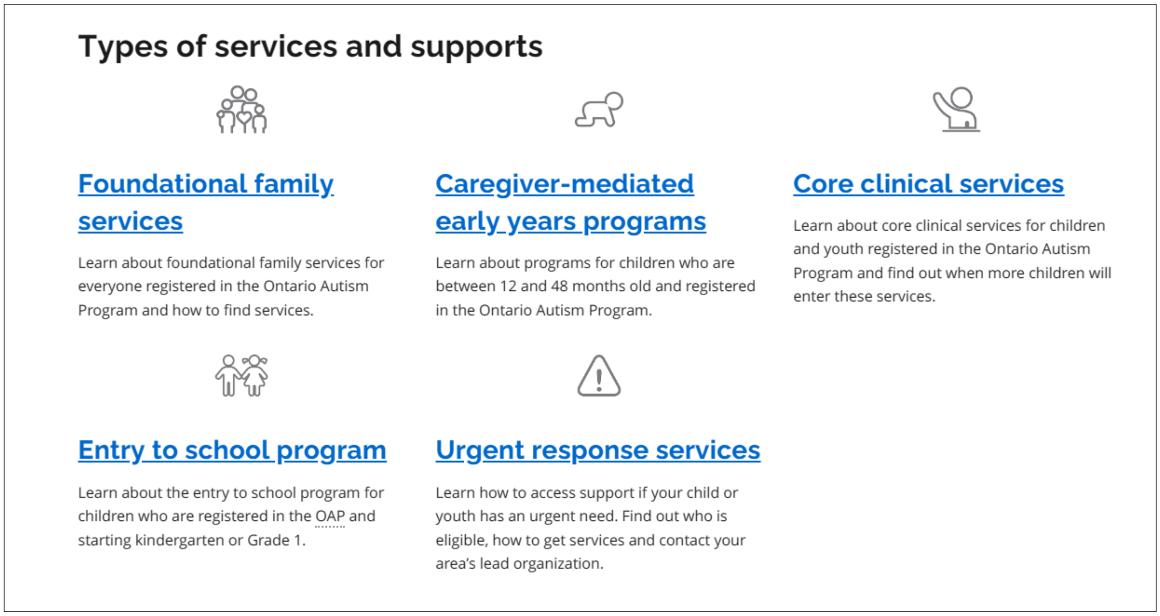
In a neoliberal society every citizen is expected to "work more, produce more and consume more" in order to accomplish the capitalist ideology of making profit from everything (McGuire, 2013). Thus, they are required to prepare and adapt themselves to enter this highly competitive system from their very early ages (McGuire, 2013). Autistic people, since they fail to perform according to the expectation of the neoliberal society, are viewed as misfits who cannot perform as per demand thus threatening the development and progress of the state, and, therefore, there is an urgency to make them 'normal' so that they could achieve 'maximum productivity'. The awareness programs and services are also designed in a way so that autism is further established as a pathological underdevelopment (McGuire, 2013).

The stigma surrounding autistic individuals is intertwined with the core structure of modern-day capitalism, personal responsibility and individualistic ideology (Grinker, 2020). They are viewed as incompetent, unable to contribute to the economy, and are blamed for their sufferings (Grinker, 2020). Interestingly, autism is also viewed as a commodity in a neoliberal world. Over the last few decades autism has gained popularity in media and literary world as the 'impairment' that has been showcased in films, novels, autobiographies and even in museum exhibitions (Mallett & Runswick-Cole, 2012). Autism related services are also conceptualised as commodities that could be sold, and profit could be made. A substantial amount of public and private investments has been made in biomedical research and intervention programs in order to 'cure' the condition so that the potential for economic productivity of autistic people could be realised (McGuire, 2013). Therefore, the efforts in terms of money, time and energy have been made with an expectation of quick return on investments. Neoliberalism also creates social class inequalities (Hill & Kumar, 2012), and as a result, it is observed that families with higher income can avail themselves of services more and earlier than those with low income amounting to a two-tier care system (McLaughlin & Schneider, 2019). Hence, autism and its related services are trapped within the neoliberal ideology in Canada, and therefore, the state is reluctant to fully fund for the needs of autistic people which is evident in my literature review.

2.3 Autism Supports in Ontario

According to the Canada Health Act the government is responsible "to protect, promote and restore the physical and mental well-being of residents of Canada" through equitable access to healthcare services without any barriers (Canada Health Act, 1985). Autism services in Canada are under provincial jurisdiction and, therefore, the funding and support programs vary across the provinces (Aide Canada, n.d. a). In Ontario, the funding for autism services for the children up to 18 years of age is done by the Ontario Autism Program (OAP) through different streams (Ontario.ca,2022a). These supports and services are not covered under the Ontario Health Insurance Plan (OHIP). However, the Ministry has been funding the different services and supports for autistic children since the year 2000 (Office of the Auditor General of Ontario, 2013). A child is required to be diagnosed by a qualified professional such as a physician, a psychiatrist, or a psychologist to receive any form of autism support services offered by the provincial government (Ontario.ca, 2022b). They use standardized professional assessment tools and diagnostic criteria according to the fifth edition of the Diagnostic and Statistics Manual of Mental Disorders (DSM-V). There are diagnostic hubs at different locations of the province to facilitate autism diagnosis (Ontario.ca, 2022b).

The current services offered by OAP are summarized in Figure 1. The government developed a capacity action plan in July 2021 and invested $62 million for building capacity to implement the needs-based program (Ontario.ca, 2021a). To access OAP, families need to register their children below 18 years of age with necessary documents that include a diagnosis from qualified personnel. The children are then enrolled for OAP funded care program in the order they have registered (Ontario.ca, 2021a). There are core clinical services that include Applied Behaviour Analysis (ABA) based therapy, speech-language pathology, and occupational, mental health and psychotherapy. OAP has gone through several reforms over the years (Ontario Autism Coalition, 2020). Despite these reforms, this mechanism has not been adequate to meet the needs of autistic people (Ontario Autism Coalition, 2020). Ontario has an estimated number of 135,000 people that are living on the autism spectrum (Autism Ontario, n.d. a), but the provincial financial support mechanism through OAP is offered only to children up to 18 years of age if they have a formal diagnosis of autism. Although the program was reformed in 2019 in order to provide supports more effectively, it has been criticised by the families because of its 'one size fits all' approach and funding caps (Autism Canada, 2019) making it difficult to access services based on individual needs (D'Mello, 2021). While the inadequacy of services and shortage of trained therapists still persists (McLaughlin & Schneider, 2019), the already existing long wait times to access OAP funded care programs have increased even further (Jeffords, 2020).



Types of services and supports

Foundational family services

Learn about foundational family services for everyone registered in the Ontario Autism Program and how to find services.

Caregiver-mediated early years programs

Learn about programs for children who are between 12 and 48 months old and registered in the Ontario Autism Program.

Core clinical services

Learn about core clinical services for children and youth registered in the Ontario Autism Program and find out when more children will enter these services.

Entry to school program

Learn about the entry to school program for children who are registered in the OAP and starting kindergarten or Grade 1.

Urgent response services

Learn how to access support if your child or youth has an urgent need. Find out who is eligible, how to get services and contact your area's lead organization.

Figure 1: Ontario Autism Program (OAP) Services (Ontario.ca, n.d.)

Public schools also lack capacity to make safe and meaningful integration of autistic children (McLaughlin & Schneider, 2019). There is even less support when the child reaches adulthood, despite the fact that continuation of support is still required especially for employment, housing, healthcare and recreation (Collie, 2020). Different reports and news articles show how all these factors put autistic people and their families in difficult situations. Since autism is a condition with relatively low incidence, compared to physical medical conditions like cardiovascular diseases and cancers, it does not get enough attention at the policy level and the concerns of families are also often ignored (Brackenreed, 2019). Furthermore, autistics and their families often need supports from a multitude of health and social programs and, thus, the onus of inclusive policy falls across several jurisdictions – complicating the picture even more.

Previously, I conducted a scoping review to assess the current knowledge about the challenges faced by autistic people and their families in accessing autism related services in Ontario (Kabir, 2022). I found that they experienced various levels of stress and challenges while accessing the services. Therefore, I was interested to further explore this issue by critically reviewing Ontario's autism support mechanism in terms of policies, programs and funding while exploring autistic challenges and searching for recommendations to overcome them.

3. OBJECTIVE AND METHODOLOGY

Given the inadequacy of supports experienced by autistic people and their families, here I trace the policy history of autism in Ontario and shifting political commitments using a critical disability lens that includes the understanding of social model of disability. I demonstrate how support for people with autism is dependent on the political context and ideology of modern day neoliberal governments and the extent to which autism is given importance in their policy and practice.To achieve this, I conducted a critical review of policy and relevant literature (both scholarly articles and grey literature) in Canadian context - with a focus on the province of Ontario - to understand the existing problem, and to make recommendations towards overcoming challenges.

I believe access to autism supports is an issue of social justice influenced by political economy, power imbalance, and inequality that need to be questioned and addressed. Therefore, my epistemological approach to knowledge generation is informed by critical social science through an emphasis on unpacking structural forces and questioning historically built reality which is shaped by social, political and economic dynamics (Meekosha & Shuttleworth, 2009). I also assume that the generated knowledge can never be truly objective or value free. A critical social science approach evolved from the critical theory proposed by the renowned Frankfurt School in the 1930s that critiqued the power structure while examining and exposing the hidden origins of social construct and cultural norms and challengedcircumstances that are otherwise believed natural or unchangeable (Meekosha & Shuttleworth, 2009). Thus, critical perspectives challenge traditional biomedical approaches to disability studies while embracing subjectivity and the social model of disability, and analyze disability as a cultural, social, historical, relative, and political occurrence (Meekosha & Shuttleworth, 2009).

Literature search for this paper was done using electronic databases (ProQuest, EBSCO, Medline) and Google Scholar for published articles, and Google for unpublished literature, public policies, expert panel reports, news articles, blogs etc. exploring literatures representing these critical perspectives focusing on Ontario and Canada over the last twenty years. The search terms included “autism”, “Ontario” and “Canada” in combination with other keywords such as “disability”, “challenges”, “neoliberalism”, “neurodiversity”, “policy”, “program”, “history”, “financing”, “ableism”, etc. while I used a critical analysis to understand the findings from these literatures. I followed the reflexive approach of thematic analysis suggested by Braun et al. (2019) where the researcher can use their subjectivity by being reflexive while interpreting data considering the social, political, cultural and economic factors (Morgan, 2022).

4. FINDINGS

In this section, I will present the findings from the literature review. I will start with the challenges autistic people encounters at different stages throughout their lives (subsection 4.1). Then I willexplore the history of autism related services in Ontario, and describe the fact that the available support services are inadequate to meet the needs of the autistics and their families (subsection 4.2 to 4.7). Lastly, I will discuss how an inclusive approach in the national strategic framework could be beneficial for them (subsection 4.8).

4.1 Autistic Challenges throughout Life

The challenges for autistic people begin from the very early years of their lives. It is believed that early childhood education and care are beneficial for them, but parents or caregivers find it difficult to navigate these services (Maich et al., 2019). The delay in diagnosis is common (Frenette et al., 2013). A study comparing the age at which children were diagnosed with ASD across four provinces in Canada revealed that South-Eastern Ontario had the highest median age of 55 months (Ouellette-Kuntz et al., 2009). There is limited information regarding the factors contributing to the delay in diagnosis (Frenette et al., 2013). However, a study in Nova Scotia found that many children were not diagnosed until they started going to school. Parental knowledge or familiarity with autism symptoms, physicians' reluctance to assign a diagnosis due to the fear of stigmatising the child, and confusing the symptoms with ADHD (Attention Deficit/Hyperactivity Disorder) were some important factors that contribute to delay in diagnosis (Frenette et al., 2013). However, in most of the cases children are not diagnosed until they enter the school system (Frenette et al., 2013).

Autistic children struggle to start their journey to the schools. They feel different and isolated from other children for reasons they do not understand being unaware of their diagnosis, which is sometimes delayed until they reach their early teens (Devita-Raeburn, 2016). It is difficult for them to communicate or engage with other children in their class (Devita-Raeburn, 2016) and they have fewer friends due to their lack of ability to engage in social interactions (Cappadocia et al., 2012). They are also at four times higher risk of being bullied in schools compared to their other classmates. Studies suggest that roughly 65% autistic children and youth experience victimization and bullying by their peers; although the forms and frequency of those experiences are underexplored (Cappadocia et al., 2012). A study was conducted among the parents of school-going autistic children (60% of whom lived in Ontario) which revealed that 77% of the children had been bullied within the previous month with varying frequencies, and 30% reported that it had happened two or more times in each week. These frequencies did not have any relation with the child's age or gender (Cappadocia et al., 2012). A systematic review and meta-analysis of studies conducted in the USA, Canada and European countries showed that nearly half of the school-aged youths with autism were victims of verbal, physical or relational bullying at schools (Maiano et al., 2016).

Schools are not always welcoming to autistic children as they lack resources and trained teachers to address the special needs for their education. This results in difficulty in completing their studies and transition to adulthood (Brackenreed, 2019). They also experience significant challenges during their post-secondary studies. University students often reported suffering from other associated mental health conditions such as primary anxiety, depression and loneliness (Kuder et al., 2021). There is often more than one of these conditions that affect them at a significant level and thus impact their experience at the university (Kuder et al., 2021).

Families of school-aged autistic children felt that the information about special programs and services were inadequate and also perceived that the service system was ‘passive rather than active’ - which made it difficult for them to find the information (Brown et al., 2012). Other major unmet needs reported by parents besides insufficient information were absence of adequate social activities for their children and continuity of services (Brown et al., 2012). There was lack of understanding and acceptance of the children’s difficulty by their peers as well (Brown et al., 2012). Educators involved with autistic children at schools encountered challenges regarding understanding and managing behaviour of the students because of school policies that fell short to meet the Ministry of Education’s standards, and lack of training and resources (Lindsay et al., 2013). There was also inadequate understanding among other teachers, students and parents that resulted in the failure of creating an inclusive environment (Lindsay et al., 2013).

Lord (2020) argues that Canada fails to meet the obligations of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2007) to ensure access to non-discriminatory and inclusive education for autistic children and there are several interrelated factors that contribute to this failure (Lord, 2020). There is inadequate support at schools and lack of meaningful participation of the parents while designing the individual education plan (IEP) for their children. Teachers are also not adequately trained to manage autistic children (Lord, 2020). Moreover, the use of language linked to the dominant medical model of disabilities in government policies portrays autistic children as ‘problematic’ which impedes their participation in a truly inclusive education system. Parents, being frustrated with all these short-falls, often choose to separate their children from the public system and go for expensive specialized private schools which can put them into financial crisis (Lord, 2020).

It is estimated that 15% of the autistic people would attain self-sufficiency in adulthood while another 15-20% would obtain certain level of self-sufficiency with some degree of external support (Edelson et al., 2021). Some of those who have been diagnosed later in their adulthood might already have learnt to adapt to their psychosocial challenges and thus have better functionality (Edelson et al., 2021). But majority of the autistic adults experience various levels of challenges throughout their lives (Edelson et al., 2021). OAP does not provide any support to the adults and most of the government's supports stop when a child becomes 18 years old (Collie, 2020). Unfortunately, adult autism never received much attention in research works or medical literature, and the needs of adult autistics had been grossly neglected by the health care professionals and policy makers (Fombonne, 2012). With a prevalence of 1%, almost similar to that of the children, autism among adults could impact the lives of the individuals and their families in the same way (Fombonne, 2012). But it is often under-diagnosed since it is not identified at the same frequency as among children (Alexander & Farrelly, 2022). Moreover, they are often misdiagnosed with other mental health illnesses such as schizophrenia or manic depression, and therefore sent to psychiatric institutions and heavily prescribed with antipsychotic medications (Wright, 2015).Autism was not well-understood few decades back and, therefore, such misdiagnosis was common (Devita-Raeburn, 2016).There have been very few research works and therefore autism in adulthood remains poorly understood till today. Therefore, there is not much information available about how they grow old or live their lives at their old age (Wright, 2015). It is difficult for autistic individuals to find or retain a job, and therefore,there is a high rate of unemployment among them (López & Keenan, 2014). In Canada, the employment rate for autistic people over 15 years of age is only 14.3% and most of them are engaged in low-wage short-term contractual jobs (Nicholas, 2020). Lack of employers' knowledge on autism, stigma, inadequate capacity to assist the autistics, and non-supportive workplace policy that fails to make necessary adjustments have been identified as some of the important factors contributing to this lower rate of employment (Nicholas, 2020; López & Keenan, 2014).

Autistic adults face numerous challenges while accessing health care that are not necessarily due to availability or affordability of the services. They are often stigmatized and there are communication barriers, inappropriateness of care environment and lack of service providers' knowledge – which reflect the shortfall of the overall understanding of autism in adulthood by the healthcare providers (Ghahari et al., 2022). A study revealed that autistic adults (ages 18-61 years) without intellectual disability had more challenges to access services such as dentistry, psychiatry or any other individual counselling when they had other accompanying medical problems, and they usually were less satisfied with the services (Vogan et al. 2017). They often struggled to find appropriate help, found the steps too overwhelming and also had negative experiences with the professionals - all of which led to higher levels of distress (Vogan et al. 2017).

Autistic adults often face physical and mental abuse by their families and society, and are even abandoned as the family members cannot keep up with the high needs in a situation where support services are not adequate. Office of the Ombudsman Ontario published an investigative report on the response to crisis situations that involved adults with developmental disabilities by the Ministry of Community and Social Services in 2016 (Ombudsman Ontario, 2016). The report revealed that the autistic individuals with higher needs of support often faced these problems regardless of age, and were wrongly placed into psychiatric facilities or shelters that did not have required expertise to address their needs. They were often criminalised, arrested by the police, and put into custody if they were involved in violent activities whilethe police did not have the appropriate training to handle autism related crises (Ombudsman Ontario, 2016). Some parents and families found it challenging to cope with the huge demands of care and support forthe autistic individuals, and thisdeteriorated their mental health condition. They became stressed out and frustrated which resulted in abuse and abandonment of their children. Once abandoned by their families, those children ended up either in hospitals, or in police custody only to be transferred later to homeless shelters (Ombudsman Ontario, 2016). They had to move from shelters to shelters but it was difficult to find a suitable placement where they could settle in (Ombudsman Ontario, 2016). The Ministry of Community and Social Services did not have any reliable statistical data regarding people with mental health challenges who were living in abusive home conditions, became homeless, or were stranded within criminal justice and correctional systems. There was not enough inter-ministerial coordination between the Ministry of Community and Social Services and the

Ministry of Health and Long-Term Care to plan resources for the appropriate transition of autistic individuals to their adulthood (Ombudsman Ontario, 2016). Families have concerns regarding the long-term future of the autistic children when they grow older and especially when parents no longer remain the main caregiver because of their illness or death (Moss et al., 2019). They often experience disruptions in their family or social lives along with the guilt feelings of not being able to do enough for their autistic children (Moss et al., 2019). Since most of the government supports are ceased when someone enters into adulthood, parents or families may have to send them to psychiatric facilities or group homes where they do not get the care they really need. They are often highly medicated at the psychiatric facilities which do not bring any long term benefit (Collie, 2020).

A survey was conducted by the Laurier Autism Research Consortium in 2019 on the impacts of autism services on family and child wellbeing in Ontario. The report reflects that the public programs are insufficient to meet the needs of the autistic children and it puts the families in acute crisis (McLaughlin & Schneider, 2019). The families have to sacrifice their career, savings and sometimes have to sell their homes in order to support their children. Those who belong to the lower socio-economic group cannot afford private service providers and therefore have to wait for the government funded services and, because of the long waiting list, the services are not received timely. This becomes a vicious cycle for these families being compelled to live less productive and less healthy lives and, therefore, becoming more dependent on government's social and health supports (McLaughlin & Schneider, 2019). Parents have to make their way through by navigating the complex system which requires significant effortsandthis further intensify the stressful situation they are already in (Gentles et al., 2019). The families struggle to find required supports since the community services are inadequate, and the enrolment criteria are confusing and exhaustive (Brackenreed, 2019). They often complain that the process of autism diagnosis is too comprehensive and lengthy which results in delay in accessing therapies that could be beneficial during the early years of life (Makino et al., 2021). They experience long waiting period at various stages between getting the diagnosis done and accessing the services and, depending on the situation, this period could vary from months to years (Autism Ontario, 2020). The maximum recommended wait time between the initial referral after earliest demonstration of symptoms and confirmation of diagnosis is five months; but in reality it varies from two to four years (Smith-Young et al., 2020). Then there is an indefinite period of waiting to actually get the services where parents have to actively navigate through varieties of service providers for suitable interventions. Children grow older during this period which results in changes in the service requirements as well – and this demands even more effort to keep up with the changing needs and availability of those services (Smith-Young et al., 2020).

Newcomers in Canada who have just settled in face challenges to explore and navigate through the complex system especially when their first language is not English or French (Provincial Advocate for Children & Youth, 2016). Immigrant mothers with one or more children with ASD have described several factors, such as, delay in diagnosis, lack of information and guidance, lack of integration and coordination of the services, long wait times, difficult enrolment systems, inadequate knowledge and awareness of service providers regarding clients' needs, and poorly funded public programs as some of the important barriers to accessing services for their children (Khanlou et al., 2017). In addition to the language barriers, there were stress of acculturation in a new environment, poverty and social isolation that acted as contributing factors making it more difficult to navigate around the services (Khanlou et al., 2017).

The COVID-19 pandemic emergency measures led to closure of many services in order to limit the spread. Lockdown measures were applied in Ontario between March and June 2020 and many of the services including school, childcare and respite services were closed resulting in disruption in regular routines of children and adolescents (Cost et al., 2022). While these closures impacted the lives of autistic people, families and caregivers also experienced stress apprehending the potential long-term impact of the disruption on themselves and on their children's mental health (Cost et al., 2022; Lee et al., 2021). As a result, there was an increased demand of coping strategies while there was none available based on evidence to support them (Lee et al., 2021). There was loss of behavioural therapies and other autism related services forcing parents and caregivers to take up those additional responsibilities on themselves. Loss of employments and strict self isolation measures contributed further to heighten the psychological distress (Lee et al., 2021). Moreover, autism diagnosis, need assessment and service delivery were hampered due to restriction on in-person meetings (Zwaigenbaum et al., 2021). Parents or caregivers were anxious about losing social and developmental gains of their children due to cessation of the interventions and care, and many had concerns whether those losses could ever be recovered (TokatlyLatzer et al., 2021; Gentles et al., 2022). A study shows that they had to spend an average of 15.2 hours per week to advocate and pursuit care for their children, which led to moderately high to markedly high level of stress (as reported by 56% and 8% of the caregivers respectively) (Gentles et al., 2022). Overall, about 70% and 48% of the caregivers reported about worsening of mental and physical health respectively due to difficulties related to their childcare during COVID-19 pandemic. While 53% of them reported that the support they received from OAP in the past 12 months was not sufficient to meet the need of their children, 16% reported that they did not receive any support at all (Gentles et al., 2022). Therefore, it is evident that despite having a dedicated program, OAP, the provincial autism support mechanism has not been successful to address the needs and challenges of the autistic people and their families. Lengthy process causing delay in being identified as an autistic, long queue for being enrolled in the programand waiting time to access the services, lack of expertise and coordination at different level, excessive dependency on ABA based therapies while ignoring other aspects of required support, little or almost no support for the adults, lack of coping mechanisms – all these contribute to the failure of the program while the COVID-19 pandemic has further increased the backlogs.

Involvement of autistics with lived experience in autism activism or policy making is limited. The advocacy and lobbying are mostly dominated by the parents of autistic children, service providing agencies and non-autistic/’neuro-typical’ allies (Tsang, 2024). These movements have been guided by evidence based research works led by dominant bio-medical and behavioural expert groups who define autism and the interventions that would be beneficial for the autistics (Orsini & Smith, 2010). Therefore the parents are more interested in securing ABA therapies for their children regardless of the effectiveness, rather than fighting for societal norms that respect and support autistic difference (Orsini & Smith, 2010). Autistic adults are hence trapped in the dilemma of choosing sides – whether to join the parent and expert-led advocacy or become self advocates themselves (Tsang, 2024). They are often silenced on the ground of either not being autistic enough or not being capable enough to articulate their needs and speak for themselves (Orsini & Smith, 2010).Organized activism of autistic adults are considered as a threat to the interests of parents and biomedical experts, and therefore, questioning their legitimacy and cognitive ability to represent themselves were used as means to suppress them (Tsang, 2024). Consequently, this systemic ableism challenges the authority of the autistics to meaningfully participate in policy dialogues and, as a result, their voices are not adequately reflected in policy documents.

4.2 Struggle of Autistic People and Their Families to Access Autism Services

Prior to the early 1970s, institutionalization was the only way to support autistic children as no other educational or support services were available for them (Autism Ontario, n.d. b). Autism was poorly understood before the 1960s and therefore the milder forms were usually treated by traditional speech therapies. Those who had more severe symptoms along with intellectual disabilities were institutionalized in psychiatric facilities (Devita-Raeburn, 2016). Parents of autistic children played crucial roles in lobbying for funding and support from the government. Especially when deinstitutionalization of people with mental health problems started in the western world during the 1970s, parents started campaigning for better diagnosis and recognition of the struggle of their autistic children (Evans, 2013). The biomedical model was still the key framework as the support they were looking for was mostly medical treatment for autism.

Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention (IBI) were gaining popularity to improve autism among children, following the success of a behaviour therapy experiment by an eminent psychologist Ole Iver Lovaas in the 1960s (Devita-Raeburn, 2016), but there was no government funding support for the families to bear the expenses. Pressures from the families and several lawsuits in different provinces (discussed later in this section) created political interest to design a funding mechanism to accommodate the needs of the autistic children (Turan, 2014).Consequently, the Ontario government introduced the Autism Intervention Program (AIP) for the first time in 1999 to fund IBI, an intensive form of therapy based on ABA principles, for children below six years age who were diagnosed as on the extreme end of the spectrum. The initial budget of this programme was $5 million (Financial Accountability Office of Ontario, 2020). Later, in 2004, the School Support Program was undertaken by the Ministry of Education to train educators on how to help autistic students (Financial Accountability Office of Ontario, 2020). After 2006, the province launched Autism Ontario Potential Program to support families with training, resource and networking, and the ASD Respite Program that would help families with in-home and out-of-home respite services (Financial Accountability Office of Ontario, 2020). However, since 2011, ABA based services were included under eligible funding and the children above the age of six were included under these services. The magnitude of funding and service delivery were low until the government transitioned to the Ontario Autism Program (OAP) in 2016 with a commitment to spend $333 million over the next five years (Financial Accountability Office of Ontario, 2020).

It has been difficult to come to a consensus by policymakers, researchers and parents regarding a sound and universal autism policy in Canada since the beginning (Shepherd&Waddell, 2015). There have been conflicts between parents and provincial governments that resulted in lawsuits as parents tried to secure funding and services by challenging the province through legal processes and using human rights frameworks (Shepherd&Waddell, 2015). For example, in 1996, a case was filed against Alberta Family and Social Services by parents who sought funding for their seven years old autistic child for a therapy program involving intensive behavioural modification and got refused by the Director of Child Welfare. The court allowed the appeal and government was ordered to fund 90% of the cost of that program (C.R. and H.R. V. Director of Child Welfare (alta.) et al., 1996).

But there are instances where parents have lost the lawsuits. Two notable examples are the Auton Case in British Columbia and the Wynberg-Deskin Case in Ontario. The Auton Case (Canada, S. C. of., 2012) was filed by parents of four pre-school aged autistic children in early 2000 who were refused funding from the province of British Columbia for a specific therapy called LEAP (Listen-Empathise-Agree-

Partner) ,based on ABA/IBI introduced by Dr. O. Ivar Lovaas in 1987, for their pre-school children. The parents argued that the province has denied equality rights of the children stated by the Canadian Charter of Rights and Freedoms as they considered that specific therapy a 'medically required treatment'. The trial judge was convinced that the provincial government's denial of funding did violate the equality rights and therefore directed the province to fund for that therapy, and also awarded each family an amount of $20,000 as compensation. The Court of Appeal also upheld that decision to continue funding for ABA/IBI treatment whenever it was prescribed by a medical professional. However, the Supreme Court dismissed the judgment of the lower courts stating that there was no infringement of equality rights of the petitioners according to the Charter and the Canada Health Act stating that the law does not guarantee every Canadian to access all medically required treatment. Moreover, the specific intensive therapy under consideration requiring $45,000 to $60,000 per year was controversial and was not proven effective universally, and therefore, could not be assumed 'medically necessary' by the court (C.R. and H.R. V. Director of Child Welfare (alta.) et al., 1996). As we will see, ABA/IBI later becomes the dominant mode of government funded treatment although it remains controversial for a variety of reasons discussed in section 4.6.

The Deskin/Wynberg Case was filed in 2003 by 30 families of 35 children following the introduction of Intensive Early Intervention Program (IEIP) by the Ontario government that provided financial support for autistic children between two to five years of age (Weir, 2006). The parents claimed that not extending the ABA/IBI support to the educational system in the schools caused a violation of Charter rights. The Ontario

Superior Court, in 2005, provided a ruling in favour of the parents stating that the Ontario government not only violated the Charter of Rights, but also violated its Education Act by not including these services at school (Weir, 2006). But later, in 2006, the Ontario Court of Appeal reversed that decision on the ground of insufficient evidence of IBI/ABA being the only appropriate special education program for autistic children (Weir, 2006).

Meanwhile in 2005, a small group of parents, who were also disappointed due to the government's decision of ending IBI/ABA therapy at age six and lack of support at school, founded Ontario Autism Coalition (Ontario Autism Coalition, 2020). Their frustration further increased when the Wynberg case was lost at the Ontario Court of Appeal. During the following years they held rallies throughout the province and met with more than 30 Members of Provincial Parliament lobbying for continuation of funding beyond age six, better services for autistic children at schools, and regulation of ABA/IBI therapists. As a result of continued pressure, the government later agreed not to cut funding beyond six years of age despite the court's verdict against it (Ontario Autism Coalition, 2020).

In 2007, the Policy/Program Memorandum 140 (PPM 140) was developed aiming to incorporate ABA methods into Individual Education Plans (IEP) for autistic students. It was intended to increase collaboration among schools, parents and community in order to create a supported learning environment for them (Ontario.ca, 2021b). The overall goal was to develop positive social behaviours and improve comprehensive language, social and academic skills among autistic children (Ontario.ca, 2021b). But there were strict benchmarks set by the advisory panel that made it difficult for those children to stay with the services (Ontario Autism Coalition, 2020). Therefore, not only the attempt at rectifying the autistic behaviour of those children towards normalcy was guided by dominant biomedical theory but it also lacked equity since many would fail to qualify for the services despite being autistic.

In the same year of 2007, a report titled "Pay Now or Pay Later: Autism Families in Crisis" was published by the Standing Senate Committee on Social Affairs, Science and Technology regarding autism services across Canada (The Standing Senate Committee on Social Affairs, Science and Technology, 2007). This report acknowledged the complexity of the whole autism spectrum, and the crisis the families were in while dealing with their autistic children – since there was not adequate funding and services to support them. It recognised that a multidisciplinary approach should be taken with that consensus among different stakeholders, and there should be more research regarding effective interventions ensuring participation of autistic people in developing treatment protocols (The Standing Senate Committee on Social Affairs, Science and Technology, 2007). This can be viewed as a step that challenged the dominance of ABA/IBI therapies for autism and acknowledged the importance of including autistic voices while designing programs for them. The committee alsorecommended that the federal government should play lead role while transferring these programs to the provinces, and develop a national autism strategy to support autistic children and adults (The Standing Senate Committee on Social Affairs, Science and Technology, 2007).

Meanwhile, there have been different competing voices emerging in the autism movement. In 2009, a big tent meeting was organized by the Ontario Autism Coalition in order to unify these different groups, and a recommendations report from that workshop was submitted to the government in 2010 (Ontario Autism Coalition, 2020). The report, comprised of 47 recommendations, detailed how to deliver services in a better way to autistic people of different age groups - from children to adults. But unfortunately, there was no formal response from the government (Ontario Autism Coalition, 2020). However, the government introduced ABA supportprograms for the first time targeting 8,000 children with an estimated cost of 25 million dollars. These government funded supports were being provided through 90 hospital or community based agencies, most of which were not-for-profit, while nine regional offices of the ministry were overseeing the delivery of programs by those agencies (Office of the Auditor General of Ontario, 2013). But the program was heavily criticised because of its clinical inadequacy and financial mismanagement (Ontario Autism Coalition, 2020). An audit was conducted in 2013 by the Auditor General's office to assess the overall management, cost effectiveness, accessibility of services, and financial system. Although, the ministry had increased the funding four-fold over the previous ten years, there were more children on wait list than those who were actually receiving government funded services (Office of the Auditor General of Ontario, 2013). It was observed that the average age of being diagnosed with ASD was over three years against the recommended age of 18 to 24 months by the Canadian Paediatric Society, and the median wait time to access government funded IBI services was four years (Office of the Auditor General of

Ontario, 2013). Mild to moderately autistic children availing ABA based services were allowed to work with only one behavioural goal at a time, although they might have needs to address multiple goals, and reapplying for a second goal after each intervention would again put them to the bottom of the waitlist (Office of the Auditor General of Ontario, 2013). It was the agency that decided whether the child would receive either direct service or direct funding to purchase the service; and the wait time and duration of services differed between those two options (Office of the Auditor General of Ontario, 2013). Half of the schools did not incorporate ABA techniques to teach autistic students and only one third of School Boards had teachers trained on ABA services. Moreover, the Ministry did not have enough information to monitor the effectiveness of the program and financial transparency (Office of the Auditor General of Ontario, 2013).

In 2010, the Children's Services Minister promised to form an expert committee in order to inform the Ministry of Children and Youth Services regarding the needs of services in Ontario ("The Autism Project", 2012) that actually started its work in 2012 (Office of the Auditor General of Ontario, 2013). The committee prepared their report in 2013 which was made public in 2016 (Ontario Autism Coalition, 2020). The expert panel recognised IBI or more specifically Early Intensive Behavioural Intervention (EIBI) for younger children to be effective in some domains but many children were not being able to access these services at pre-school age due to the long waitlist and, therefore, were aging out before being enrolled (Autism Spectrum Disorder Clinical Expert Committee, 2014). In addition, they also pointed out that IBI was merely one of the services which were useful but often not very effective for children with complex ASD (Autism

Spectrum Disorder Clinical Expert Committee, 2014). Thus, autistic children required a wide range of support and services for meaningful transition into their adulthoods, and it wasnecessary to ensure a continuum of comprehensive care for bothautistic children and youth (Autism Spectrum Disorder Clinical Expert Committee, 2014).

In 2016, the provincial government announced an amount of 333 million dollars for the new Ontario Autism Program for five years starting from 2018 (Financial Accountability Office of Ontario, 2020). The aim was to reduce wait times, integrate services and expand access to ABA therapy, but there was a new cut-off age of five years to be eligible for receiving IBI services. This enraged the parents and the families and, as a result of their province wide protests during the next few months, the cut-off age was removed (Ontario Autism Coalition, 2020). Average spending per client during this period increased to $29,000 with expansion of IBI services and maximum hourly rate for behavioural therapies increased from $39 to $55 per hour (Financial Accountability Office of Ontario, 2020). There was a yearly provision of $10,000 for children on the waitlist to access ABA services from private sources. The funding support to public schools was increased for autistic students. Five new regional diagnostic hubs were established along with introduction of 45 new family support coordinators (Financial Accountability Office of Ontario, 2020). However, the issues regarding long wait times, inadequate services and lack of accountability still existed. In addition, there was not enough support for those who entered into their adulthoods (Ontario Autism Coalition, 2020).

The Ontario Autism Program was redesigned in 2019 in order to facilitate more access to services, reduce waiting time, and improve outcomes for children (Financial Accountability Office of Ontario, 2020). The annual program budget was doubled to an approximate amount of 600 million dollars. Families who were on waitlists for services could access an interim funding of $20,000 for a child aged up to 5 years and $5,000 for a child or youth aged between 6 to 17 years (Financial Accountability Office of Ontario, 2020). New funding caps were introduced ranging from $6,600 to $65,000 based on children's age and family income, and not according to the individual needs of the children, which actually limited the ability to get the required services (Autism Canada, 2019). Moreover, instead of reducing the wait time the new model actually made it worse as there were 24,900 children on the waitlist in 2018-19 which increased to about 27,600 by 2019-20 (Financial Accountability Office of Ontario, 2020).

Following continuous advocacy by parents an advisory panel was created in June 2019 in order to come up with recommendations that would help redesigning the program to address individual needs of children within the yearly budget of $600 million and would accommodate as many children, youth and families as possible (The Ontario Autism Program Advisory Panel Report, 2019). The panel recommended a balanced, equitable and needs-based program built on trust, transparency and communication that would serve as many children and youth as possible by eliminating waiting lists and service caps. The panel also raised concern about the needs of autistic adults not being addressed and their participation not being incorporated inthe current program design (The Ontario Autism Program Advisory Panel Report, 2019). Later in 2022, the province planned to include 8,000 children into the core services by the fall 2022 out of 56,000 who had signed up, but only 888 invitations were sent at the end of summer (Taekema, 2022). It can be anticipated that at this pace it would be difficult for the government to clear the backlog and many children, especially those who were diagnosed at a later age, would age out before they could enrol or be able to achieve the benefits of the program.

From above information we can see that the journey of autistic people and their families has not been easy. They had to go a long way for their struggle and need for support to be recognised. But the programs were underfunded, fragmented and not efficiently managed - which left many autistic children deprived of services. Many were left without service due to strict benchmarks, delay in various steps of formal procedures, mismanagement and inequitable allocation of resources, and thus being denied of their human rights.The perspective of neurodiversity was absent in program designs which made ABA/IBI the main therapy that had been offered. The literature suggests that the people with lived experience of autism did not frequently participate in the movements as those were mostly led by their families. In the later sections I will discuss how the conflicting interests of autistics with the society and their families lead to silencing of their voices while their struggles continue at different stages of their lives since the support services remain non-inclusive and inadequate.

4.3 Varying Funding Amounts for Autism Services

As mentioned earlier, the OAP was redesigned in 2019 to provide needs-based supports following continuous pressure from families and recommendations from the advisory panel. The OAP covers funds for programs like core clinical services, foundational family services, caregiver mediated early years programs, entry to school program and urgent response services (Ontario.ca., 2022a). The OAP invited registered families from the waitlist to assess needs and level of support required in order to allocate funding for a year. The amount of funding varied based on intensity of the support required (categorised as limited, moderate and extensive) and age of the child, and the amount ranged from $6,600 to $65,000 depending on those factors. All those services must be received from regulated providers in order to make the expenses eligible (Ontario.ca., 2022a).

	0 – 3 years	4 – 9 years	10 – 14 years	15 – 17 years
Limited	$10,900	$8,900	$7,600	$6,600
Moderate	-	$24,500	$18,800	$18,300
Moderate+	-	$36,800	-	-
Extensive	$65,000	$65,000	$41,400	$31,900

Figure 2: Yearly amount of OAP funding based on age and severity (Ontario.ca., 2022).

However, families who previously received the childhood budget and were transitioning to the new program would be allocated an interim one-time funding to purchase services (van Rensburg & Gower, 2020). The amount of funding would be $22,000 for a child under the age of 6 and $5,500 for a child or youth aged 6 – 17 (Ontario.ca., 2022a). Since there was a delay in rolling out the new program it was estimated that families would receive that interim funding for at least a year (van

Rensburg & Gower, 2020). These delays in transition cascaded over time and resulted in many children being trapped in long waitlists for services.

The Financial Accountability Office of Ontario (FAO) published an independent analysis and financial review of autism services in 2020 following a request from the Legislative Assembly of Ontario (Financial Accountability Office of Ontario, 2020). The report showed almost a ten-fold increase in spending from 2004-05 ($67 million) to 2019-20 ($608 million). The creation and scaling up of OAP and introduction of childhood budget resulted in an average annual growth of 24% of spending between 2015-16 and 2018-19. However, the highest percentage of growth (68%) took place from 2018-19 to 2019-20; and, out of the total budget of $608 million, $271 million were spent for need based services, $270 million for childhood budgets and interim one-time funding, and the remaining $67 million were spent for other services (Financial Accountability Office of Ontario, 2020).

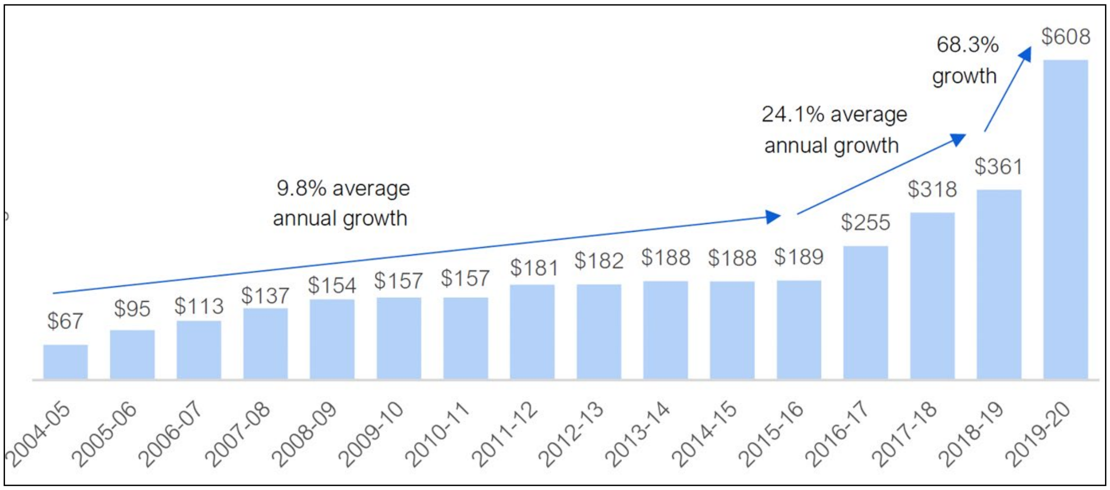


Figure-3: Autism funding trend in million dollars (Financial Accountability Office of Ontario, 2020)

According to the FAO report (2020) the waitlists also increased significantly, at the same time. Expansion of eligibility criteria for support resulted in further increase in demand. Since the province failed to meet the demand there was an increase in time on waitlists. There was an annual growth of 22.9 percent in the waitlist during the period between 2004-05 and 2011-12 and 47.8 percent between 2011-12 and 2018-19 (Financial Accountability Office of Ontario, 2020). As the Ministry was reforming the OAP in 2019-20, there was a pause in enrolling new children for the need-based funding and thus the waitlist increased by the highest 10.8% during that period leaving 27,600 children waiting for services (Financial Accountability Office of Ontario, 2020). According to Ontario Autism Coalition this number was increased to more than sixty thousand by the end of 2022 (Ontario Autism Coalition, n.d.).

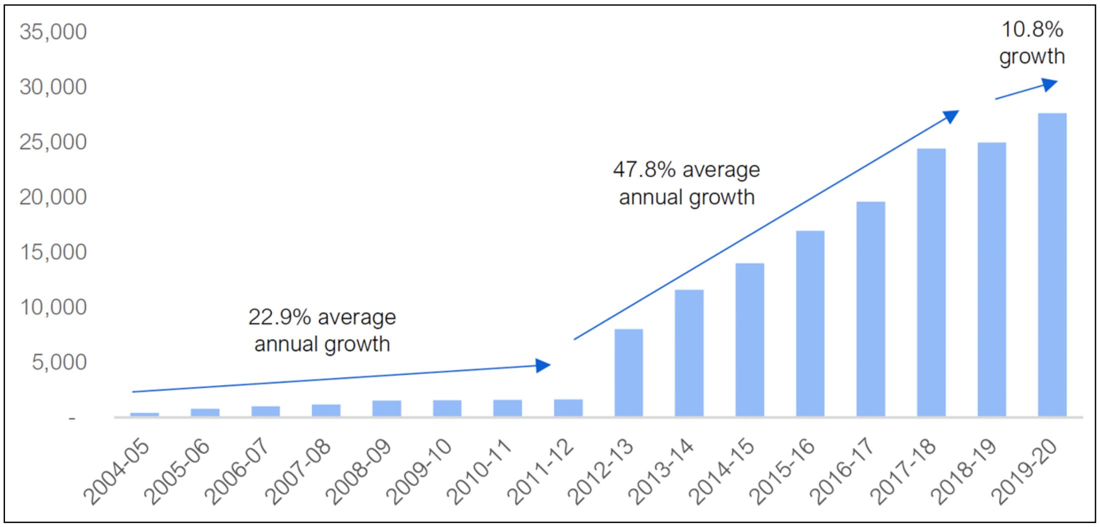


Figure-4: Trend of increasing waitlist for autism funding (Financial Accountability Office of Ontario, 2020)

Ontario government planned to launch a new needs-based autism program from 2021 with an annual budget of $600 million and enrol 8,000 children from the waitlist by the end of the year (Financial Accountability Office of Ontario, 2020). With double the amount allocated yearly compared to that of 2019, the program was launched in March 2021 and initially invited 600 children from the waitlist to get enrolled (Iudiciani, 2022). The plan for including only 8,000 children left more than fifty thousand other children who would be waiting in uncertainty for an indefinite period. However, at of the end of second year, the Ministry even failed to meet their enrolment target of 8,000 children (Jones, 2022).

FAO has published another report in 2023 on Ontario's health sector spending plan which reveals that the province has allocated $21.3 billion less than the projected need from 2022-23 to 2027-28 (Financial Accountability Office of Ontario, 2023). The government has made such a decision amid the growing needs of healthcare infrastructure and workforce. It is predicted that the current shortage of health workforce will persist and, thus, jeopardise sustainability and any plan for expansion of current health programs (Financial Accountability Office of Ontario, 2023). It is not yet clear that how the province will fund the future autism programs, but it can be assumed that a shortfall in funding will negatively affect the program and fail to clear the backlog of an increasing waitlist.

4.4 Declining School Supports for Autism

There are legislations and regulations by the Ontario Ministry of Education to accommodate and support autistic children at schools (Autism Ontario, n.d.). There is a resource guide for the educators in elementary and secondary schools to aid them inplanning and implementing education programs effectively for autistic children (Ministry of Education, 2007). A School Support Program -Autism Spectrum Disorder (SSP-ASD) was formed in 2004 in collaboration with the Ministry of Children and Youth Services, the Ministry of Education, school boards in Ontario, and other selected community agencies. These agencies, nine in number, worked with the school staff - which included the teachers and the Principals -to help them address the needs of autistic students. In addition, between the years 2006 to 2008, the Ministry funded Geneva Centre for Autism to provide training for educational assistants working with autistic children (Ministry of Education, 2007). The Policy/Program Memorandum (PPM) 140 that was released in May 2007 emphasised inclusion of ABA methods while designing programs for autistic students and the Ministry offered training sessions to school boards to explain the expectations from them (Ministry of Education, 2007). The PPM required school boards to offer special education programs to autistic students with appropriate ABA methods where necessary, and make suitable transition plans at every step during their school lives (Ontario.ca, 2021b). It was important for the schools and the families working together in order to plan for the successful transition (Ontario.ca, 2022c). Together they would design an Individual Education Plan (IEP) for each autistic child that would reflect their strengths and weaknesses, required special services or programs, learning expectations, accommodations, teaching strategies, and assessment methods (Autism Ontario, n.d. c). An Identification, Placement and Review Committee (IPRC) would decide whether or not the child required special education services or programs. This committee is comprised of at least three school board employees and the meeting is convened by the principal of the school. The parents are invited to those meetings and the student placement is made with their consent (Autism Ontario, n.d. d). The processes of IEP include the children's transitions starting from their entry to school and may continue till their postsecondary destinations and/or workplace (Ontario.ca, 2022c). However, there are concerns among parents regarding the benefit of this support services at school. Starr and Foy (2012) conducted a survey among 144 parents of autistic children in Ontario regarding their perception and level of satisfaction with the education at schools. Parents were concerned about the ability of the teachers to handle the children's behaviours at school especially those associated with aggression (Starr & Foy, 2012). They also feared being resented and discriminated against by other parents since their autistic children could take up much of the teachers' time and thus deprive the other students in the class (Starr & Foy, 2012). There was varying degree of dissatisfaction regarding their children's education and it was observed that parents of senior grade students were more dissatisfied than that of kindergarten and junior grade students – indicating that the education system was not meeting the expectations as the children grew older (Starr & Foy, 2012). Parents also perceived that there was lack of knowledge about ASD among the teachers and administrators (Starr & Foy, 2012). Moreover, the provincial government has reduced the budget for the education sector directly or indirectly and this has affected the funding for autistic children (Lord, 2020; Tranjan, 2023). Over the last few years, the provincial government has reduced the overall school budget and especially funding for autistic children. The government has reduced over $1,200 per student since 2018, and developed a plan to reduce over 10,000 teaching positions by the year 2023-24 (Tranjan, 2023). This has forced teachers to deal with larger numbers of students and work for longer hours, therefore, making it difficult for them to address the diverse needs of autistic students (Lord, 2020). The government has also stopped the behaviour plan budget (also known as legacy funding) for 4,000 children and thus forcing them into the mainstream school system where the schools are not ready with necessary educational assistants to aid them (Mulligan, 2023). This budget cut has been made in a situation where Ontario is already in shortfall of nearly $23 billion in the education sector according to the Financial and Accountability Office's prediction (Littlewood, 2023).

4.5 Support Scarcity for Autistic Adults

The Ontario Autism Program does not cover support services for adults. However, considering autism as a 'disability' there are some funding support options for the autistic people above the age of 18 (Autism Ontario, n.d. e). The Ontario Disability Support Program (ODSP) provides with some monthly income supports to cover the basic needs, shelter allowance and health benefits. The program also offers employment support in order to find and retain a job, or start a business (Ontario.ca, 2022d). But the screening process of fulfilling ODSP eligibility is rigorous, and applicants have to establish that there are severe mental or physical impairments that make them unable to work, take care of themselves, or participate in community life (Aide Canada, n.d. b).The amount of financial support is inadequate and almost half of the applications are rejected because of the strict screening process (van Rensburg & Gower, 2020). The Disability Tax Credit (DTC) is another option where the non-refundable tax credit from the federal level aids people with disability financially, or their supporting family members to reduce their income tax amount (Government of Canada, n.d.). The Ministry of Children, Community and Social Services (MCCSS) of Ontario has the Passport Program for people with developmental disability that helps adults with autism live independently and get involved in their community. The program also offers financial aids for caregiver respite services as well (Developmental Services Ontario, 2022). The Specialized and Clinical Supports Program helps people with high support and complex care needs which may include assistance in the justice system or coordination of service access across different sectors (Ontario.ca, 2022e). The Adult Protective Service Worker (APSW) Programsupports adults living in their communities "as independently, safely and securely as possible". It assists in finding and maintaining housing and social services, health care, dental care and emotional counselling (Ontario.ca, 2022e). There are also residential supports provided through different community agencies that include independent or group living arrangements, family homes through the Host Family Program, and specialised supports for mental health issues or any other additional needs (Ontario.ca, 2022e). However, autistic adults find these services inadequate compared to their needs (van Rensburg &Gower, 2020). Stringent and restrictive program criteria along with limited amount of resources and service providers put them into a “lifetime of difficult transition” to their adulthood (Milen & Nicholas, 2017).

4.6 ABA/IBI Therapy and Its Dominance

Applied Behavioural Analysis (ABA) has been the cornerstone of autism related interventions for the children as most of the services are based on its principle. ABA is comprised of behavioural interventions that manipulate environmental variables targeting to improve socially significant behaviours (Leaf et al., 2021). Autism therapies are based on these psychological principles and aim to modify behaviours of autistic persons towards ‘normalcy’ (Children’s Support, n.d.). Thus ABA is not a strictly prescribed method of therapy but rather contains some conceptually reliable techniques used in different combinations based on situations in order to bring changes in behaviour through systemic and measurable means (Keenan, 2015). These methods have been supported and recommended by many researchers as the primary method of treating autism since these are believed to have emerged from scientifically established principles of behaviour, and include the factors for effective autism intervention among children in educational and treatment settings that have produced comprehensive and lasting results (Foxx, 2008).

In the 1960s, Ole Ivar Lovaas, an eminent psychologist, introduced a behaviour therapy to treat children with autism that actually laid the foundation of today’s ABA therapy (Devita-Raeburn, 2016). Lovaas made a trial of that therapy on 20 autistic childrenfor 14 months with the goals to correct what was seen as ‘inappropriate speech and behaviour', and improve social interactions (Lovaas et al., 1973). The intervention exhibited encouraging results. The self-stimulation and echolalia (repeating other's words or sentences) were decreased, and there was improvement in behaviour and speech as the children demonstrated increased social interaction, spontaneous use of language and appropriate speech, socially accepted activities and other non-verbal behaviours (Lovaas et al., 1973). There were also improvements in their IQs and social quotients. Furthermore, those improvements persisted more among those who later lived in an environment where their caregivers were trained to carry out the behaviour therapy than those who were institutionalized (Lovaas et al., 1973). However, the therapy mostly focused on eliminating behaviours considered abnormal as per neurotypical standard rather than building skills accepting their neurodiversity.

Nevertheless, this was groundbreaking as parents finally found some hope for their children other than institutionalizing them in psychiatric facilities (Devita-Raeburn, 2016). Intensive, comprehensive, behavioural intervention started to be considered as life changing for those diagnosed with ASD and their families (Leaf et al., 2021). Initially, Lovaas's technique was based on positive reinforcement to change specific behaviours with provision for using aversive measures to prevent life threatening self-injury or aggression. Aversive measures, ranging from slaps on the thighs to low doses of electric shock, were used until the late 1980s and these were later stopped following growing controversies (Smith & Eikeseth, 2010). Nevertheless, these methods created hope among the parents of a normal life for their children and they soon started to demand ABA therapy as a default option for treating their autistic children (Devita-Raeburn, 2016). Although there have been doubts regarding the magnitude of outcomes and the quality of research on these interventions ABA, especially its early intensive methods (such as IBI), have achieved widespread acceptance in managing autism (Smith & Eikeseth, 2010). Currently, ABA is considered as a broad umbrella that includes different techniques and flexibility to provide speech and occupational therapy (Devita-Raeburn, 2016). Newer techniques namely Pivotal Response Training (PRT) and Early Start Denver Model (ESDM) based on ABA principles have emerged and gained popularity (Pantazakos, 2019). Pivotal response Treatment targets the ‘pivotal’ aspects for children’s development such as motivation, self-management and self-initiationin order to obtain generalised improvements in their behaviour (Verschuur et al., 2014). On the other hand, ESDM is a play based intensive model based on ABA teaching approach to deliver comprehensive early interventions to toddlers. This model is believed to be effective among young children aged between one and four years and, therefore, the success depends highly on early diagnosis of autism (Rogers & Dawson, 2020).

Despite the claims of success these models of interventions have been criticised for many reasons. The first backlash was regarding the use of aversive measures such as slapping, shouting and electric shocks to alter harmful behaviours during the early days of ABA (Pantazakos, 2019). Fortunately, these abusive measures are not in practice anymore and have become illegal (Pantazakos, 2019). But according to a survey conducted in 2008, there were still a reasonable number of experts who would argue in favour of those abusive practices (Devita-Raeburn, 2016). ABA therapies attempt to make autistic individuals conform to standards of normalcy and consider them problematic and unfit for society. It does not make any attempt to understand why they exhibit certain behaviours but aims to rectify them. The regimental nature of the ABA programs train children to adopt and repeat socially accepted behaviours so that they do not exhibit any sign of autism or appear different from the others. This often makes them turn into 'robots' merely repeating the phrases they have learned during their therapy sessions (Devita-Raeburn, 2016). Moreover, there has not been any strong evidence that could generalize the positive effects of ABA therapies among all autistic children. Warren et al. (2011) conducted a systematic review of the studies published between 2000 and 2010 on ABA/IBI therapies used on autistic children aged between 2 to 12. It revealed that not all children receiving these therapies exhibited rapid improvement and many even continued to demonstrate major areas of 'impairment'. There was lack of evidence of the practical effectiveness and feasibility of ABA therapies beyond highly controlled research settings, and therefore, it was doubtful whether success would transfer from these controlled studies to a larger scale in communities (Warren et al., 2011). Moreover, there are examples of autistics who were diagnosed in their adulthood, and therefore did not have ABA therapies during their childhood, have adapted to their psychological challenges (Edelson et al., 2021) – suggesting that ABA may not be a necessary intervention to achieve functionality. Despite all those controversies ABA, being the only recommended service, makes the parents feel hopeless when they are unable to enrol their children in it (Devita-Raeburn, 2016). Hence the behavioural therapy based on the biomedical understanding of autism prevails as the prime focus of the provincial support program since it has been framed as the solution towards 'normalcy'.

4.7 Need for Patient and Family Centred Care

In this section I explore how major reforms in the organization of health care services can be used to better integrate autism services, and patient and family care. The patient and family centred care model has the potential for integrating autism services to ease accessibility - which would be a great support for families who struggle navigating through the complex system. Among many recommended practices for early childhood interventions for children with special needs this is one of the mostly suggested care model which includes team process in natural and inclusive environment (Bruder, 2010). Thus, it is an integrated team approach which requires collaboration between the families and the professional care providers (Coogle & Hanline, 2016). This approach is based on the core concepts that include respect and dignity towards the care recipients and the families, sharing information, participation of care recipients and families in care and in decision making, and collaboration at all levels (Institute of Patient and Family Centred Care, n.d.). Trivette and Dunst suggested the family-centred framework through relational and participatory help giving practices in 1998, and it was observed that families with young autistic children experienced positive impacts in their lives when early interventions were given using that framework (Coogle & Hanline, 2016). A study revealed that the emergency departments that practiced the principles of family centred care enhanced experiences of the families despite the intensive nature of the environment (Nicholas et al., 2020).

In 2019, the province put forwardthe idea to form Ontario Health Teams which supports the principles of patient and family centred care model and aims to provide coordinated services to the people. The government acknowledged that the overall health system of Ontario itself was complex and, therefore, was difficult to navigate and get access (Ontario.ca, n.d. f). The lack of coordination at different levels made people to wait long to receive services, and there were duplications in terms of collecting their health history and filling out forms whenever they are transferred from one level to the next level of care (Ontario.ca, n.d. f). The concept of Ontario Health Teams was adopted with the "quadruple aim" of enhancing health outcomes of the patients and population, improving experience of patients, families and caregivers, improving experience of the service providers, and increasing value while reducing the per-capita health care cost (Ontario.ca, n.d. f). Thus, it would give an opportunity to build an integrated care delivery model through partnership among patient, families, communities, healthcare providers and leaders where the system would operate within a single clear accountability framework funded through an integrated single stream funding (Ontario Ministry of Health and Ministry of Long-Term Care, n.d.). For this purpose, health care providers at different levels across the province were invited to join the HealthTeams and included after initial assessments by the Ministry (Ontario Ministry of Health and Ministry of Long-Term Care, n.d.). So far, 54 Health Teams have been formed dividing the province into six regions and invitations have been sent to the providers to submit their applications to create four more teams (Ontario Ministry of Health and Ministry of Long-Term Care, n.d.). This is still an ongoing process which is expected to be matured over the years in order to deliver the full and coordinated continuum of care.

While reviewing the intake process by the Ministry (Ontario.ca, n.d. f), it was observed that the process was passive rather than an active one. It was up to the providers whether they would like to join the Health Team and thereby participate in the recruitment process. Therefore, all health care providers were not obliged to include themselves in the process, and while looking at the list of partner organizations it is observed that currently only a few organizations that provide autism related services are part of the Ontario Health Teams. There have been perceptions of uncertainty across the organizations because of inadequate direction from the policymakers (Embuldeniya et al., 2021). The service providers are also unclear about the value of this model and their role in it (Embuldeniya et al., 2021). In addition, the future health budget proposed by the provincial government, which is $21.3 billion less than the projected required amount (Financial Accountability Office of Ontario, 2023), may potentially affect the targeted expansion and maturity of the Health Teams and, thus, put the expected rollout at risk (Financial Accountability Office of Ontario, 2023). Surveillance is also required to identify families who are likely to fall through cracks in the system in order to provide targeted supports and reduce distress (Zaidman-Zait et al., 2018). But challenges remain as there are inadequate knowledge and experience among the staff regarding autism, and insufficient communication with the families. Overall, there are lack of resources and support, and a complex and rigid system in place that can hinder the successful implementation of this potentially benefiting family centred care (Nicholas et al., 2020).

4.8 Update on Autism Framework in Canada

There was no national autism strategy or framework in Canada until very recently when a bill was approved in Canadian parliament in March 2023 to legislate the "Federal Framework on Autism Spectrum Disorder Act". Through this act the federal health Minister was mandated to develop a coordinated federal framework that would support autistics, their families and caregivers (Canada.ca, 2023). Although the government was committed to developing a strategy by working with autistic people and their families, and the stakeholders from provinces and territories, it took so long to make it happen.

The Federal Government has spent 1.67 million dollars to conduct a broad and inclusive assessment (Canada, P. H. A., 2022a). The process was led by the Canadian Academy of Health Sciences and they published their report after conducting an assessment over a 19 month period (Canadian Academy of Health Sciences, 2022). The assessment engaged a wide range of stakeholders including families from different socio-economic groups, people with lived experience, Indigenous people, researchers and service providers. It acknowledged that the diversity of experiences by autistic people needed diversified services (Canadian Academy of Health Sciences, 2022). It also confirmed that there had been inequities in accessing services especially for Indigenous, and racialized people, and who those lived in rural and remote areas. Social acceptance and inclusion had been identified as of key factors as autistic people often felt not accepted because of the services, such as education, housing, transport and other community services, did not meet their needs(Canadian Academy of Health Sciences, 2022). The report also suggested that research works had to be improved through inclusion of diverse group of autistic people and following them up throughout their lives. Overall, a change in the system was necessary through collaboration not only among all levels in the government sectors but also with the autistic people and their families (Canadian Academy of Health Sciences, 2022).

In 2018, the Public Health Agency of Canada announced a five-year budget of $9.1 million for an Autism Spectrum Disorder Strategic Fund in order to support community-based innovative projects that would allow the autism community to obtain knowledge, skills and resources through activities that would lead to physical, mental and social wellbeing of autistic people and their families and caregivers (Canada, P. H. A., 2021). In 2021, they called for proposals from eligible organizations emphasising on addressing the negative impacts of COVID-19 on autistic community (Canada, P. H. A., 2021). A national autism conference was held in November 2022 by the Public Health Agency in Canada in order to inform and bring together the views of the autistic people, their families and caregivers, and advocates from the provinces, territories and Indigenous population towards developing the national strategy (Canada, P. H. A., 2022b). Various topics including physical and emotional safety, financial security, autism-inclusive support, employment, housing, overall inclusion and equity aspects were discussed in the conference. It was expected that the wide range of discussion would be helpful for prioritising areas for action for an inclusive strategy (Canada, P. H. A., 2022b).

On March 30, 2023, Bill S-203 regarding the Federal Framework on Autism Spectrum Disorder received Royal Assent (Canada.ca, 2023). The Parliament recognised the needs of timely financial and social supports for autistic persons throughout their lives including their families since autism was a lifelong condition (Parliament of Canada, n.d.). According to the act, the health minister is required to coordinate with a wide range of stakeholders such as the ministries of finance, revenue, employment and social development, and any other relevant ministries, representatives of provincial governments, people with lived experience, researchers, service providers, autism advocates, Indigenous community, and organizations focusing on autism. Scope of this framework would be extended to look for long-term solutions to support autistic people above 18 years of age who are often left out in current provincial programs (Parliament of Canada, n.d.). According to the Act, the minister is obliged to develop and present the framework within 18 months from the time of its (the Act) legislation (Parliament of Canada, n.d.).

However, it is notable that the Act defines autism as a ‘neurodevelopmental disorder’ resonating the biomedical view of the condition; therefore, there is a possibility that the framework would be guided by this dominant view looking to ‘cure the disease’ and not by the concept of neurodiversity. Despite this, parents and families have welcomed the fact that finally the government has considered the matter seriously enough to take this ambitious step while, at the same time, raised concern that it would take a long time to roll out the planned activities across the country (Tran, 2023).

DISCUSSION

The Canada Health Act (1985) ensures that the state takes responsibility of every Canadian's physical and mental wellbeing without any barriers irrespective of someone's status in the society. The residents of Ontario with any type of disabilities are protected by the Ontario Human Rights Code from discrimination or harassment in any form and they are entitled to receive services, housing or employment. But in case of autistics, we do not observe this to happen in reality. Society influenced by the biomedical system views autism as an anomaly to normalcy, and thus makes attempts to either cure autistic people or leave them behind. Due to the 'ableist' attitude of the society autistics face discrimination, negative stereotyping and abuse, and are often stigmatized. They are abused at home, bullied at school, and they find it difficult to access services or get employed.

The Ontario Autism Program is guided by a neoliberal ideology as ABA (Applied Behaviour analysis) therapy is the main element that is funded by the government. The core idea of these services is to cure autism or to modify their behaviour towards normalcy, so that they could be accepted in the society without being frowned upon. Dominant biomedical researchers have promulgated ABA as a solution towards cure and despite controversies regarding its efficacy it has gained popularity among experts, parents and even some autism advocates. These services are expensive and are not covered by the provincial health insurance program (OHIP). The families have to apply for funding to cover the expenses of ABA therapies and, after a long waiting period, what they receive only covers part of the total cost. The waitlist for the provincial funding has been doubled since 2019 and currently more than 60,000 children are waiting to be enrolled. Under the circumstances, many children will start receiving the services late, some will age out before achieving the full benefit of the program, and some may not receive them at all. Despite the fact that there were several reforms in the program and budget was increased significantly the province could not manage the fund efficiently. The autistic people and their families were not adequately consulted while designing and reshaping the program and thus their needs were not properly addressed. This exhibited the paternalistic and patronising behaviourderived from the dominant biomedical view of considering autistic people unable to make decisions for themselves. Furthermore, frequent changes in the program were not well planned out which made it difficult for the workers who would actually execute it. There is not enough support for adult autistics and, therefore, parents have concerns about the future of their children once they reach adulthood. Autistic adults face challenges to find suitable jobs or access care, and struggle to live independently. They often live in poverty and experience homelessness in absence of necessary government support.

Families find it hard to navigate through the services in a complex healthcare system. They have to actively browse through services that are appropriate for their children in a scenario where information is not readily available and inter-organizational coordination is poor. Newcomers in Canada struggle more as they are already in a difficult situation while adopting themselves in a new country. All these stress factors such as long waiting time, difficulty in accessing and affording care, worries about the future of their children negatively affect physical and mental health of the parents and family members. These often result in verbal, physical or emotional abuse of children, and sometimes abandonment from family. There is no reliable information available at the Ministry about the number of people with developmental disabilities living in abusive home conditions. We have seen an end to the institutionalization era long ago but now it appears in new forms. Apart from abuse and abandonment autistic people are often inappropriately placed in the psychiatric facilities irrespective of their age. Autistic adults who are in high needs experience challenges to find a suitable livelihood and struggle to live independently.They sometimes face homelessness, and end up in shelter homes – if they are lucky enough to find one, or sometimes even in jails. The patient and family centred care could be beneficial to reduce the inconvenience experienced by autistics and their families while navigating and accessing services in a complex healthcare system. Integration of autism services and expansion of this model is therefore necessary to improve overall stress they are already experiencing.

Parents and families played an important role in developing and reshaping the autism program after the post deinstitutionalization era. They lobbied, filed cases at court, and organized meetings and processions for recognition of their autistic children's rights and needs. The extent of involvement of people with lived experience of autism was not much since their role in that movement had been suppressed by questioning their ability to determine what was beneficial for them. It was the constant push from the families that played a crucial role to convince the policymakers understanding the importance to address these needs and hence the OAP was initiated. Since the concerns of autistics were not considered, measures to ‘cure’ their autism and ‘rectify’ their behaviours became the prime objective of the program. Parents embraced ABA/IBI therapy with the hope to cure their children. However, these services have never been adequate to meet the demand and a huge backlog has been created keeping a large number of children on waitlist. Autistic children struggle to get proper education because schools are not welcoming due to lack of trained staff and resources to support them. Despite all these facts the provincial government has decided to reduce the health and education budget that would further deteriorate the situation.

Foucault (1998) described the main focus of dealing mental health issues “cruel and controlling” as it tends to either cure the problem or to isolate the people who are suffering in order to protect the society. The autistic community seems to be trapped in between the biomedical and neurodiversity debate and, therefore, there are fewer initiatives for their acceptance and meaningful inclusion to the society. The support programs are guided by the neoliberal ideology that emphasises on individual responsibility, recovery and productivity. But since the return on investment is low based on that ideology, government seems to be reluctant on giving it enough importance. Hence, we observe the budget cuts in both health and education sectors that put autistic people in further uncertainty. Because of its low incidence, autism did not draw much attention of the policymakers. So far the province has acted reactively to the pressure created by parents of autistic children but the concerns of those with lived experience were not addressed.

CONCLUSION

Canada is finally going to have anational autism framework and the groundwork of developing the strategy is ongoing. According to the Ministries' website a wide range of stakeholders including experts, families and people with lived experience will be consulted to make it an inclusive strategy. It will be interesting to see how human rights perspectives and socio-political factors would be addressed in the framework in a scenario where biomedical view and neoliberal ideology are dominant, and how the programs would be rolled out at provincial levels. It should be ensured that the voices of autism community and their families are heard this time, and their challenges and concerns are well addressed. Need for diversified services, social acceptance and inclusion have been identified as some of the key areas to be incorporated in the framework. In order to achieve the universal health coverage and protect the rights of every person the support services need to be made available and easily accessible to all. Therefore, there should be more advocacies to include these services under the provincial insurance plan. Autistic people should be accepted along with their differences, and programs should be designed to explore their individual potentials that could contribute to the society rather than trying to make them fit into the so called normal people's world.

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