



Autism in Canada: Considerations for future public policy development

Weaving together evidence and lived experience



May 2022

Canadian Academy of Health Sciences

The Canadian Academy Of Health Sciences

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The Canadian Academy of Health Sciences

The Canadian Academy of Health Sciences (CAHS) mobilizes the best scientific minds to provide independent and timely assessments that inform policy and practice addressing critical health challenges affecting Canadians. CAHS helps put change into action for a healthier Canada.

The CAHS recognizes Canadians of great achievement in the academic health sciences. Founded in 2004, CAHS now has over 850 Fellows and appoints new Fellows on an annual basis. The organization is managed by a voluntary Board of Directors and a Board Executive.

The Academy brings together Canada's top-ranked health and biomedical scientists and scholars from all disciplines across our nation's universities and its healthcare and research institutes to make a positive impact on the urgent health concerns of Canadians. These Fellows evaluate Canada's most complex health challenges and recommend strategic, actionable solutions.

Since 2006, CAHS has successfully engaged the sponsorship of a wide variety of public and private organizations representing patients and families, professionals, health system leaders, policy-makers, and service and private industry providers. It has co-invested in rigorous, independent assessments that address key health issues with outcomes that have shaped its strategic policy and initiatives.

Acknowledgements

The Canadian Academy of Health Sciences (CAHS) established a committee structure to conduct this assessment on autism. All committees included a diversity of very accomplished Autistic adults, family members, clinicians, and researchers from across Canada. We encourage you to read their biographies on [our website](#).

Committee members worked closely together and, with staff support, collectively spent well over 3,000 hours reviewing documents, considering stakeholder input and discussing material related to this assessment. All of their work was done virtually, as this assessment took place during the COVID 19 pandemic. Their commitment to this project was remarkable. The CAHS greatly appreciates their significant contribution.

The Oversight Panel provided overall leadership and developed the assessment report:

- | | |
|------------------------------------|--------------------|
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| Vice Chair: Aaron Bouma | ShanEda Lumb |
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| John “Jackie” Barrett | David Nicholas |
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An **Indigenous Advisory Committee** provided guidance to the Oversight Panel on how to best to reflect the unique issues of First Nations, Métis and Inuit Peoples within the context of a pan-Canadian assessment:

- Lisa Aitken, worked with and learned from many Nations in Ontario
- Grant Bruno, member of Samson Cree Nation
- Michelle McCallum, member of Lac La Ronge Indian Band
- Kennith James Skwleqs Robertson, member of Secwepemc Nation
- Caroline Tait, member of Métis Nation Saskatchewan and Métis Local 126

A **Lived Experience Committee** advised staff and the Oversight Panel on language, process and the overall report to ensure that our key findings are meaningful for Autistic People and their families.

- | | | |
|-----------------------|-----------------------|-------------------|
| Lisa Aitken | Shirley Chua-Tan | Kimberly Maich |
| John “Jackie” Barrett | Umbreen Rosa Gastaldo | Michelle McCallum |
| Aaron Bouma | Adam Glendon | Kennith Robertson |
| Mark Chapeskie | ShanEda Lumb | |

This group of **Peer Reviewers** provided feedback on the objectivity and quality of a draft of the assessment report. Their submissions, which will remain confidential, were considered in full by the Panel, and many of their suggestions were incorporated into the report. They were not asked to endorse the conclusions, nor did they see the final draft of the report before its release.

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A dedicated **Staff Team** worked alongside the committee members, reviewing the literature, facilitating stakeholder engagement and supporting meetings:

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Message from the CAHS President

On behalf of the Canadian Academy of Health Sciences (CAHS), I am pleased to introduce this Assessment on Autism. I have every confidence that this important piece of work will inform policy makers, for years to come, as they consider strategies and programs related to autism.

The CAHS would like to express its sincere appreciation to the Chair of the Oversight Panel, Lonnie Zwaigenbaum, its Vice Chairs, Aaron Bouma and Mélanie Couture, as well as all the members of the Oversight Panel and Working Groups for their immense contributions to this assessment.

The staff that supported the panel also did an outstanding job. I would like to specifically thank the Project Director for this assessment, Sonya Kupka.

This Assessment inaugurated a new approach to CAHS' assessments, whereby lived experience individuals were included in the Oversight Panel and the Working Groups to better inform the scientific process.

I would also like to thank the peer-reviewers who provided excellent feedback on the draft report and the members of the CAHS Assessment and Scientific Affairs Committee for their guidance throughout the process.

Finally, I would like to recognize the Public Health Agency of Canada (PHAC) who sponsored this assessment. We are grateful that PHAC turned to the expertise and experience of CAHS for this work, and we applaud its ongoing commitment to evidence-informed policy making.

Sincerely,



Sioban Nelson, RN, PhD, FAAN, FCAHS

President, Canadian Academy of Health Sciences

Message from the CAHS Chief Executive Officer

The development of this report was an incredible journey. Throughout, we were all guided by knowing the importance this assessment would have for the lives of Autistic people, their families, friends, the greater community — and beyond.

There are many individuals and organizations across the country to thank. They provided guidance, information, and feedback to the process. There were thousands of individual touchpoints made during our consultations. Many shared their personal stories. The efforts of participants and volunteers contributed significantly to inform this final report.

I participated in many of these discussions, and I certainly learned a great deal about autism, from multiple perspectives. I think that it is fair to say that all those who participated in this process did as well. I am proud of the work we accomplished together and am confident that this report will continue to enable policy makers — and Canadians in general — to learn more about autism and Autistic people.



Serge Buy

Chief Executive Officer, Canadian Academy of Health Sciences

Message from the CAHS Oversight Panel

The Canadian Academy of Health Sciences appointed us to produce a report that could inform the development of a national autism strategy. The key findings in this report not only reflect up-to-date academic evidence, policy and practice about autism, but also the perspectives of the many diverse Canadians who have informed the framing of this report.

To the best of our abilities, we have implemented authentic and inclusive collaboration and co-development throughout this assessment process. We learned so much through this open and ongoing dialogue amongst committee members and multiple stakeholders. Through this process, we developed a deeper understanding of autism and the complexity, diversity, and breadth of needs, priorities and aspirations of Autistic people and their families in Canada. We hope that this dialogue can continue through attentive and respectful listening and centring of Autistic people's perspectives.


Recognition of the neurodiversity paradigm and the social model of disability is fundamental to ensuring a positive transformation of society towards acceptance and true inclusion for all. It is also necessary so that we can modulate the types of supports and services available to focus on the expressed needs of Autistic people.

This work would not have been possible without the unwavering and committed support of the Working Groups, the Indigenous and Lived Experience Advisory Committees, and the staff team at the Canadian Academy of Health Sciences. We also thank our families for allowing us the time away from them to contribute to this important endeavour.


We would also like to acknowledge the input of the stakeholders from across Canada, especially Autistic people and their families. We are grateful to the people from First Nations, Inuit and Métis communities who participated in this project. They allowed us to discover a culture rich in the acceptance of all differences and respectful of nature — an inspiration for the appreciation of neurodiversity.


Making our country the best possible place for Autistic people and their families to live and thrive is so important! We are very excited to present this report that we hope will lead to concrete policy change. We did not always agree at first, but we always found common ground and this body of work reflects that.

We thank the Canadian Academy of Health Sciences and are honoured that we had the opportunity to collaborate on this important work. The Assessment on Autism Oversight Panel has now completed and is respectfully submitting this assessment report.


Lonnie Zwaigenbaum, Chair


Shirley Chua-Tan


David Nicholas



Aaron Bouma, Vice Chair

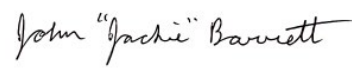

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Table of Contents

- Summary** 15
 - Autism in Canada..... 15
 - The Assessment on Autism 15
 - Themes 15
 - Conclusion 20
- Chapter 1: Overall Approach**21
 - 1.0 Introduction22
 - 1.1 What is Autism? 23
 - 1.2 Canadian Context27
 - 1.3 International Context..... 29
 - 1.4 Why a National Autism Strategy? 34
 - 1.5 Meaningful Engagement of Autistic People..... 35
 - 1.6 The Charge and Methodology 39
 - 1.7 The Report..... 48
 - 1.8 Chapter Summary 51

Chapter 2: Priority Considerations that are Cross-Cutting	52
2.0 Autism, Diversity, and Intersectionality	53
2.1 Autism and Indigenous Peoples	56
2.2 Autism and Diversity related to Race and Ethnicity	63
2.3 Autism and New Canadians and Language Minorities.....	65
2.4 Autism, Gender, Gender Identity, and Sexual Orientation.....	67
2.5 Autism and Diversity of Family Structures	70
2.6 Complexity of Support Needs	72
2.7 Autism and Rural and Remote Communities.....	73
2.8 Autism and Socioeconomic Status.....	74
2.9 Addressing the Needs of Equity-Seeking Groups	75
2.10 Chapter Summary	76
Chapter 3: Social Inclusion	77
3.0 Elements of Inclusive Communities	78
3.1 Addressing Stigma and Ensuring Human Rights	79
3.2 Promoting Physical and Emotional Safety	98
3.3 Enhancing Community Participation and Accessibility	112
3.4 Social Inclusion through Technology	125
3.5 Chapter Summary	130

Chapter 4: Diagnosis, Supports, and Services	131
4.0 Introduction	132
4.1 Equitable Access to Diagnosis, Supports, and Services.....	133
4.2 Recognition and Diagnosis across the Lifespan.....	147
4.3 A Lifespan, Family-Centred Approach.....	153
4.4 Preschool and Early Childhood (0 - 5) Supports and Services.....	161
4.5 Supports and Services for School-Aged Children and Adolescents	171
4.6 Adulthood	192
4.7 Advances related to Neurobiology	206
4.8 Chapter Summary	206
Chapter 5: Economic Inclusion	208
5.0 Introduction.....	209
5.1 Financial Stability	209
5.2 Post-Secondary Education and Lifelong Learning.....	219
5.3 Employment Pathways.....	228
5.4 Autism-Inclusive Housing Options.....	240
5.5 Chapter Summary	251
Chapter 6: Positioning for Impact: Ongoing Evaluation	252
6.0 Introduction	253
6.1 Data Collection and Sharing.....	255
6.2 Research.....	260

6.3	Collaboration: From Data and Research to Practice	268
6.4	Chapter Summary	273
	Report Conclusion	274
	Glossary	275
	Reference List - Alphabetized	281
	Index	406

Summary

Autism in Canada

*Autism*¹ is a neurodevelopmental condition that impacts individuals across the lifespan. There is diversity in how this condition presents and evolves over time. *Neurodiversity* describes autism as a condition or identity rather than a disorder. This line of thinking reflects a more neutral framing of the neurological differences inherent to autism. Many Autistic individuals and their families face social and economic barriers that affect their quality of life. Co-occurring conditions also introduce further complexities and challenges.

About 1 in every 50 (2%) Canadian children and adolescents is autistic, according to the Public Health Agency of Canada. This rate has continued to increase over time. Less is known about how many Autistic adults there are in Canada.

The Assessment on Autism

Over a 19-month period, the Canadian Academy of Health Sciences conducted an arms-length Assessment on Autism on the themes of *Diversity, Social Inclusion, Diagnosis, Supports, and Services*, and *Economic Inclusion*.

The assessment involved a comprehensive evidence review and pan-Canadian stakeholder consultation. Guided by shared expertise, the assessment concentrated on what could be learned from research evidence and stakeholders about how to better serve and support Autistic Canadians and their families. This assessment culminated in the report *Autism in Canada: Considerations for future public policy development*.

Themes

Intersectionality and Diversity

Autism intersects with other identities such as race, ethnicity, culture, socioeconomic status, gender, and sexuality. This *intersectionality* creates diversity in experiences and needs.

Research about the diversity of Autistic people in Canada is limited. But, it is known that they face additional and unique barriers especially if they live in rural and remote areas or are part of *equity-seeking groups*. At the same time, there are opportunities to build on the strengths of this diversity.

¹ All teal, italicized terms can be found in the glossary at the end of this report.

Approaches developed in partnership with equity-seeking groups, such as Indigenous and *racialized people*, can help better meet their needs and build on their strengths. Indigenous-led, culturally-relevant, and localized approaches to supporting Autistic people are central to respecting, recognizing, and addressing the distinct experiences of Canada’s First Nations, Métis, and Inuit peoples. Traditional and cultural Indigenous practices could also offer valuable contributions to our understanding of *inclusion* and supports and services that may benefit all Autistic people.

Social Inclusion

Social inclusion is an integral aspect of wellbeing and quality of life for all Canadians. Inclusive communities for Autistic people offer belonging, acceptance, meaningful participation, and emotional and physical safety. They also provide equitable access and accessibility to resources and opportunities.

Addressing Discrimination and Promoting Autism Acceptance

Autistic people do not always feel safe or meaningfully included in their communities. Such experiences can have harmful outcomes to their health, safety, and quality of life.

Stigma and discrimination can be addressed by shifting public attitudes towards *autism acceptance* and awareness through public campaigns, social contact, training, and education programs. Sometimes Autistic people need increased support to make decisions about their lives. It is important that this decision-making support does not place them at risk for financial abuse or neglect. It should promote dignity and maximize autonomy as much as possible.

Physical and Emotional Safety

Physical and emotional safety can be fostered by promoting autism-inclusive, *neuro-affirming*, and accessible spaces, programs, and understanding in local communities. Collaborative service delivery and specialized training amongst public safety personnel and mental health providers may improve crisis interactions and outcomes. Best practices for suicide prevention can also be adapted to better meet the needs of Autistic individuals at risk for suicide.

Promoting Community Participation

Improving the accessibility and inclusion of public transportation, recreational facilities, leisure programs, and technology can enable community participation of Autistic people. These improvements can occur through planning, infrastructure, localized needs assessments, and staff development. Other promising practices include skill-building techniques and providing autism-specific *accommodations* and supports.

Diagnosis, Supports, and Services

Equitable Access

Each province and territory offers autism diagnostic and support services. Yet, there is wide variability in what is available which can contribute to delays and disparities. Some Autistic people are particularly disadvantaged, such as those living in rural and remote areas, equity-seeking groups, and Autistic adults.

Addressing these systems gaps could be supported through *capacity building* of a diverse and skilled autism workforce, expansion of tele- and e-health, and enhanced navigation services. Other jurisdictions have also implemented national clinical autism guidelines or consensus statements, safety standards, and increased transparency regarding wait times.

Recognition and Diagnosis

It can take months or years for a child to access a publicly-funded diagnostic assessment for autism. These assessments may not be available in adulthood. A stepped approach can address such barriers. In a stepped approach, first a primary care physician is consulted. If the diagnosis is too complicated or they do not have the skills, either a specialist or diagnostic team would become involved. Research to develop valid and meaningful, strengths-based diagnostic tools and improve access to diagnostic assessments for Autistic adults is also suggested.

Families

The responsibilities of supporting an Autistic individual within a complex and fragmented system can affect all *family members*. Adopting family-centred services available across the lifespan can promote the health and wellbeing of the entire family. It also empowers families to be involved in service delivery.

Autism Supports and Services

Early Childhood Supports and Services

Young Autistic children benefit from early access to supports and services because this is a time of significant development. A stepped service approach can be helpful. This approach is needs-based, rather than constrained by diagnosis or to a single intervention. It is driven by assessments of the child's needs (e.g., in terms of service type, amount, and duration) in the context of their family and culture.

Effective early intervention approaches:

-
- Are of needs-based intensity and duration,
 - Are provided with fidelity by skilled *service providers* in and across multiple community settings,

- Promote family participation and integration into daily life, and
 - Are accompanied by continuous and rigorous evaluation of child- and family-oriented outcomes.
-

Naturalistic developmental behavioural interventions (NDBI) can exemplify these principles. Early intervention services can be offered across multiple settings, including early learning and childcare settings and the home.

School-Aged Supports and Services

Equitable access to school and community supports across a range of life domains can promote academic success, life and social skills, and improve mental health. Peer acceptance and inclusion programs can also help prevent bullying and other forms of exclusion.

Transition to and through Adulthood Supports and Services

Leaving secondary school represents one of life's most significant transitions. It can be a challenging time for Autistic individuals as services and supports end with few comparable options available for Autistic adults.

Implementing health and education transition policies and practices may help manage and prevent mental and physical health challenges and promote better adult outcomes. However, research about autism in adulthood is limited. For example, not a lot is known about the support needs of Autistic parents and the growing population of older Autistic people.

Economic Inclusion

Economic inclusion involves removing barriers to financial stability, managing autism-related costs, and maintaining meaningful employment. It also involves the impacts of financial instability over time on individual and family wellbeing.

More than half of Autistic Canadians rely on disability benefits. Financial stability can be supported by reforming access to benefit and tax credit programs, offsetting common out-of-pocket costs, and making sure that resources are available to support Autistic persons and their families in managing money and planning for the future. Offering flexible income and/or medical benefits and encouraging job participation through more flexible disability policies may also promote more stable employment pathways.

Labour market participation of parents of Autistic individuals benefits the entire family. It can be supported through workplace policies and provisions offered through unions, employee assistance plans, and human resources.

Post-Secondary Education Pathways

With appropriate supports, many Autistic individuals can participate in post-secondary education, but they are still not enrolling to the same extent as non-autistic and other disabled students. Available academic supports and accommodations do not always meet the diverse range of Autistic students' needs and abilities.

Autism-specific programs offer a combination of supports such as transition services, residence life planning, peer mentoring and support groups, tutoring, academic accommodations and counselling, and *life skills* coaching. While such programs are offered in the United States, few exist in Canada.

Post-secondary costs can be prohibitive for Autistic students. Allowing for more flexible tuition requirements that consider the extra time needed by some Autistic students to complete their degrees can help decrease these costs. Autistic students can also benefit from enhanced access to internships, cooperative education, and campus employment services.

Employment Opportunities

Despite many Autistic people wanting to work, many are not included in the labour market. There are societal benefits of inclusive workplaces and Autistic workers' contributions. Some ways to create more inclusive workplaces and improve employment outcomes can involve:

-
- Providing autism-inclusive employment supports and accommodations by knowledgeable providers,
 - Access to supported work experience and internships,
 - Addressing benefit disincentives, and
 - Promoting workplace autism acceptance.
-

Autism-Inclusive Housing Solutions

With the limited availability of affordable housing in many regions, autism-inclusive housing is in even shorter supply across Canada. The need is only expected to grow. Autistic individuals without co-occurring *intellectual disability* or physical impairments may not be prioritized or eligible for supportive or affordable housing. Autism-inclusive or friendly housing means residential spaces and models that consider the unique needs of Autistic people within the design, layout, activities, geographic location, and where necessary, staffing complement and access to other community supports, such as mental health services. The accessibility of affordable housing often does not consider modifications relevant to many Autistic people.

Improving housing supply and adequacy could include:

- Adopting person-centred planning and skill acquisition approaches,
 - Designing and scaling up autism-inclusive housing models,
 - Addressing waitlists and eligibility,
 - Hiring skilled support staff,
 - Offering nearby or linked community supports, such as access to mental health services,
 - Engaging in long-term planning with individuals and families, and
 - Proactive social and community planning.
-

Positioning for Impact

Data collection and sharing, research, and collaboration are key enablers for system improvement. To obtain more meaningful knowledge, the data on autism diagnosis rates needs to be linked to information about service use and health and wellbeing outcomes. It is only through a new data sharing infrastructure that such valuable information can be produced.

Most autism research has focused on causes, prevention, and characterization in childhood. This research offers important insights, but overlooks many of the day-to-day needs and priorities of Autistic individuals and their families across the lifespan.

Strategies to improve future autism research include:

- Balancing research across multiple areas and disciplines of research, including clinical, systems, biological, and social sciences,
 - Alignment to the priorities and needs of Autistic people and their families,
 - Recruiting diverse Autistic collaborators, researchers, and participants,
 - Longitudinal designs about changes over the lifespan,
 - Cross-sectoral research by transdisciplinary teams,
 - Focusing on service delivery, quality improvement, workforce capacity, and systems-level program evaluations,
 - Translational efforts from research to practice, and
 - Building capacity of autism researchers, including Autistic researchers.
-

Conclusion

This assessment highlighted the breadth and complexity of needs of Autistic people and their families. Sustainable and efficient health and social care systems can flexibly address the broad range of needs of this growing population. Such system change is likely only possible through ongoing collaboration amongst all levels of government and Autistic people and their families.



Chapter 1: Overall Approach

Summary Point

Autism is a neurodevelopmental condition that impacts individuals across the lifespan. There is diversity in the way in which this condition presents and evolves. Co-occurring conditions introduce further complexities and also affect quality of life.

1.0 Introduction

Across Canada, *Autistic people*² – children, youth, adults, and older adults – require a variety of supports in terms of health, education, and social services. There is considerable variability in access to services offered across provinces, territories, and regions, as well as across the lifespan. Many *family members* play a key role in supporting Autistic family members.

A national *autism* strategy has been suggested as a way to provide a compelling central vision and direction to improve the health and wellbeing of Autistic children and adults and to support parents and caregivers (Government of Canada, 2021a). The Canadian Academy of Health Sciences' Assessment on Autism was commissioned to inform the potential development of this strategy.

The Canadian Academy of Health Sciences' Assessment on Autism involved and built on an extensive analysis of published research related to the needs of Autistic people. It also focused on discerning best and promising practices from the academic literature and pan-Canadian/international policy to meet these needs at individual, community, and societal levels. Further, significant stakeholder engagement generated input from Autistic individuals, families, *service providers*, and key pan-Canadian, provincial/territorial, and local and grassroots organizations. This engagement also provided a practical perspective on the wide range of issues and possible solutions relevant to Autistic people.

An essential cornerstone of this assessment was collaborative decision-making with Autistic individuals and family members as members and leaders within the assessment's committee structure. A key value of collaborative decision-making was citizen engagement, demonstrated through our commitment to seek out and amplify the direct voices of Autistic people, while also recognizing that some Autistic people may rely on family members or other *supporters* to have their voices heard. Throughout this assessment, this first-person perspective has been presented in quotes from Autistic individuals and family members who participated in our stakeholder consultation.

² We have used identity-first language in terms of autism and disability throughout this report to align with the growing consensus among those with lived experience and in the academic literature.

1.1 What is Autism?

“We’re complicated and diverse, and no two Autistic people are the same, even if we have certain things in common. We all have different needs, different personalities, and various things to contribute.”

- Autistic adult

1.1.1 Evolving Understandings of Autism

How autism is understood has shifted significantly since Kanner (1943) first described the condition almost 80 years ago. The implications of this shift are only beginning to be understood and open up many new avenues for dialogue and research. Critically, there is growing recognition of the importance of person-centred and strengths-based approaches that emphasize *inclusion, self-determination*, quality of life, including health and wellbeing, and equitable opportunities similar to those afforded to non-autistic individuals. Incorporating this modern understanding of autism has had implications for the framing of the questions guiding this assessment and the analysis of evidence that informed the key findings. Guided by the shared expertise of Autistic people, families, academics, and clinicians, this work has concentrated on how current and future policy and service provision can better serve and support Autistic Canadians of all ages and their families.

Concepts related to autism have and will likely continue to evolve. As such, there is ongoing debate and a diversity of perspectives within the expansive field of autism studies, which spans multiple disciplines from genetics and neuroscience, to sociology and disability studies, to medicine and economics. The multiple paradigms across this field have been considered and acknowledged within this assessment. We did not embrace one lens or paradigm to the exclusion of others, but rather, integrated the most up-to-date evidence from within and across multiple disciplinary and methodological perspectives (Figure 1). The multiplicity of perspectives shared in this report is aligned to the scope and charge of this assessment as a policy-oriented evidence synthesis process aimed at guiding a policy-maker audience (see Charge and Methodology for further details).

Approaches that focus exclusively on autism as a behaviourally-defined diagnosis associated with deficits and impairments have increasingly been critiqued and contrasted to more emancipatory or critical social science perspectives, through, for example, the *neurodiversity* paradigm and the social model of disability (or autism). While an exhaustive discussion of these ongoing debates is beyond the scope of the current assessment, prior to providing a characterization of autism, we feel it necessary to highlight some of these tensions, and the rationales for some of our choices pertaining to terminology and positioning within this report.

Biomedical approaches have typically focused on classifying and categorizing autism based on a shared set of diagnostic criteria, typically referred to as symptoms³. The Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013), currently in its fifth edition, and the International Classification of Diseases (ICD-11), currently in its 11th edition (World Health Organization, 2019), are the major texts through which the diagnostic boundaries of autism have been understood within the medical and scientific community over the past four decades. This approach has offered a shared understanding of, and lexicon for, autism from which to study any number of scientific, sociological, or clinical questions. By many, this shared lexicon is viewed as essential to representing the clinical needs and heterogeneity of autism. Yet, the language used within DSM-5 or ICD-11 focuses on deficits, which leads to broader discourse about autism that has been critiqued as pejorative, ableist, and stigmatizing (Yergeau, 2017; Bottema-Beutel et al., 2021).

The neurodiversity paradigm has diverged from this approach to consider neurological differences as an integral aspect of human variance, and by extension, a distinct identity (Orsini, 2012) as further discussed in Chapter 2. When neurodiversity is considered in tandem with the social model of disability (discussed further below), the barriers experienced in relation to autism can emerge through a mismatch between the surrounding environment and the individual, particularly when these environments are set up for non-autistic populations. Accordingly, this assessment, through the invaluable contributions of Autistic people, their families, and other supporters, has been shaped by recent research and theoretical understandings of autism as a condition or identity, as well as a DSM-5⁴ defined diagnosis.

Given the breadth and complexity of the issues covered in this assessment, it was important to consider multiple theories and paradigms to meaningfully frame and contextualize the available evidence. Feedback from our committee and stakeholder consultations (see below), as well as recommendations from the peer-reviewed literature (e.g., Bottema-Beutel et al., 2020), were also used to inform the language of this report. Specifically, we aimed to use descriptive terms that avoided ableist, pejorative, and/or stigmatizing connotations. For clarity, we have introduced the language and classifications of the DSM-5 in some areas of the report, but have amended the language along these lines to summarize the evidence and articulate key findings (see Importance of Language section for further details). For example, we have used autism throughout this report in place of autism spectrum disorder. The hope and commitment to adopting this approach to language is both to be respectful of Autistic people and to promote a more fulsome discourse.

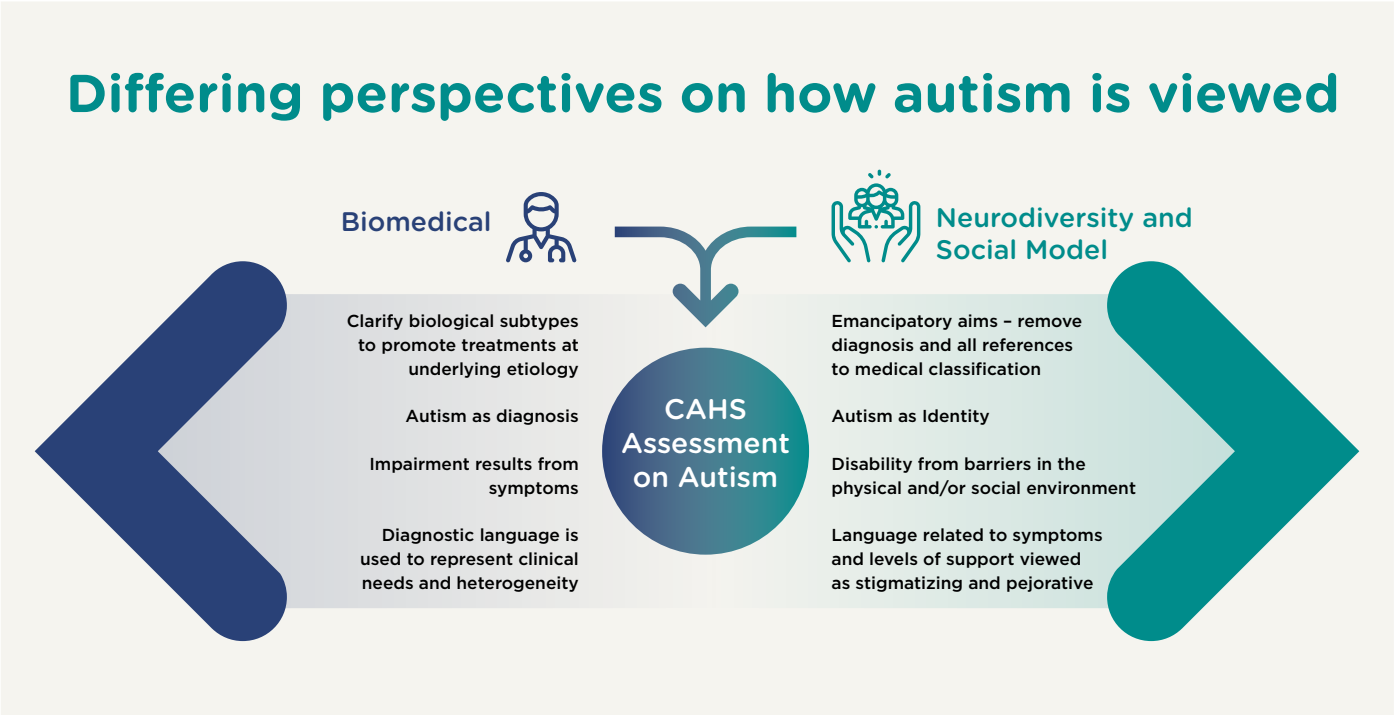
³ We have chosen in this report to use characteristics in place of symptoms where this substitution does not impact the original intent of the evidence.

⁴ Because the DSM-5 is the primary diagnostic system used in Canada, moving forward we only refer to the DSM-5 in terms of diagnosis, and not the ICD-11.

Furthermore, following the emancipatory aims of neurodiversity and the social model, wherever possible we have identified evidence-informed ways to remove existing barriers within contexts and systems. We have also described biomedical or clinical strategies used to lessen the possible challenges associated with this condition. Each approach is grounded in evidence and may offer opportunities to improve the health, wellbeing, and opportunities of Autistic people. For example, to support health, considering biologically-based strategies to mitigate the impacts of conditions associated with autism could be beneficial, as well as person-centred strategies to empower self-management of health conditions and enhance access to and experience within the primary care system.

Additionally, in order to recognize and acknowledge the wide diversity of neurological differences amongst Autistic people, we have addressed and discussed, where pertinent, co-occurring conditions, such as *intellectual disability*, and those related to mental and physical health. While these conditions have been viewed in this report as distinct from (that is, related but not intrinsic to) autism, they add layers of complexity in terms of the supports and services that can enhance function, participation, and quality of life.

Figure 1. Balancing the Evolving Understandings of Autism within this Assessment.



1.1.2 Characterizing Autism

Autism is a neurodevelopmental condition that manifests across the lifespan and affects how people perceive and process information, communicate, and interact with others (Milton, 2021; Department of Health and Social Care, & Department for Education, 2021a). Autism is also often referred to as a spectrum condition because it can present very differently in people, although the limit of its heterogeneity remains an open scientific question (Mottron & Bzdock, 2020). It encompasses many defining social and communication characteristics, with Autistic individuals presenting with different combinations of these characteristics and experiencing them to differing degrees (Ripamonti, 2016).

Sensory over- and under-sensitivity and intense and/or highly focused interests⁵ are core features of autism, while perceptual and self-regulation differences are also common features (Samson et al., 2014; Weiss et al., 2014). Autistic people also frequently have one or more physical health (for example, epilepsy, gastrointestinal problems, sleep difficulties) (Davignon et al., 2018; Fombonne et al., 2020) or mental health condition (for example, anxiety, depression, obsessive compulsive disorder) (Fombonne et al., 2020; Lai, Kasee et al., 2019), at rates higher than in non-autistic individuals (Croen et al., 2015). Intellectual and learning disabilities are also common (Rydzewska et al., 2019). Thus, although autism is increasingly viewed as a different way of experiencing and interacting with the world and not inherently a disorder (Milton, 2021; Department of Health and Social Care, & Department for Education, 2021a), for many, there are associated challenges that have significant implications for life experiences and support needs⁶.

Autism is associated with a wide range of strengths and challenges. Some Autistic people may live self-sufficiently with little to no support, while others may require high levels of care (Chandross et al., 2018; Farley et al., 2018; Magiati et al., 2014; Steinhausen et al., 2016). Not all Autistic people may require supports and services at every stage of life. Needs often vary across life domain/context and the lifespan. Services and support needs may include assistance with daily living tasks, formal and informal support accessing and participating in community activities, learning at school, and engaging in post-secondary or employment pathways (Department of Health and Social Care, & Department for Education, 2021a). Participation and inclusion can also be promoted through changes to the social and physical environment, as well as to the attitudes and understanding of non-autistic people.

⁵ In accordance respectively, to sensory hypo and hyperreactivity and restricted and repetitive behaviours of the DSM-5.

⁶ More information about co-occurring conditions can be found in Chapter 2 in the section on Complexity of Support Needs.

1.2 Canadian Context

1.2.1 Prevalence of Autism in Canada

Summary Point

Existing data collection and sharing methods pertaining to Autistic people in Canada are fragmented resulting in significant gaps and inconsistencies.

Recognizing the importance of collecting pan-Canadian data on autism, the Public Health Agency of Canada established the National Autism Spectrum Disorder Surveillance System (NASS) to better understand the prevalence of autism and how this varies across Canada (Public Health Agency of Canada, 2018). Their initial publication, *Autism Spectrum Disorder Among Children and Youth in Canada 2018*, reported on children and adolescents (aged 5 - 17) in six provinces and one territory⁷. Based on 2015 data, it was estimated that one in 66 children and youth had an autism diagnosis, corresponding to a prevalence rate of 1.5%. Nearly half of children and youth who had been diagnosed by age 17 received their diagnosis after age six. Males were diagnosed four times more often than females. Autism prevalence varied across jurisdictions, ranging from 0.8% in the Yukon to 1.8% in Newfoundland and Labrador. For provinces that had tracked rates over time, the prevalence of autism (among five to 14-year-olds) had increased three to four-fold between 2003 and 2015. Similar time trends have been reported in other studies based on provincial data (Diallo et al., 2018).

In February 2022, the Public Health Agency of Canada released updated autism prevalence estimates based on data from the 2019 Canadian Health Survey on Children and Youth, a pan-Canadian survey completed by parents of Canadian children and youth aged one to 17 years from all provinces and territories. The survey also included information on age at diagnosis, physical and mental health status, and functional challenges. Key findings included:

- An overall autism rate of 2.0% (one in 50), varying by province/territory (from 0.8% in Saskatchewan to 4.1% in New Brunswick) and age group (1.1% in one to four-year-olds, 2.5% in five to 11-year-olds, and 1.9% in 12 to 17-year-olds),
- No differences in autism rates based on ethnicity⁸, urban versus rural residence, or parental education,

⁷ Included provinces and territories were Newfoundland and Labrador, Nova Scotia, Prince Edward Island, New Brunswick, Québec, British Columbia, and the Yukon.

⁸ All non-white groups with the exception of Indigenous peoples were grouped into a single category.

- Poorer general and mental health in Autistic children compared to non-autistic children. For example, 84% of parents rated the mental health of their non-autistic child as very good or excellent, compared to 39% of parents of Autistic children), and
 - Autistic boys were 3.9 times more numerous than Autistic girls.
-

Notably, children and youth living on First Nations reserves, and those living in foster homes, group homes, and other congregate settings were not included. As well, in contrast to the 2018 National Autism Spectrum Disorder Surveillance System (NASS) report, autism diagnoses were not linked to provincial/territorial health and/or educational data.

The trend seen between the 2018 and 2022 Canadian data towards increasing prevalence in children has been demonstrated around the globe (see Table 1 for comparison across US, Australia, England, and Canada). Whether this trend reflects an actual increase in prevalence or changes in diagnostic practices and/or methodology used to make estimates remains an open question, with some Canadian research suggesting that diagnostic substitutions and false positives being responsible for at least a portion of the expanded cases of the past two decades (Coo et al., 2008; Klag & Ouellette-Kuntz, 2018; Yuen et al., 2018).

Comparable pan-Canadian data on Autistic adults is currently not available. Gathering data on the prevalence of Autistic Canadians aged 17 and over would support better understanding of necessary support services in adulthood. Using simulation models, the United States (US) Centers for Disease Control and Prevention estimated that approximately 2.21% of the US adult population aged 18 and over is autistic (Dietz et al., 2020). In addition to expanding understanding of autism across the lifespan, current Canadian autism data in relation to other characteristics (for example, socioeconomic status, intellectual disability, gender identity) is extremely limited. The potential value of enhanced Canada-wide autism data collection is further discussed in Chapter 6.

1.2.2 Meeting the Needs of Autistic People in Canada

The issues that Autistic people and their families face are complex, requiring collaboration within and across pan-Canadian, provincial/territorial, and local levels of government, as well as partnerships with Indigenous governments, and businesses, schools, charities, and community sectors and organizations.

In Canada, some steps have been taken at the pan-Canadian level to identify ways to strengthen the provision of supports and services for Autistic people and their families. Released in 2006 by the Standing Senate Committee of Social Affairs, Science and Technology, *Pay Now or Pay Later: Autism Families in Crisis* was the first governmental report published on this topic. It outlined several recommendations including a suggestion to consult with Autistic individuals and family members to develop a national autism strategy (Eggleton & Keon, 2007). Nearly fifteen

years later, in November 2021, a private member's bill was tabled by Senator Leo Housakos in the Senate of Canada for the development of a pan-Canadian framework designed to support Autistic Canadians, their families, and their caregivers. At the time of publication, a second reading was complete and the bill was under study by the Standing Senate Committee of Social Affairs, Science and Technology (Federal Framework on Autism Spectrum Disorder Act, 2021). A final decision on the passage of this bill is not expected until after the release of this report.

In Canada, responsibility for the planning and delivery of most health and social services and supports rests with the provinces and territories. As described in more detail in Chapter 4, supports and services are implemented in and across complex systems of care and generally span multiple ministries. Some Canadian provinces have moved to develop autism-specific legislation or plans. These policies, which have typically focused on childhood, generally set out the structure, eligibility, and ministries responsible for the provision of autism services (see Government of Nova Scotia, 2011; Manitoba Government, 2011; Ministère de la Santé et des Services sociaux, 2017). Autism-specific programs and services that currently exist primarily focus on early childhood supports and services, educational supports for school-aged children and adolescents, respite, and recreational opportunities of Autistic children and their families.

Each province and territory offers some form of services and supports for adults with **developmental disabilities**. Some Autistic adults are eligible for these services and benefits, which include subsidized and/or publicly-funded housing or residential services, disability/income supports, transportation, supported employment, day programming, respite, and staffing supports. However, access to such services is based on eligibility requirements related to intellectual disability. As such, some Autistic adults (particularly those without co-occurring intellectual disability) do not qualify for such services.

Understanding the needs, challenges, variability, and promising practices across the country was an important aspect of ensuring this assessment was relevant to the Canadian context. Recognizing that several organizations have developed policy briefs and reports with relevant elements to a national autism strategy, we launched our stakeholder engagement process with an invitation to these organizations to provide input. The 54 responding organizations are listed in the [stakeholder engagement report](#). We appreciate their input and acknowledge the insightful perspectives articulated in their previous reports.

1.3 International Context

An important aspect of the assessment was identifying examples of autism policies and services that are working well in Canada and in other countries. These examples are interspersed throughout the report where most relevant. We also sought out more detailed information from three international comparators with relevance for the Canadian context:

the United Kingdom, the United States, and Australia. Each of these countries has strengths in terms of their approach to autism policy, services and supports, as well as key similarities with Canada.

1.3.1 United Kingdom

Canada and the United Kingdom are amongst the oldest parliamentary democracies in the world and hold many shared values particularly in terms of building inclusive societies founded on democracy, human rights, and the rule of law (Government of Canada, 2021b). Further, both countries have universal health systems that are predominantly publicly-funded (Government of Canada, 2016; Tunstall, 2021).

England, the largest country in the United Kingdom, has over a decade of experience in developing and implementing autism-related policy. The Autism Act of 2009 was the first autism-specific legislation adopted in Europe, which placed statutory duty on the government to develop a national autism strategy and to provide *autism awareness* training to health and social care service providers (Della Fina, 2015). This legislation ultimately led to the development of England's first strategy in 2010. Since then, England has made several updates to their strategy, with their most recent one, [The National Strategy for Autistic Children, Young People and Adults 2021 to 2026](#), published in 2021 (Department of Health and Social Care, & Department for Education, 2021a). The other countries in the United Kingdom each have their own national strategies⁹, which are referenced throughout this report.

1.3.2 United States

Canada's relationship with the United States (US) is one that is characterized by shared geography, historic alliance, common interests, and multi-layered economic ties (Government of Canada, 2021c; Prime Minister of Canada, 2021a). The two countries have very similar standards of living and inevitably have an influence on each other's health, social, economic, and political environments (Krueger et al., 2009). Further, like Canada, the system of government in the United States is one where the federal and state governments share power, with each state retaining a degree of sovereignty (National Constitution Center, 2021). Additionally, both Canada and the United States have large immigrant populations with about 21.9% of the Canadian population (Statistics Canada, 2017) and 13.7% of the US population (Budiman et al., 2020) being foreign-born.

The United States enacted their first autism-related legislation in 2006, the Combating Autism Act of 2006 (Interagency Autism Coordinating Committee, 2019). The Act was amended to the Autism Collaboration, Accountability, Research, Education and Supports Act in 2014, which

⁹ Wales: [Refreshed Autistic Spectrum Disorder Strategic Action Plan \(2016\)](#) (Welsh Government, 2016), Northern Ireland: [The Autism Strategy \(2013 - 2020\) and Action Plan \(2013 - 2016\)](#) (Department of Health, Social Services and Public Safety, 2015), and Scotland: [The Scottish Strategy for Autism](#) (Scottish Government, 2011).

was subsequently reauthorized in 2019. This updated act ensures support, including financial support, for research, services, prevalence tracking, and other government activities covering the entire lifespan of Autistic people. The Interagency Autism Coordinating Committee (IACC) is the federal advisory committee coordinating all federal activities related to autism. They developed its first strategic plan in 2009, which is updated annually. The [Strategic Plan for Autism Spectrum Disorder 2018 - 2019 Update](#) is the most recent version (Interagency Autism Coordinating Committee, 2020). Along with the development of the initial strategic plan, significant investments have been made towards autism-related research in the United States. Shared mass media and research networks amongst the US and Canada mean that such research findings have direct implications for how autism is understood and addressed in Canada, for example through the awareness and popularity of certain therapeutic approaches.

1.3.3 Australia

Like Canada, power is shared between the federal and state governments in Australia. Further, both countries have large land masses, with extensive areas of low population density (Beaujot & McDonald, 2016). Both countries also have a substantial Indigenous population who share a similar history and challenges (Government of Canada, 2019). In Canada, about 4.9% of the population identify as First Nations, Métis, or Inuit (Statistics Canada, 2019), while 3.3% of Australia's population identify as Aboriginal or Torres Strait islanders (Australian Bureau of Statistics, 2018).

As is the case in Canada, Australia is currently in the process of considering the development of a national autism strategy. In 2019, the Australian Senate passed a motion that “encourages the government to develop a national autism strategy in partnership with Autistic people as well as their families and carers, to determine a set of actions with measurable outcomes to improve the life outcomes of Autistic people” (Parliament of Australia, 2019, p. 4802). A Select Committee on Autism was also established in 2019 to inquire into the service and support needs of Autistic people (Australian Government, 2021). While Australia does not currently have federal autism legislation or a strategic plan, they do have a Disability Discrimination Act that came into effect in 1992, which prohibits discrimination towards disabled people and aims to promote equal rights, opportunities, and access (Australian Human Rights Commission, n.d.). Australia also published the [Disability Strategy 2021 - 2031](#), but recognizes that a national autism strategy would complement this existing disability strategy (Parliament of Australia, 2019).

There are several rationales put forth for the development of a separate autism strategy. As per the Australian Autism Alliance (2020), in Australia more than a third of those receiving benefits through the National Disability Insurance Scheme have a primary or secondary diagnosis of autism. Yet, the life outcomes of Autistic Australians are still substantially poorer than other disability groups (for example, in terms of comparative rates of high school dropout,

unemployment, post-secondary attainment, and social isolation). Accordingly, the Australian Autism Alliance, as well as several other non-autistic-led bodies, such as the Royal Australasian College of Physicians, the Autism Cooperative Research Centre, the University of Melbourne, and the Australian Association of Social Workers have all promoted the development of an autism-specific strategy. In contrast to a generalist disability strategy, the autism strategy would be tailored to addressing the distinct challenges and enablers of Autistic people. Ultimately, it was suggested that an autism strategy and the Disability Strategy could be complementary and would benefit from a shared architecture.

Table 1. Cross Comparison of Country Exemplars to Canada. This table provides a cross comparison of England, the United States, Australia, and Canada. *N/A = not available

Country	Total population/ rural population	Size of health (and social care) workforce	Autism prevalence	Autism strategy	Major autism legislation
England	56.6 million / 9.7 million (17.1%) (Department for Environment Food & Rural Affairs, 2021)	Over 1.2 million healthcare staff (Department of Health and Social Care, 2019a)	1.8% (Department of Health and Social Care, & Department for Education, 2021a)	National strategy for Autistic children, young people and adults: 2021 to 2026 (Departments of Health & Social Care, 2021)	Autism Act (2009)
United States	333 million (United States Census Bureau, 2021) / 46 million (14%) (Dobis et al., 2021)	22 million workers in the healthcare industry (Laughlin et al., 2021)	2.3% among 8-year olds (Maenner et al., 2021)	Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder 2018 - 2019 update (Interagency Autism Coordinating Committee, 2020)	Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019 (revision of the Combating Autism Act of 2006)
Australia	25.8 million (Australian Bureau of Statistics, 2021) / 7 million (27.2%) (Australian Government, 2020)	Over 586,000 people in the health workforce (Australian Government, 2020)	0.7% (Australian Government, 2017)	N/A*	N/A
Canada	38.5 million / 6.1 million (15.9%) (Statistics Canada, 2021a)	Over 1.4 million workers in health occupations (Hou & Schimmele, 2020)	1.5 - 2.0% (for children and youth 5 - 17 years of age) (Public Health Agency of Canada, 2018; 2022)	N/A	N/A

1.4 Why a National Autism Strategy?

Canada has already developed several public health strategies or frameworks over the past decade including: A Dementia Strategy for Canada (Public Health Agency of Canada, 2019), The Federal Framework for Suicide Prevention (Public Health Agency of Canada, 2016), and The Mental Health Strategy for Canada (Mental Health Commission of Canada, 2012). Currently, Employment and Social Development Canada (2021a) is also developing the Disability Inclusion Action Plan. While each plan addresses different issues, they share some common intentions which can be used as framing for some of the potential benefits of a national autism strategy.

1.4.1 Planning for Now and for the Future

As described earlier, the reported prevalence of autism diagnoses in Canada and elsewhere in the world continues to rise, with an increasingly diverse range and intensity of presentations and cognitive profiles (Arvidsson et al., 2018; Lundström et al., 2021). A strategy may help in planning for sustainable and efficient health and social care systems that mitigate existing barriers and support the quality of life and participation of Autistic individuals and their families in their communities and in the Canadian economy. These systems must also be prepared for future developments that may bring new pressures as the growing population of Autistic children become adults and their needs change. Viewing the strategy as a dynamic or ‘living’ guidance as suggested in the New Zealand Autism Guidelines (New Zealand Ministries of Health and Education, 2016), may be helpful and allow for new cross-governmental actions, associated strategic priorities, and mechanisms for further refinement in response to evolving needs and ongoing evaluation.

1.4.2 Addressing the Breadth of Needs and Complexities

A Canadian autism strategy can provide a framework for considering and responding to the complexity, diversity, *intersectionality*, and breadth of needs across the country. While not all Autistic people consider themselves to be disabled, many of the social disadvantages, exclusion, and violation of human rights experienced by Autistic people are similar to those experienced by disabled people. As such, some stakeholder groups have instead expressed support for a strategy that is inclusive of all disabled Canadians (Autistics for Autistics, 2021).

“The things that help Autistic people are often things that should be taken into consideration for other disabled people too.”

- Autistic adult

The United Nations’ Convention on the Rights of Persons with Disabilities adopts a broad definition of disability and its application to Autistic people was highlighted in a resolution by

the World Health Assembly in 2014 (World Health Organization, 2014). Throughout this report we have drawn upon the United Nations’ Convention on the Rights of Persons with Disabilities as a framing for relevant issues and to suggest that many promising practices that benefit other neurodiverse or disabled groups, may also benefit Autistic people (and vice versa). However, in addition to viewing autism within the context of disability rights and more generalized disability policy, the experience in Australia has been that an autism-specific strategy is still viewed as required, even with an active disability strategy in place (Parliament of Australia, 2019).

1.4.3 Facilitating Collaboration

As outlined in the Minister of Health’s 2021 [mandate letter](#), the Government of Canada will work collaboratively with provinces, territories, and stakeholders toward the creation of a national autism strategy (Prime Minister of Canada, 2021b). The Canadian government is uniquely positioned to facilitate collaboration and provide an important leadership and infrastructure role. As will be discussed in more detail in Chapter 6, collaboration involves multiple levels of government, the non-profit sector and community service organizations, and Autistic people and their families.

1.5 Meaningful Engagement of Autistic People

Multiple countries have recognized the value and importance of including Autistic people and their supporters in decisions about policies, research, and supports and services that affect their lives. The principles of citizen engagement and co-creation, described below, are best practices and were central principles to this assessment.

1.5.1 Citizen Engagement

The United Nations’ Convention on the Rights of Persons with Disabilities requires that disabled people and their representative organizations be meaningfully engaged in decision-making processes that affect their lives (Article 4(3), United Nations, 2006).

“Most importantly the changes ... need to be led by Autistic people themselves ... Autistic people have the competence and capacity to occupy leadership roles in our community ... Autistic people are best equipped to understand the needs and goals of our community.”
- Autistic adult

Authentic citizen engagement signifies a new form of participation of disabled citizens, whose voices have typically been absent within public administration (Holmes, 2011). Citizen engagement moves beyond consultation, which is typically considered a one-way flow of information from citizens to government, to promote a bi-directional flow of information, knowledge, and experiences (Prince, 2009). Concepts such as *‘co-design’, ‘co-creation’, and*

'co-production' have emerged to describe this systematic pursuit of sustained collaboration between government agencies, non-government organizations, communities, and citizens (Holmes, 2011).

Citizen engagement is not a new concept, although its application in autism policy, practice, and research has only occurred more recently. In 1969, Arnstein published the Ladder of Citizen Participation, which describes the degree of citizen participation along a continuum from nonparticipation, where citizens have no power, to tokenism, to actual citizen power in leadership and decision-making. Its development signified a shift within liberal democracies from viewing the public as (health) consumers who should be consulted to now viewing the public as citizens who have the right to participate in the decisions that affect their lives (Holmes, 2011).

In the United Kingdom, national standards for public involvement in health research have been established, which strive for citizens, such as Autistic people and their supporters, to be actively included in research projects and organizations. In practice, active involvement is about research being carried out 'with' or 'by' Autistic people rather than 'to', 'about', or 'for' them (INVOLVE, 2021).

Genuine engagement is complex, challenging, and requires a significant cultural and operational shift for decision-makers in government, research, and various service sectors (Holmes, 2011). In some cases, well-intentioned engagement efforts have been experienced by Autistic people as tokenistic and therefore, not meeting the desired goal of meaningful engagement (Milton, 2019; Petri et al., 2017). Furthermore, historically, Autistic persons' voices have not been included to the same extent as other supporter groups. Typically, the perspectives of parents of Autistic people, service providers, and policymakers have been included the most (Renwick et al., 2019), despite some efforts to offer Autistic persons a seat at the table (Boyce et al., 2001). When engaging with Autistic people, it is also recommended to adopt a *trauma-informed* approach¹⁰, where care and attention are paid to preventing unintentional re-traumatization, recognizing that many of these individuals have previously experienced adversity and maltreatment (Kerns et al., 2020; Peterson et al., 2019; Autism United Canada, 2019). Positive, collaborative, practical, non-pathologized, and change-oriented approaches for engaging disabled persons in policy- and decision-making (McColl, 2019) can support Autistic people to participate in decision-making processes that are safe and inclusive, value their insights, promote equity, and are based on freedom of choice (Prince, 2009).

¹⁰ For more information on trauma-informed care, see Chapters 2 and 4.

1.5.2 Co-Creation of Policies, Programs, and Services

The involvement of Autistic people, families, and other supporters can contribute to programs, services, policies, and research priorities that more meaningfully address their needs.

“It [national autism strategy] needs guidance from Autistic people ... grounded not in professional perceptions of autistic ‘behaviours’, but the inner experiences, perspectives, needs and priorities of Autistic people themselves. We are creative thinkers and care so much about the world. Our insights will only strengthen a national autism strategy.”

- Autistic adult

Collaboration requires continuous structured dialogue and active involvement throughout implementation — that is the design, development, and review of relevant policy and practice options and models (McColl, 2019, Prince, 2009). There are models of participatory and inclusive civic engagement to guide this collaboration and tools developed by Autistic people in partnership with researchers to support this approach (see Academic Autism Spectrum Partnership in Research and Education, 2020). Autistic individuals should also be supported and enabled to self-advocate. *Self-advocacy* is a key component of self-determination. Self-advocacy refers to autistic-led advocacy initiatives, in contrast to ‘advocacy’, which typically refers to supporters advocating on behalf of Autistic people (Rosqvist et al., 2015; Waltz et al., 2015). Self-advocacy is largely considered a critical component for fostering more inclusive practices and cultures (van den Bosch et al., 2019) and is reflected in the language of the United Nations’ Convention on the Rights of Persons with Disabilities (United Nations, 2006). However, recognition of the benefits of self-advocacy for Autistic individuals has been relatively recent (Waltz et al., 2015; van den Bosch et al., 2019).

Some Autistic people who would like to participate in civic engagement may benefit from mentorship or coaching in what may be a new and/or socially-complex arena. Civic skills, such as those required to participate in governance meetings and processes, are typically acquired in non-political institutional settings of adult life, such as the workplace, organizations, or religious settings (Brady et al., 1995). Yet, due to systemic discrimination and lack of opportunities, many Autistic people may not have had as many opportunities to hone these skills.

Underlying principles from participatory and inclusive research can also be applied when designing policies, programs, and services for Autistic people (Maye et al., 2021). Participatory research approaches are further described in Chapter 6. From this growing literature base, a key consideration for the effective collaboration with Autistic people is recognizing and addressing existing power imbalances amongst Autistic and non-autistic people so that Autistic people can actively and meaningfully participate (Nicolaidis et al., 2011). Emerging best

practices (Nicolaidis & Raymaker 2015; Luke et al., 2012; Satkoske et al., 2020; Maye et al., 2021) suggest:

-
- Normalizing inclusive practices such as accepting and accommodating diverse ways of communicating (such as the use of text-based, online media, and easy read options),
 - Collaboratively determining a process for inclusive decision-making such as the use of the five-finger method¹¹ (Academic Autistic Spectrum Partnership in Research and Education, n.d.) for making decisions and arriving at a consensus,
 - Ensuring that all partners are involved at each step of the process,
 - Providing people with enough time and information to make informed decisions,
 - Removing potential distractions, and
 - Providing respectful and emotionally-safe environments.
-

Ultimately, it requires the ability of the team to remain flexible and a willingness to adapt as new learnings emerge (Nicolaidis & Raymaker 2015; Jordan, 2008). Such meaningful collaboration takes significant time, intention, and efforts on the part of everyone involved. Without this collaboration, however, well-meaning processes can rapidly devolve into tokenistic processes or committee structures that fall short of the intended goals (Pandya-Wood et al., 2017; Parsons et al., 2020; Strnadová & Walmsley, 2018). In addition to participatory or inclusive approaches, there is also a growing body of research by Autistic researchers (for example, see Botha, 2021; Grant & Kara, 2021).

When considering who to include in collaborative decision-making, it may be appropriate to involve supporters, in particular parents and/or other family members (Nicolaidis et al., 2011; Goldsmith, 2021). This involvement may be particularly relevant in informing initiatives aimed at supporting Autistic children or adults with *complex support needs* (e.g., those with co-occurring conditions, such as intellectual disability or mental illness that impact on daily living and communication skills, and/or those who may require full time and/or highly specialized care and support). Family members of Autistic people often serve as the most immediate support and may be well-positioned to understand and communicate their Autistic family member's needs, which they can then share with the wider community (Lewis et al., 2015). Many family members advocate tirelessly on behalf of Autistic family members in order to access services and promote systems change. Some Canadian parents have written books about their family experiences and political perspectives (see Kavchak, 2020; Chua-Tan, 2019). Their stories, and

¹¹ The 'Five-Finger' or 'Fist to Five' method has been applied by boards of directors, government groups, and organizations as a visual method to determine consensus. It is accomplished by raising hands as in voting, with the number of fingers raised indicating the level of agreement. While no formal academic research could be found about this method, it aligns to the principles of meaningful/civic engagement and accessible communication. In addition, the method was found to be acceptable and useful in practice by our Working Groups and Oversight Panel members, particularly in an online meeting environment and with a diverse group of individuals with differing communication preferences. If preferred, committee members could also type the number of fingers into the chat.

others', provide one avenue to understand some of the strengths and challenges experienced by parents of Autistic Canadians.

Family members must often self-educate about advocacy and could benefit from additional support in this area (Boshoff et al., 2018; Goldsmith, 2021). At times, family members and other supporters may hold values and priorities that differ from those of the Autistic individual and, therefore, particular effort needs to be made to prioritize and centre the perspectives of Autistic people (Nicolaidis et al., 2011; Fletcher-Watson et al., 2019). Greater representation of and engagement with *equity-seeking groups* of Autistic people also needs to be a priority, particularly for those who have been historically underrepresented and underserved (Maye et al. 2021), such as those described in Chapter 2.

1.6 The Charge and Methodology

The Canadian Academy of Health Sciences committed to completing this assessment to inform policy makers as they develop a national autism strategy. Our goal was to synthesize current and emerging evidence across a breadth of relevant issues that would inform approaches aimed at addressing the needs of Autistic Canadians and their families.

1.6.1 Setting the Stage

The assessment was structured around the key themes of Social Inclusion, Diagnosis, Supports, and Services, and Economic Inclusion. While we recognize that across and within these themes, there are many interconnected social, economic, environmental, and cultural factors that affect the health and wellbeing of Autistic Canadians, they provided a guiding structure for this broad assessment.

Aligned to each theme, our sponsor, the Public Health Agency of Canada, provided thematic questions to guide the assessment scope and approach. Illustrative questions that guided the nature of this work were focused on *how a national autism strategy could*:

-
- Help Autistic individuals feel understood, accepted, and included in their community
 - Support equitable access to evidence-based supports and services for Autistic individuals
 - Support Autistic individuals to meaningfully participate and contribute to Canadian society
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Accordingly, the scope of this assessment was focused on evidence-based strategies to meet the needs and enhance the quality of life of Autistic Canadians across the lifespan.

The Canadian Academy of Health Sciences (CAHS) [Assessment and Scientific Affairs Committee](#) established a structure for this assessment whereby an Oversight Panel and three Working Groups ([Social Inclusion](#), [Economic Inclusion](#), and [Diagnosis, Supports, and Services](#)) provided leadership. The CAHS appointed the Chairs, Co-Chairs, and the members of the

Oversight Panel and Working Groups and ensuring that Autistic people and parents were included in leadership positions.

A Project Charter was developed with the Oversight Panel and the Working Groups to provide an overview of the direction and process for the assessment. This charter included a plan for completing project deliverables, measures to ensure independence and shared values, project organization, roles and responsibilities, communication, decision-making, and principles for the stakeholder engagement process.

The Autistic and family representatives were identified through an open call to stakeholders. Other members of the Oversight Panel and Working Groups were selected based on relevant academic and professional expertise, with diverse representation across Canada, as well as career stage, sex/gender, ethnicity, and language (French/English). Following our recommended best practice, all committee members, including the Lived Experience Committee members, were involved in reviewing all written work, supporting in the development and facilitation of stakeholder consultation activities, comparing evidence and stakeholder input, and making decisions regarding language, images (e.g., on the Engagement Hub and in the easy read report), and communication dissemination tools.

Peer reviewers were selected by the CAHS Assessment and Scientific Affairs Committee to independently and anonymously review the final document. Reviewers brought a broad range of expertise and experience covering all areas of health, including extensive experience of reviewing the relevant scientific, health policy, and other academic literature. This blinded review process further strengthened this assessment process and the final report.

Importance of Language

As noted in *What is Autism*, language about personal identities is an extremely important, deeply personal, and sensitive issue. Engaging persons with *lived experience* about the terminology and phrasing of questions is a best practice in inclusive research and policy-making (Strnadová & Walmsley, 2018; Frankena et al., 2015). Accordingly, beginning early in the assessment, the Oversight Panel engaged in several processes focused on respecting the language preferences of Autistic people.

Identity-first language (e.g., Autistic person) was generally preferred by our Lived Experience Committee members, rather than person-first language (e.g., person with autism). Identity-first language recognizes autism and/or disability as an inherent part of an individual's identity. This contrasts person-first language, which views autism and/or disability as an attribute of a person and not a core part of who they are (Hoya, 2011).



Summary Point

Throughout this assessment, evidence was understood across a continuum:

- *Evidence-based* is used where there is extensive, high-quality research about Autistic individuals, clear consensus within the recent academic literature, and effective practice or service delivery models that have been rigorously evaluated.
- *Evidence-informed* was used where there was an established evidence base of varying quality or for broader, overlapping populations¹³, multiple practice examples, and growing consensus of best practices.
- *Emerging evidence and promising practices* were used for practices with some evidence accompanied by useful models in practice or policy.

The preference for identity-first language among persons with lived experience is consistent with reports within the academic literature (Botha et al., 2021; Bury et al., 2020; Kapp et al., 2013; Kenny et al., 2016) and aligns with the perspective that autism is “inseparable from and fundamental to an individual’s experience of the world” (Sinclair, 2013; cited by Bottema-Beutel et al., 2020, p. 4). Preferences vary, particularly outside of the lived experience community (Kenny et al., 2016), leading some authors to adopt a less uniform approach (e.g., Lord et al., 2021). By and large¹², we adopted identity-first language throughout the assessment process and in this report in relation to both autism and disability. By extension, we also reserved the term “Autistic parent” for Autistic people who are parents. In this assessment, the term ‘parents’ includes Autistic and non-autistic parents, unless differences are specifically noted.

Lived Experience Committee members were also integrally involved in decisions regarding question content, format, and language used in our stakeholder engagement. Existing guides produced by autism organizations also helped to inform our word choices and communications throughout the stakeholder engagement process (e.g., Aut’Créatifs, 2015; Autism Canada, 2016; Canadian Autism Spectrum Disorder Alliance, 2020a). This ongoing and evolving process focused on continually working towards more accessible and inclusive language and communication processes.

¹² It should be noted that Autistic individuals and individuals with intellectual or developmental disabilities differ somewhat in their preferences for person- versus identity-first language. For that reason, there are times when “people/persons with developmental disabilities” have been used. Furthermore, where the official title of a report or program adopted person-first language, we have not amended the language to identity-first.

1.6.3 Overall Approach

During this assessment, we engaged in an evidence synthesis that, in line with best practices for policy-oriented reviews, aimed to be inclusive, transparent, rigorous, and accessible (Donnelly et al., 2018). Given the assessment timelines, a rapid review process, endorsed by the World Health Organization for conducting policy-informed evidence syntheses, was adopted (Langlois & Daniels, 2018). The Oversight Panel, in collaboration with the Working Groups, ensured that the assessment was based on a comprehensive review of current and emerging evidence by analyzing peer-reviewed scientific literature, best practices, and existing policies in Canada and across the globe. In addition, the Oversight Panel and Working Groups benefited from input from a diversity of voices through an extensive stakeholder engagement process. This approach provided the Working Groups and the Oversight Panel complementary data that informed the assessment (see Figure 2).

1.6.3 Reviewing the Evidence

The review process involved three phases:

- **Phase 1 - an autism policy review.** This phase aided in informing the framing of the stakeholder consultation and also provided examples of autism policy and practices from jurisdictions in Canada and abroad.
- **Phase 2 - a series of subtheme-specific rapid, modified umbrella reviews.** This phase, overseen in parallel by the three Working Groups, provided a rigorous and transparent review process for searching, screening, extracting, and summarizing research evidence across 15 sub-themes.
- **Phase 3 - targeted, follow-up reviews.** This phase involved incorporating specific literature to elaborate on gaps uncovered during the synthesis of the research evidence and stakeholder consultation findings.

Search, Screening, and Data Extraction

Phase 1. We followed a pre-established method (Godin et al., 2015) for searching, screening, and extracting grey literature, such as policy documents. Using this method, we found and extracted data from 88 English and French strategic policy documents. These international and Canadian documents (2006 - 2021) included plans developed by government, health institutes/ advisories, community agencies, and advocacy organizations at international, national, and provincial/territorial levels.

Phase 2. Five sub-theme specific reviews were completed by each Working Group. For each review, they applied a consistent, a priori rapid review approach. Each review involved the

¹⁵ Broader, overlapping research populations included persons with neurodevelopmental conditions, developmental or intellectual disabilities, and other disabled groups.

systematic search of at least three academic databases (PubMed/Medline, CINAHL, and APA PsycINFO). Additional databases relevant to specific subthemes were also used, such as ERIC, JSTOR, and Sociological Abstracts. Each search required a set of subtheme-specific search terms and database-specific subject/MESH headings which were developed and reviewed by subject experts from within the Working Group. Preliminary searches were limited by date (2011-2021), language (English or French), and article type (peer-reviewed; review, systematic review, scoping review, meta-analysis, meta-synthesis, and practice guidelines). The total number of hits, final inclusions, and major reasons for exclusions (e.g., duplicates; not about autistic population), were recorded for each database. A PRISMA flow diagram was developed for each review process.

Phase 3. Supporting, targeted searches using the above databases were undertaken where no or few systematic reviews had been uncovered during phase 2, but the topic was viewed as integral to the assessment (e.g., based on expertise of the Oversight Panel and from results of the stakeholder consultation). In these cases, the search parameters were widened to include original research and wider time spans.

During all three phases, through expert consultation with Working Group members, additional articles were contributed through manual and hand searches specific to the Canadian context. In total, more than 6500 interdisciplinary research documents, governmental reports, and data sources were reviewed and analyzed.

The data extraction process was similar across all three phases. Excel spreadsheets and MAXQDA coding software were used to organize the data. Data on bibliographic, subtheme-relevant, and policy and practice recommendations were extracted into pre-established data charting templates. Extracted data was analyzed descriptively, synthesized across phases, and then shared with Working Group members.

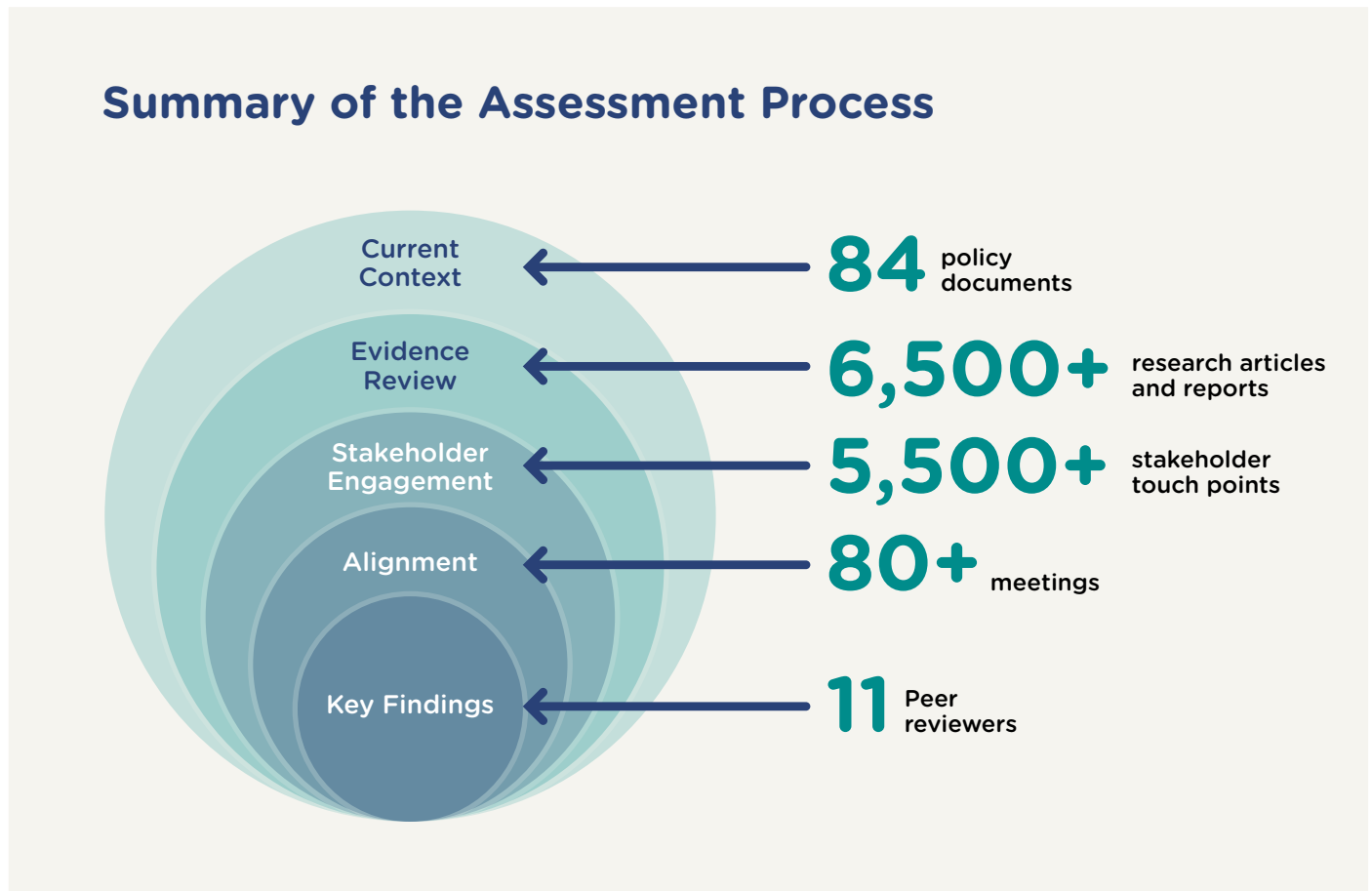
Synthesis of Research Evidence with the Stakeholder Consultation

An comparative analytic framework was designed to compare findings from the research evidence and the results from the stakeholder consultation. The goal of this process was to determine areas of potential alignment, as well as deduce potential gaps. Each Working Group was tasked with reviewing and consolidating summary information from each stakeholder consultation platform with the findings from the research evidence. Each Working Group presented their results to the Oversight Panel. At this time, gap areas for potential expansion were flagged. Accordingly, the third phase of evidence review was initiated under the ongoing guidance of the Assessment Chairs and two rounds of extensive feedback from the Oversight Panel.

Peer Review

The full assessment report received approval from the Oversight Panel in January 2022. Next the assessment report was sent for a blinded peer review by 11 Canadian autism and Autistic researchers in February 2022. The assessment report was also reviewed by the CAHS Scientific Affairs Committee at this time and authorized by the CAHS Board.

Figure 2. Overall Approach.

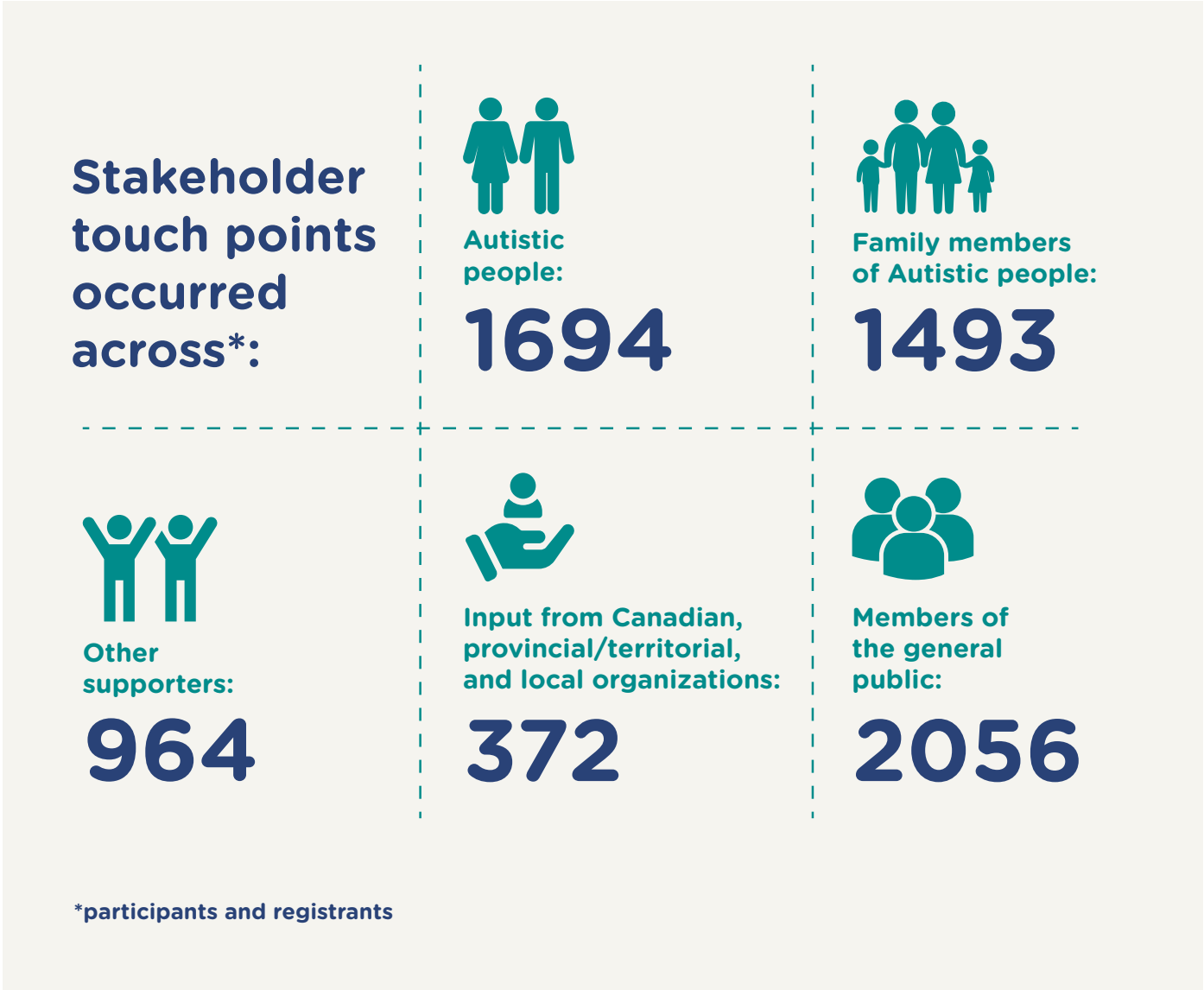


1.6.4 Summary of the Engagement Process

A key aspect of the assessment was to engage stakeholders, especially Autistic people and their families. This process was aimed at identifying gaps in knowledge, validating findings from other sources, and amplifying the voices of individuals with lived experience whose perspectives are essential, yet are often excluded from decision-making processes. Stakeholder consultations helped to further delineate thematic issues and identified areas where there was a need to supplement the literature and policy review.

To that end, we used a large variety of stakeholder engagement methods. The aim was to expand the reach towards diverse communities and generate a wide and deep range of insights and lived issues experienced by different stakeholders. The activities took place between February and August 2021, and involved over 5500 participant touch points, more than 1600 of whom were with Autistic adults (Figure 3).

Figure 3. Stakeholder Touch Points by Participant Group.



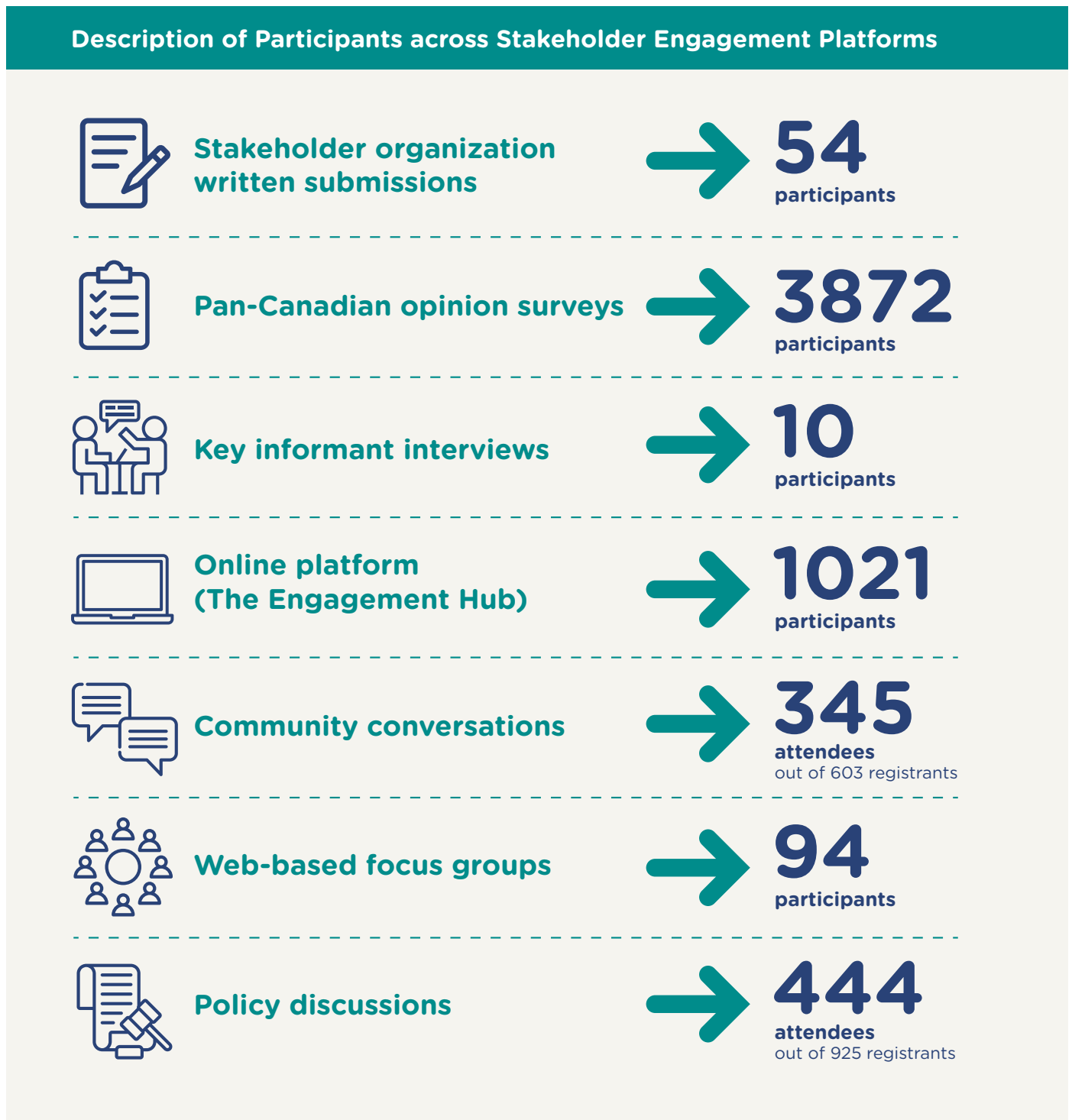
The creation of an Oversight Panel and Working Groups, which included Autistic people, family members, service providers, and researchers, added yet another layer of relevance to the stakeholder engagement process. In particular, we engaged in ongoing dialogue with the Autistic and family committee members and they, along with other Autistic advisors and stakeholders, provided valuable feedback and advice on how to foster an inclusive and safe environment for Autistic participants to discuss important and sensitive issues. Thus, as an integral part of the process, Autistic people, their families, service providers, and researchers were offered multiple platforms where they could share their thoughts and concerns, through varied communication input technologies and in both English and French.

Due to the ongoing global COVID-19 pandemic, all stakeholder consultations were held virtually or through online platforms. This process allowed for more frequent communication and a more iterative and incremental process than if our interactions had been limited to a few in-person meetings. It may have also increased accessibility for people who would have needed to travel long distances or would feel less comfortable in large group settings. Through stakeholder feedback, we also heard the use of online platforms was preferred by many Autistic (as well as non-autistic) participants, although we also acknowledge some of the limitations associated with online mechanisms (see Limitations section).

A wide range of direct engagement approaches were used in our stakeholder consultation: opinion surveys, written submissions, questionnaires, online focus groups, community conversations, policy discussions, key informant interviews, and an online platform known as the Engagement Hub (Figure 4). Throughout our large group processes, a facilitation team (including a peer mental health facilitator) strove to provide emotionally-safe spaces and privacy for Autistic people. This included designating individual breakout rooms in advance and focusing efforts into encouraging participants to communicate their experiences.

Following the completion of each stakeholder engagement platform, a thematic summary from each target audience was produced. A key consideration in the data analysis was to report the results by stakeholder group to preserve the distinct voices of Autistic adults, family members, service providers, and organizations. A final stakeholder engagement report can be accessed [here](#).

Figure 4. Participation across each Stakeholder Engagement Platform.



1.7 The Report

1.7.1 Structure of the Report

The assessment report includes six chapters. In Chapter 2, several guiding, cross-cutting issues such as diversity, intersectionality, and neurodiversity are introduced, drawing emphasis to existing inequities amongst Autistic people and to Canada's unique relationship with Indigenous Peoples. This chapter will support readers to understand the complexity and heterogeneity of autism as well as the multiple and intersecting ways it can be experienced by each individual. Chapters 3 through 5 provide a comprehensive review of sub-themes related to Social Inclusion (Chapter 3), Diagnosis, Supports, and Services (Chapter 4), and Economic Inclusion (Chapter 5). These chapters follow a similar format of:

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- **Summary Points.** Within each chapter, summary points are highlighted in light green boxes.
 - **Background.** For each sub-theme, there is a background section summarizing the evidence to date, where possible, focused on the Canadian context and data sources. Generally, the background lays out the current needs and barriers faced by Autistic people and their families.
 - **Best and promising practices.** For each sub-theme, possible policy directions to address existing needs and barriers are provided. These best and promising practices emerged from the research evidence and a synthesis of international autism policy documents.
 - **Key Findings.** For each sub-theme, a set of actionable, policy-oriented key findings from the evidence are provided as potential pathways forward. The Key findings can be found in the blue boxes.
-

The final chapter, Positioning for Impact (Chapter 6), identifies and describes cross-cutting enablers of data sharing, research, and collaboration.

As noted in the introduction, the report includes relevant quotes from Autistic people, their family members, and service providers so that readers benefit from the first-person perspective. All quotes came from our stakeholder engagement process. As per our commitment to participants, we removed all personal and identifying information for those who have provided input.

1.7.2 Scope and Limitations of the Assessment Report

The scope of this assessment focused on presenting a framework of 'key findings' for policy guidance. This charge should be differentiated from other forms of reviews aimed at developing clinical or research guidelines. Although clinical and research issues, such as diagnosis, therapeutic programs, and surveillance were included in the review, it was not the purview of the Working Groups to assess the quality of single studies or to discuss or compare in detail the methodological rigour of these studies.

In phase 2, our review process focused on meta-analyses, scoping/systematic reviews, and clinical practice guidelines although during phase 3, we did incorporate original research as required to cover the full extent of sub-themes and questions. Where possible we included Canadian research and figures. However, we did not directly compare provincial/territorial service models and little evaluation data is publicly available. We have specifically identified Canadian research where the findings provide context-specific information, such as rates, prevalence, or interprovincial/territorial or geographic variability.

As outlined in the charge and methodology, this was not an exhaustive assessment. The three thematic areas selected by the Public Health Agency of Canada did not generally include questions that had a strong etiologic focus, although we acknowledge the relevance of biomedical considerations in respect to promoting health and wellbeing of Autistic individuals. While the Diagnosis, Supports, and Services theme might have included more detailed discussion about the use of biologically-based measures (e.g., genetic testing) to inform etiologic factors, these points were not central to the broader issues of access to clinical diagnosis and services. Furthermore, within this section we refer to practice statements that elaborate on the medical testing recommended for newly-diagnosed individuals. Likewise, while we are entering an era of ‘precision medicine’ and the potential for treatments targeted to underlying biological mechanisms, these have generally not yet advanced to human trials.

There were some other general challenges in reviewing evidence on autism:

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- Critical disability approaches have begun to deconstruct what we may have thought about autism in the past. There is an evolving understanding that we need to further prioritize what contributes to the quality of life of Autistic people, and their opportunities to participate in societal roles, as well as how to support and enable parents who have caregiving roles. While research is shifting in this direction, earlier studies may over-represent certain biomedical or clinical perspectives (e.g., related to describing features and underlying mechanisms). Moreover, research, even more recent studies, generally do not include the level of diversity reflective of Canadian society or the clinical heterogeneity of Autistic people.
 - There are many sources of information that can contribute to evidence-based practice and policy-making, including lived experience and clinical expertise. However, to date, certain lines of clinical intervention research have had the most significant impact on current policy. Research that focuses on real-world implementation is also necessary but remains relatively sparse.
-

In terms of the makeup of the Oversight Panel responsible for this assessment, we did not have any Autistic researchers, and we fully acknowledge that the CAHS is a non-autistic-led organization. To mitigate this admitted limitation, Autistic people, and Autistic and non-autistic parents of Autistic individuals contributed as leaders and members of the Oversight Panel and Working Groups. We also consulted with Autistic researchers throughout the process, and had two Autistic researchers as reviewers during the blinded peer review process.

In adopting an intersectional and inclusive lens on Canadian health and social care systems, at times, systemic barriers, which many Canadians face, emerged as highly relevant to the challenges faced by Autistic people. These barriers were particularly pertinent to the health inequities and systemic racism experienced by equity-seeking groups of Autistic people (see Chapter 2). However, in keeping with the scope of the assessment, our analysis of potential solutions to these challenges was limited to evidence within autism research and policy. As such, there may be other systems-wide solutions to these challenges that are not referenced within this report.

Yet, in aiming to create a more inclusive society that is sensitive to and accessible to the needs of diverse Canadians, there may also be broader applications to the strategies suggested here in relation to Autistic people. Accordingly, while the scope of this assessment was specific to Autistic people, many of the conclusions may be applicable to other groups in Canada who face similar challenges and barriers. For example, there may be relevance to the pending Disability Inclusion Action Plan (Employment and Social Development Canada, 2021a).

Despite defining the scope of this Assessment on Autism, the inherent heterogeneity within this condition and its intersections with other conditions and social identities presented deep complexities. At times, the population-level outcomes and recommendations from the research literature did not fully or realistically reflect the heterogeneity of the lifetime needs of Autistic Canadians. The lack of Canadian data (e.g., about the outcomes of Autistic adults) often required the inclusion of non-Canadian evidence where the policy contexts might be quite different (e.g., United States, United Kingdom, Australia).

In addition to some of the complexities described above, this assessment took place during a pandemic, necessitating adaptations to communication and collaboration approaches. All meetings and stakeholder consultation were conducted by video conference or online platforms rather than in-person, which may have prevented the participation of some people due to internet access/reliable Wi-Fi and/or difficulties navigating the technology. Further, participants provided input while experiencing unique work and personal challenges. We are grateful for the extraordinary input and support of our diverse leadership and contributing committee members and stakeholders.



Key Finding - Meaningful Engagement of Autistic People

Applying principles of citizen participation, co-design, self-advocacy, and collaborative decision-making in policy and program design helps to better meet the needs of Autistic people and their families.

1.8 Chapter Summary

Autism is a neurodevelopmental condition that impacts individuals across the lifespan. There is diversity in the way in which this condition presents and evolves. Co-occurring conditions can introduce further complexities.

Pan-Canadian data published in 2022 suggests that an estimated 2% of Canadian children and adolescents are autistic and experience poorer physical and mental health than their non-autistic peers. Pan-Canadian level data on Autistic adults in Canada remains limited. In the Canadian context, the supports and services required by Autistic people and their families are provided through a complex network across health (including mental health), social, community, and educational sectors.

The Canadian Academy of Health Sciences was tasked with carrying out an Assessment on Autism to inform the development of a national autism strategy, as a way to provide a vision and direction to improve the health and wellbeing of Autistic people and their families. This 19-month, arms-length, peer-reviewed assessment process included a comprehensive review of more than 6500 academic studies and governmental reports/data. Additionally, a pan-Canadian stakeholder consultation with more than 5500 participants, included over 1600 Autistic adults with varying communication preferences. An essential cornerstone of this assessment was collaborative decision-making with Autistic individuals and family members within the assessment's committee structure.



Chapter 2:

Priority Considerations that are Cross-Cutting

Summary Point

Autism intersects with other aspects of identity such as race, ethnicity, culture, socioeconomic status, gender, and sexuality. These intersecting identities create a wide range of experiences and support needs among Autistic people.

2.0 Autism, Diversity, and Intersectionality

The Social Determinants of Health are often utilized to describe how social conditions can contribute to creating and maintaining health inequities. According to the World Health Organization (2022), health inequities reflect unfair and avoidable differences in health status seen amongst individuals. Discrimination and stigma, socioeconomic status, and geographic location are some examples of social determinants of health. Even within a particular group, such as those who share an identity such as *autism*, there can be individuals who are less likely to access, receive, and/or benefit from the systems and services put in place to support them.

“... My race, sexuality, gender identity, spiritual practice, and assigned sex have all impacted how I am treated by people in the colonial culture. My difficulty navigating the colonial culture’s social norms has made me more vulnerable to sexualized and racialized harassment and violence. I have also experienced discrimination due to my race, sexuality and gender identity, in employment, schooling and accessing services.”

- Indigenous Autistic adult

When framed by intersectionality, the perpetuation of discrimination and exclusion that is experienced by Autistic people becomes clearer. For example, in a recent qualitative review, family, cultural, and structural barriers contributed to racial, ethnic, and socioeconomic disparities associated with autism (Singh & Bunyak, 2019). These barriers were evident across many service domains including access to early assessment, diagnosis, and services.

This chapter begins by describing the heterogeneity of Autistic people, using *neurodiversity* as a framework. Next, diversity and *intersectionality* are introduced to further demonstrate how experiences of autism (and autistic identity) shape and are shaped by and through intersections with other social identities, such as ethnicity, culture, socioeconomic status, gender, and disability to create a wide range of experiences among Autistic people (Saxe, 2017).

Through this assessment we have identified specific groupings of Autistic people where there are cross-cutting considerations. We begin with Indigenous Peoples (First Nations, Métis, and Inuit), acknowledging and respecting Canada’s unique relationship and responsibilities in considering their experiences and needs. We then summarize the existing evidence specific to other groups of Autistic people, acknowledging that the limited evidence base reflects the need for prioritization.

While this chapter is unable to capture every intersectional experience of all Autistic Canadians, it is hoped that it will begin to exemplify the concerning health and social disparities that exist within and across Canadian jurisdictions. This lens of complexity and critical awareness of systemic discrimination is a cross-cutting theme within the remainder of the report.

As briefly introduced in Chapter 1, originally based on the activist work of Jim Sinclair, neurodiversity represents an autistic-initiated activist movement promoting recognition and respect of the diversity and divergence of differently-wired brains (Ortega, 2009). It was first coined by Judy Singer, and further popularized by Steve Silberman and Harvey Blume (Singer, 2017). Neurodiversity is a relatively new paradigm that has been widely debated and discussed within the autism field in recent years (e.g., see Bailin, 2019 and Baron-Cohen, 2019). Broadly, it recognizes that such neurological, biological, and genetic variation are intrinsic to an individual's distinct identity, sense of self, and personhood, that should be respected like any other intersecting identity, such as race or gender (Orsini, 2012). This line of thinking reflects a more neutral understanding of neurological differences without suggesting that any way of being is better or worse than another (Singer, n.d.). In this respect, all people, regardless of the extent of their neurological divergence, have value and rights (Bailin, 2019).

While certain ways of being may diverge from the neuro-normative¹⁴, such heterogeneity is part of natural human variation. These variations (such as autism, intellectual disabilities, and attention deficit disorder), like any identity, can influence how the world is experienced for the individual, at times providing unique strengths, and at other times creating specific challenges. Such challenges can be disabling for some, in terms of impacting function or causing distress (Baron-Cohen, 2019). Both 'differences' and 'disability' are encompassed within the neurodiversity framework: the environments in which Autistic people are situated and the supports that are provided greatly influence the degree to which they experience disability (Bottema-Beutel et al., 2021).

Services and supports that prioritize dignity, diversity, and the identity of Autistic people are needed across the lifespan, as are efforts needed to ensure meaningful inclusion in all desired societal roles. These supports can be developed and enhanced through adopting a neurodiversity lens (DeThorne & Sears-Smith, 2021; O'Dell et al., 2016). One of the strengths of this lens is that rather than focusing only on pathologies or deficits, it takes a more balanced view of the individual, with attention paid to capacities and competencies (Baron-Cohen, 2019).

¹⁴ Neuro-normative can refer to non-autistic populations who as a majority group may consciously or unconsciously develop norms or 'typical' ways of being that do not reflect or incorporate neurodiverse ways of being.

“The Neurodiversity movement that embraces autistic strengths and advocates for accommodations is so important ... the medical deficit model isn’t the only model for Autistic people. We are not people to be fixed or cured. Our brains just work differently. We are no better or worse than neurotypical Canadians.”

- Autistic adult

Diversity involves recognizing, respecting, and valuing differences based on ethnicity, gender, age, race, religion, (dis)ability, and sexual orientation (Victoria State Government, 2019). Neurodiversity is a form of diversity. Diversity can also include the infinite range of unique individual characteristics and experiences, such as communication style, life experience, educational background, geographic location, income level, marital status, and/or parental status that influence personal perspectives.

Intersectionality identifies how an individual’s multiple social identities interact and combine in complex ways to affect their experience of advantage or disadvantage (Crenshaw, 1989). The notion of **double stigma** is often used to describe the stigma experienced by individuals or groups who have two (or more) highly-stigmatized conditions or identities (Turan et al., 2019). The impact of such stigma is not simply additive, but creates multiplicative experiences of disadvantage. Drawing upon an intersectional lens also provides a deeper and more nuanced understanding of the barriers that confront Autistic people due to their multiple social identities. Not only is this lens useful for furthering recognition of an individual’s experiences, but it can also allow for a better understanding of how to promote **inclusion** of those Autistic individuals who are particularly oppressed by societal barriers (Crenshaw, 1989). Adopting an intersectionality lens to understand the diverse experiences of Autistic people is important to ensure that the needs of those who are most disadvantaged are not inadvertently overlooked.

2.1 Autism and Indigenous Peoples

Summary Points

Indigenous Peoples of Canada hold worldviews that promote acceptance of Autistic people and greater inclusion in community and family events. Traditional ways of Indigenous Peoples include Elder teachings, land-based activities, therapeutic interaction with animals, art, and music. Further understanding of these practices could be a valuable contribution to our understanding of effective supports and services for all Autistic people.

Colonization and related inter-generational traumas that have been experienced, as well as complexities of accessing care from multiple pan-Canadian and provincial/territorial jurisdictions, are important and unique considerations for Autistic First Nations, Métis, and Inuit peoples and their families. This context exacerbates the existing barriers many Autistic people face, such as access to healthcare and autism diagnosis (especially in rural or remote communities) and culturally-responsive, evidence-informed supports and services, as well as safety concerns.

There is very little data and research on autism and Indigenous Peoples in Canada. What exists is mainly non-Indigenous-led which is not aligned with essential standards, which include Indigenous leadership and data sovereignty.

The Public Health Agency of Canada contracted the Canadian Academy of Health Sciences to undertake an Assessment on Autism that included consultation and engagement with Indigenous Peoples of Canada. Canada's Constitution (Rights of the Aboriginal Peoples of Canada, 1982) recognizes three distinct Indigenous groups: *First Nations*¹⁵, *Métis*¹⁶, and *Inuit*¹⁷. While the term Indigenous does not reflect the uniqueness of each group, it is used in this report where we could not be more specific.

¹⁵ There are 634 First Nation communities (or reserves) with First Nation Governments across Canada and over 50 distinct nations and language groups (Assembly of First Nations, n.d.).

¹⁶ A distinct Indigenous Peoples and Nation from the historic Northwest, which includes Manitoba, Saskatchewan, Alberta and some areas of Ontario, British Columbia, the Northwest Territories, and the northern US (Métis National Council, 2022).

¹⁷ Indigenous people living primarily in 51 communities across Inuit Nunangat, which consists of the Inuvialuit Settlement Region (Northwest Territories), Nunatsiavut (Labrador), Nunavik (Québec) and Nunavut (Inuit Tapiriit Kanatami, 2022).

This section serves as an introduction to experiences of autism among Indigenous Peoples in Canada, calling attention to some of the unique inequities experienced by Indigenous Autistic people. In support of truth and reconciliation, this Assessment on Autism sought to hear and amplify the voices of Indigenous Autistic individuals and their families. Many quotes are used to ensure their perspectives are directly and respectfully included.

We recognize the right of Indigenous Peoples of Canada to exercise sovereignty over their data. This assessment respects treaties between First Nations and the Canadian government that outline commitments and obligations of both groups, including First Nations peoples' right to health services, as well as international conventions. As a signatory to the United Nations Declaration on the Rights of Indigenous Peoples, Canada has committed to uphold rights to self-determine healthcare delivery, to access traditional medicines and health practices, and to access all social and health services available to other citizens (United Nations, 2007).

The Oversight Panel and Working Groups included Indigenous individuals who helped guide the integration of perspectives of Indigenous Peoples of Canada from the published literature and our consultation process. Stakeholder engagement also included First Nations (Status and Non-status), Métis, and Inuit peoples through our opinion survey, online community conversations, online engagement platform (the Engagement Hub), and with targeted, in-depth interviews.

This section is limited in scope by the available research and the barriers inherent with being a non-Indigenous-led process. We recognize the limitations of our engagement processes to reach and engage with the diverse First Nations (Status and Non-status), Métis, and Inuit peoples of Canada to fully explore the rich variations due to history, language, geography, population size, and living on or off reserve, among others.

Though preliminary, requiring confirmation and further exploration through Indigenous-led consultation with First Nation, Métis, and Inuit people and health leaders, there are important considerations outlined in the following sections related to:

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- Acceptance of diversity,
 - Prevalence of autism,
 - Barriers to accessing healthcare and autism diagnosis and culturally-safe, evidence-informed supports and services,
 - Funding mechanisms, and
 - Safety concerns related to being Indigenous and autistic.
-

2.1.1 Acceptance of Diversity

Indigenous Peoples of Canada hold worldviews that espouse acceptance of diversity. For example, among British Columbia’s First Nations, communities have been noted to be inclusive with strong family systems, such that disabled people are included in community and family events (Lindblom, 2017).

“When we are able to gather with other First Nations [people], it is such a relief because my children are accepted as they are. They are loved and welcomed.”

- Family Member of an Indigenous Autistic person

During the stakeholder engagement process, Autistic individuals and their families told stories about experiencing acceptance and support within their Indigenous communities, resulting in positive social and economic inclusion.

“Culturally there is less stigma in [my First Nations] community around being autistic and more patience with people who do not know cultural norms and protocols ... I have found it easier to learn social skills as an adult reconnecting with [my First Nations] context than I have in a white context, despite being raised in a white family as a child.”

- Indigenous Autistic adult

2.1.2 Prevalence of Autism in Indigenous Communities

Precise prevalence rates of autism among First Nations, Métis, and Inuit children in Canada are currently unknown. Research from Canada and other countries, however, indicate that autism is significantly under-diagnosed among Indigenous populations (Lindblom, 2014; Ouellette-Kuntz et al., 2006; Burstyn et al., 2010; Leonard et al, 2011; Roy & Balaratnasingam, 2010). Data collection efforts to gather baseline information about Indigenous Peoples and autism have been recommended outside of Canada (New Zealand Ministries of Health and Education, 2016).

2.1.3 Barriers to Accessing Healthcare and Autism Diagnosis

Indigenous families experience numerous barriers to accessing general health services for children including (First Nations Information Governance Centre, 2016):

- Services and knowledgeable healthcare professionals not available locally,
 - Costs to attend services out of the area,
 - Lack of culturally-responsive services, and
 - Difficulties with accessing traditional care.
-

Barriers to accessing autism diagnostic and supportive services parallel these general challenges and include:

- Cultural and language challenges (Roy & Balaratnasingam, 2010),
- Perceptions by some groups that diagnosis is not necessary or offers little benefit (Ouellette-Kuntz et al., 2006; Bernier et al., 2010; Tincani et al., 2009), and
- Living in remote areas (Burstyn et al., 2010; Leonard et al., 2011; Tincani et al., 2009).

“He must’ve been probably 4 or 5 years old [when diagnosed]. We did a number of trips to [larger urban centre] in order for him to get the diagnosis ... it’s a four-hour drive ... that was hard ... We had other kids too as well so [my partner was] home half the time with our other kids, while I went on [these] road trips with [our son].”

- Family Member of a First Nations Autistic person

Racism within the healthcare system can deter Indigenous families from seeking services. In British Columbia, 84% of First Nations, Métis, and Inuit people surveyed reported experiencing discrimination in the healthcare system (Turpel-Lafond, 2020).

“Parents ... have a huge fear of the public health system ... there is racism ... and you just don’t want to deal with that ... They’re going to see me as an Indigenous person first and that’s going to dictate how they’re going to treat me ...”

- Family Member of a First Nations Autistic person

Furthermore, access to reliable and affordable broadband internet is often limited or non-existent on remote reserves, which makes virtual care less available (Collier, 2021). Recent COVID-19-related in-person service and economic disruptions have also widened these gaps.

Culture has been shown to influence understandings of autism, disability, and health conditions, as well as expression of autism characteristics, which may influence healthcare-seeking behaviours and preferred models of care (Daudji et al., 2011; Ravindran & Myers, 2012; La Roche et al., 2018). Structural barriers built into the health system, such as the use of culturally-insensitive diagnostic and assessment tools (Ouelette-Kuntz et al., 2006; Bernier et al., 2010), under-recognized cultural presentations of autism (Mandell & Novak, 2005; Bernier et al., 2010; Anthony, 2009), and clinicians’ cultural biases (Bernier et al., 2010) may result in delayed or misdiagnoses.

“It can often be a struggle for First Nations individuals to get a proper diagnosis ... Because it is a First Nations family, they first look to Fetal Alcohol effects as a diagnosis because of stereotyping and prejudice ... If the parents do not have a support system or an advocate, they will settle for that wrong diagnosis because they trust a doctor.”

- Family Member of a First Nations Autistic person

Indigenous people understandably mistrust the healthcare system where care is often provided by the dominant culture that bears responsibility for Indigenous cultural discontinuity and disintegration of Indigenous family units (Brascoupe & Waters, 2009; Baker & Giles, 2012). During the stakeholder engagement process, Indigenous parents expressed feeling hesitant to initiate contact with the healthcare system due to their communities’ experiences of historical trauma. Some parents worried that their children could be apprehended without cause if they sought assistance and support for their Autistic children.

“... There is a negative stigma against Indigenous parents and I just felt ... that insecure feeling ... are they going to take my kids away? It’s always in the back of my mind ... even though I’m a good parent.”

- Family Member of a First Nations Autistic person

2.1.4 Culturally-Responsive, Evidence-Informed Supports and Services

Provision of evidence-based supports and services can be culturally safe when they are delivered in a culturally-relevant manner, respecting the values, beliefs, and traditions of the individual (Smith et al. 2011). Culturally-responsive services are those that are delivered to people in ways that recognize, validate, and respect their unique identity and/or needs and that integrate their cultural background and experiences (Gill & Babacan, 2012). Such practices require ongoing learning and self-reflection, as well as collaboration with service recipients to develop shared knowledge and understanding. These practices, in turn, can foster cultural safety, which is the sense of safety experienced when people’s identities and needs are not challenged or denied. For this reason, supports and services that integrate with Indigenous worldviews, such as Elder teachings, land-based activities, therapeutic interaction with animals, art, and music may be especially suitable to implement in First Nations, Métis, and Inuit contexts (Srinivasan et al., 2018; Berry et al., 2013; Schweizer et al., 2014; Lindblom, 2017).

“We do lots of on the land stuff like camping, hunting ... arts and doing hides ... [He] is always into everything like berry picking – whatever we’re doing, fishing, and practicing the smudging ... that really helped him last year actually ... It really calmed him down.”

- Family Member of a First Nations Autistic person

Culturally-safe care could be enhanced by specially-trained system navigators across health, education, and disability sectors and the development of autism resources in appropriate and relevant language using a range of media (New Zealand Ministries of Health and Education, 2016).

“He loves being out in the wild, and he loves fishing. He has such a strong passion for it ... being out on the land with animals ... That’s what he truly enjoys ... [He] does really well with our cultural practices.”

- Family Member of a First Nations Autistic person

Community organizations are positioned to address systemic inequalities and power imbalances between healthcare providers and Indigenous parents by advocating and supporting parents to connect with appropriate supports and services.

“It was a team effort between me and [local service agency]. When we had to enrol him in school, [she] ... helped me with the forms ... a lot of times I just feel out of place or kind of unsure ... just need that reassurance from them ... When I felt like I couldn’t speak up or ask for something, [she] would do that for me.”

- Family Member of a First Nations Autistic person

2.1.5 Funding for Supports and Services Across Canada

Under Jordan’s Principle, funding is available to First Nations children for products, services, and supports to meet a wide range of health, social, and educational needs, including those associated with disability (Indigenous Services Canada, 2022). During stakeholder engagement, Indigenous families shared challenges with filling out what they described as excessive and confusing funding applications for pan-Canadian programs (e.g., non-insured health benefits or Jordan’s Principle funding). They reported that their applications were often denied due to insufficient information, resulting in delays and appeals. In addition, parents perceived that there was inconsistency in the administration of these programs across Canada. Parents appreciated the advocacy and navigation support of community-based organizations to access funding and services.

“ ... The non-insured health benefits for Indigenous people (on reserve) ... under Health Canada ... The process would be gruelling ... Some people would get denied ... just because of technicalities or the band says no ... appeal to Ottawa ... would approve or deny ... bureaucratic nightmare ... you just want to get your child help, not this ... endless cycle of deny or delay ... later diagnosis and miss out on those early childhood development factors ... that’s the most critical time.”

- Family Member of a First Nations Autistic person

2.1.6 Safety Concerns associated with being Indigenous and Autistic

Stakeholders indicated several safety concerns, including being taken advantage of financially and not feeling safe in schools. They also spoke about the importance of trusted emergency contacts and effective autism-sensitive police responses.

“Train police officers to identify differently. My greatest fear is not of being taken advantage of, or of someone tricking me into something – both are possible, but neither of those things scare me nearly as much as a police officer asking me questions unprompted. Eye contact is not easy for me to make, and I tend to convey ideas that I don’t mean to, as well as backtrack over my words. These traits double when I am under stress ...”

- Indigenous Autistic adult

2.1.7 Engagement with Indigenous Peoples of Canada

This assessment provides some initial information to support further engagement with Indigenous Peoples of Canada as they voice their concerns and identify how best to shape supports and services that respect neurodiversity within their communities and respond to their needs. Considerations for further research and engagement include (First Nations Information Governance Centre, n.d.; Datta, 2018) developing an Indigenous-led process:

- Consistent with the First Nations principles of ownership, control, access, and possession,
 - Culturally-responsive, respectful, honouring, and careful of the Indigenous community,
 - Creating a positive impact on the community,
 - Helping ensure Indigenous Peoples regain control over Indigenous ways of knowing and being, and
 - Advancing social justice.
-

“We need to nurture kindness and leading from the heart. That being a kind, caring, compassionate person is valued. We need equity and justice. This involves mental health supports, programs on healthy families, programs for abusive men and how to become caring fathers and partners — that needs to start in schools.”

- Family Member of an Indigenous Autistic person

Key Finding - Autism and Indigenous Peoples

Indigenous-led, comprehensive, culturally-relevant and localized approaches to meeting the needs of Autistic people are central to respecting, recognizing, and addressing the distinct and unique experiences of Canada’s First Nations, Metis, and Inuit peoples.

2.2 Autism and Diversity related to Race and Ethnicity

Canada is a multicultural society, where citizens have come from many countries of origin and cultural backgrounds (Brosseau & Dewing, 2018). However, there is scant population-level, race-based autism data publicly available in Canada.

Race or ethnic background may influence rates and time of diagnosis. Systemic racism refers to patterns of behaviour, policies, or practices that become normalized and legitimized as part of organizational or societal structures, including health and social systems, which create and perpetuate disadvantages for *racialized persons* (Ontario Human Rights Commission, n.d.). A Canadian study found that foreign birthplace was significantly associated with a later age of autism diagnosis, while conversely, children from racialized communities were diagnosed slightly earlier (Coo et al., 2012). In the United States, African-American children were three times more likely to receive an alternative diagnosis, such as conduct or adjustment disorder, prior to being diagnosed with autism (Mandell et al., 2007). In turn, in the United Kingdom, diagnosed prevalence of autism is higher in Black and mixed-race pupils (Roman-Urrestarazu et al., 2021). The increased prevalence in some racialized communities may be due to referral bias. However, biases may also lead to under-representation. For example, as described earlier in this chapter, autism is also significantly under-diagnosed among Indigenous populations (Lindblom, 2014; Ouellette-Kuntz et al., 2006; Burstyn et al., 2010; Roy & Balaratnasingam, 2010).

“... My being [First Nations], in addition to differences in sensory processing, processing of pain, and in my emotional affect, causes non-Indigenous doctors to assume that I am not actually experiencing what I am describing, but to write me off as a drug seeker.”

- Indigenous Autistic adult

Summary Point

Biases, discrimination, and systemic racism exist within the Canadian healthcare and social service systems. As a result, Autistic people from racialized communities are less likely to get needed diagnoses, supports, and services.

Delays in autism diagnosis and service access for racialized communities have been attributed to factors such as:

- Clinician prejudices and biased responses to parents' and other *family members'* concerns (Constantino et al., 2020; Mandell & Novak, 2005),
 - Cultural factors affecting a parent's recognition and interpretation of their child's presentation (Daley, 2004),
 - Limited understanding or expectations of extended family and parents for child development or rehabilitation potential based on traditions or knowledge from their country of origin (Chiri & Warfield 2012; Miller-Gairy & Mofya, 2015),
 - Denial, shame, and stigma related to autism in certain communities (Dababnah et al., 2018),
 - Language barriers including low availability of early detection and assessment tools in preferred language (Harris et al., 2021) and reduced and/or narrower service provision to individuals/families whose primary language is not English, such as newcomers to Canada (Khanlou et al., 2017; Lim et al., 2021; St. Amant et al., 2018),
 - Fear and previous maltreatment in healthcare and childcare settings (Burkett et al., 2015), and
 - A lack of and/or unequal geographic distribution of racial and language diversity among clinicians (Broder-Fingert et al., 2020).
-

“Since I was not born in Canada, some of my differences are blamed on where I was raised as a child and my culture.”

- Autistic adult

Access to autism supports and services can also be challenging. For example, racialized families of an Autistic child were half as likely to be involved with a case manager (Thomas et al., 2007). Due to the perpetual traumatic experiences of oppression and discrimination in healthcare systems, there is significant distrust by various racialized groups (Burkett et al., 2015; Turpel-Lafond, 2020). This distrust is a further barrier to service access. Traditional beliefs and values of some groups may also influence follow-up with services and professional supports (Kummerer et al., 2007). As mentioned earlier, cultural safety can be fostered through culturally-responsive care (Gill & Babacan, 2012).

“Potentially because I am considered to be a brown woman, I find that healthcare professionals are very inclined to doubt or outright dismiss my autism diagnosis, which makes it harder to access accommodations from them.”

- Autistic adult

The school system has often failed to address the unique needs of Autistic children and adolescents from diverse ethnic, cultural, linguistic, and gender/sex backgrounds (Odom et al., 2021). For example, studies from the UK, have shown that teachers tend to have low expectations for Black students (Gillborn & Mirza, 2000; Gillborn et al., 2012), and that they are overrepresented in special education programs (Tomlinson, 2014). Racial disparities persist during the transition to adulthood, with Autistic adults from racialized communities experiencing challenges, such as lower rates of employment, social participation, and post-secondary education compared to white Autistic adults (Eilenberg et al., 2019). Racialized Autistic people may also be more likely to be stigmatized (Harrison et al., 2017).

“He [Autistic family member] is a large, black male, moderately verbal, living in an urban centre. This intersection affects how he is perceived and how people interface with him with either low or stereotypical and negative assumptions about him. For example, being questioned or followed in a store when he is curiously and closely looking at items.”

- Family Member of an Autistic person

2.3 Autism and New Canadians and Language Minorities

New Canadians and non-dominant language speaking families of Autistic individuals have less access to acute care, specialized services, educational services, and community services compared with higher income and white families (Smith et al., 2020; Sritharan & Koola, 2019).

New Canadians are often embedded within an immigration process, which includes added barriers such as (Khanlou et al., 2017):

- Reduced economic resources,
- English or French as a second language,
- Lack of social networks, and
- Acculturation challenges.

Summary Point

Families of Autistic individuals from non-dominant language groups face additional barriers to diagnoses, supports, and services due to communication and other cultural differences. These barriers have been linked to the under-identification of autism in immigrant families.

A study of Canadian immigrant experience (parents of Autistic children from a range of nationalities living under adverse socioeconomic circumstances in Montreal) indicated that uncertainties about factors associated with their child's developmental challenges extended to the potential role of exposure to multiple languages and bilingual environments (Pondé et al., 2019). However, several international studies have found that multiple languages spoken at home are not associated with the presence of autism (Hambly & Fombonne, 2014; Ohashi et al., 2012; Petersen et al., 2012), and that growing up in a bilingual environment does not disadvantage the language development of Autistic children (Hambly & Fombonne, 2014; Ohashi et al., 2012).

Various studies in high-income countries have observed higher rates of autism among specific immigrant groups, ranging from 25% higher among immigrants from Eastern Asia to 76 to 250% higher among those from Eastern Africa as compared to non-immigrants (Becerra et al., 2014; Dealberto, 2011; Bolton et al., 2014; Pavlish et al., 2010; Fairthorne et al., 2017). The mechanism through which specific immigrant groups may be more likely to have an autism diagnosis has not been determined.

Families of Autistic people where English or French is their second language, may face additional barriers to accessing diagnostic and support services access due to language differences, including:

- Insufficient access to information about available resources (Burkett et al., 2015),
- Being less likely to receive timely diagnosis, effective referrals, or follow-up services and supports (Blacher et al., 2019; Smith et al., 2020),

- Services may not be linguistically- or culturally-responsive because they are based on Euro-Canadian standards of care (Khanlou et al., 2017), and
- Culturally-insensitive or unresponsive assessment measures can lead to over- or under-identification of autism in children from low socioeconomic or immigrant families (Durkin & Yeargin-Allsopp, 2018; Roman-Urrestarazu et al., 2021).

“There was/is a big issue with lack of resources on autism in Chinese and Vietnamese, much less neurodiversity-affirming ones. My parents were also not super literate throughout my childhood – because of growing up in stark destitution and poverty in war-torn Vietnam, then having to come to Canada and learning an entirely new language. So if there were written resources ...(or) someone who could speak to them aloud in Cantonese, Mandarin, or Vietnamese, at the right time in my childhood, and teach them about autism, I think my struggles with getting assessed would be different.”

- Autistic adult

While having written materials and access to skilled translators can ameliorate some of these obstacles, these are not always available. For example, Korean parents of Autistic children living in British Columbia expressed that when these resources were not available, they felt unaccepted and unwelcomed in their communities (Fong et al. 2021). In place of translators, healthcare professionals may commonly rely on a family ‘spokesperson’ (Lindsay et al., 2012). However, this family member may not always be the most knowledgeable about the child, may not be able to translate the cultural nuances of a family, and such practices place a significant pressure on family dynamics.

2.4 Autism, Gender, Gender Identity, and Sexual Orientation

Summary Point

→ Autism tends to be under-recognized in girls, women, and individuals assigned female at birth. There is wider diversity in gender identities and sexual orientation among Autistic people than the general public. The ‘double stigma’ experienced by Autistic people who also identify as **2SLGBTQIA+** places them at higher risk of maltreatment and mental health challenges.

The prevalence of autism has been consistently reported as higher among males compared to females (Fombonne, 2009; Werling & Geschwind, 2013; Public Health Agency of Canada, 2018; 2022). However, there is growing consensus that autism may present partially differently in girls, women, and individuals assigned female at birth (Lai, Lin, & Ameis, 2021). Further, stereotypes about autism and gender may impede clinical recognition. As such, girls, women, and individuals assigned female at birth are more likely to be mis-, un-, or under-diagnosed, and/or receive late diagnoses (Green et al., 2019; Gesi et al., 2021; Lai & Szatmari, 2020; Loomes, Hull, & Mandy, 2017).

“I experienced a series of psychiatric misdiagnoses before finally accessing culturally competent healthcare ... Doctors [were] telling me that I was experiencing things that were not true to my actual experiences and prescribing medications that were inappropriate ... The first specialist believed that women / female-assigned people were not likely to be autistic and that Autistic people were incapable of doing well in school ... [They] assured me that I could not be autistic without conducting any further assessment.”

- Autistic adult

A delayed diagnosis can contribute to mental health concerns, affect Autistic females’ abilities to access needed supports and *accommodations*, and serve as an obstacle to greater self-understanding and self-acceptance (Tint & Weiss, 2018; Leedham, Thompson, Smith, & Freeth, 2020; Bargiela et al., 2016). Autistic females may also experience unique struggles, including being held to different social standards than Autistic males (Saxe, 2017), resulting in a greater pressure to mask their autism characteristics (Bargiela et al., 2016; Cook et al., 2021; Libsack et al., 2021) or compensate for social challenges in neurotypical contexts (Livingston, Shah, & Happé, 2019). Masking and compensation (sometimes referred to as ‘camouflaging’ [Lai, Hull et al., 2021]) refer to the acts of covering up one’s natural autism characteristics and behaviours in favour of those that are considered more socially acceptable, even if it makes the Autistic individual uncomfortable (Pearson & Rose, 2021). In a recent Delphi study, psychologists and psychiatrists experienced in assessing Autistic women also emphasized the complexities of differential diagnosis, which can lead to discordance between clinical judgement and self-identification (Cumin et al., 2021).

“Because people think I’m a woman (assigned female at birth), I feel like I am held to a much higher standard in terms of expectations of my communication when compared to men. It is much less acceptable for me to be blunt or spend a lot of time info-dumping without asking questions.”

- Autistic adult

There is also emerging evidence of greater diversity in gender identity and sexual orientation among Autistic people compared to the general population. This diversity includes an increased likelihood of identifying as non-heterosexual (Hellemans et al., 2007; Barnett & Maticka-Tyndale, 2015; Rudolph et al., 2018; Dewinter, De Graaf, & Begeer, 2017; Weir, Allison, & Baron-Cohen, 2021), higher rates of gender fluidity and gender variance (Barnett & Maticka-Tyndale, 2015; Janssen et al., 2016; Dewinter et al., 2017), and a greater likelihood of identifying as a different gender from that assigned at birth (Shumer et al., 2016; De Vries et al., 2010; Glidden et al., 2016; van der Miesen et al., 2016; Thrower et al., 2020). Large-scale studies show Autistic children are more than four times as likely to be clinically diagnosed with gender dysphoria than non-autistic children (Hisle-Gorman et al., 2019). Conversely, transgender and gender diverse individuals are three to six times as likely to be autistic than are cisgender individuals (Warrier et al., 2020).

“I feel that my experience of gender is uniquely tied to my being autistic ... I have not internalized [non-autistic] social norms about gender, and [am] more likely [to] question gender as a social construct ... ”

- Autistic adult

And yet, Autistic people who identify as 2SLGBTQIA+ report having their ability to determine their gender identity or sexual orientation questioned (Kusalanka et al., 2018; Strang, Powers et al., 2018). Incorrect assumptions that all Autistic people are not competent to make medical decisions may create additional barriers that reduce trans Autistic people’s access to gender-affirming medical services such as hormone therapy and surgery (Strauss et al., 2021). Ensuring that Autistic people are supported and empowered in their health decision making and access to such care is essential (Strang et al., 2021). Other mistaken assumptions that Autistic people may lack sexual desire and direct actions to prevent Autistic people from exploring their own sexuality have also been reported (Hannah & Stagg, 2016; van Schalkwyk et al., 2015; Pecora, Hooley, Sperry, Mesibov, & Stokes, 2021). Ensuring access to sexual education and sexual healthcare for all Autistic people across the lifespan should remain a priority (Turner, Briken, & Schöttle, 2017; Weir et al., 2021).

Some 2SLGBTQIA+ Autistic people have reported experiencing discrimination and a lack of acceptance from both the 2SLGBTQIA+ community and by other Autistic people (Hillier et al., 2020; Strang, Meagher et al., 2018), which may contribute to higher rates of mental health challenges (George & Stokes, 2018; Hall et al., 2020; Mahfouda et al., 2019). Further, stigma may act as a barrier to accessing needed physical and mental healthcare (Hillier et al., 2020). For instance, Hall et al. (2020) found that 2SLGBTQIA+ Autistic people were often reluctant to seek

healthcare, due to previous negative experiences and stigmatizing attitudes held by *service providers* about autism as well as gender and sexual diversity. The intersection of other social identities, such as race and ethnicity, further amplify the discrimination, exclusion, and negative experiences that are felt by Autistic people (Lovelace et al., 2021).

“I understand that Autistic people are more likely to be 2SLGBTQIA+ and ... trans ... Autistic trans people face barriers to accessing transitioning services and other healthcare services, [we] are told that we are confused about being trans because we are autistic, and face ableism¹⁸ within the 2SLGBTQIA+ community.”

- Autistic adult

2.5 Autism and Diversity of Family Structures

2.5.1 Experiences of Parenting: Autistic Parent Perspectives

Autistic people experience and navigate many roles in their adult lives, including becoming parents. Indeed, consistent with known genetic contributions (Woodbury-Smith & Scherer, 2018) and the heritability of autism-related characteristics (Loncarevic et al., 2021), rates of autism among children born to Autistic adults are higher than in the general population (Xie et al., 2019). Self-reflection regarding their child’s diagnosis can lead to a parent’s realization that they may share autism characteristics and initiate the journey toward self-identification or formal assessment and diagnosis (Crane et al., 2018). The experiences of Autistic parents have received remarkably little attention (McDonnell & Delucia, 2021), although, based on recent research, there is now a growing body of literature, with a focus on lived experience, stigma, and support needs.

Core aspects of autism, such as sensory differences, have been linked to unique pregnancy and parenting challenges (Hudson et al., 2019; Rogers et al., 2017). For instance, the physical sensation of breastfeeding may be unpleasant for some Autistic mothers, despite a strong desire to breastfeed (Gardner et al., 2016). Further, evidence suggests that Autistic women are more likely to experience depression during and after pregnancy (Pohl et al., 2020; McDonnell & DeLucia, 2021). Autistic mothers have also reported experiencing executive functioning difficulties including challenges with multi-tasking, staying organized, and managing domestic responsibilities for which they may require supports (Pohl et al., 2020). Autistic parents have also described difficulties with navigating professional services (Marriott et al., 2021).

Communication differences can make it difficult to interact with educational, medical, or social

¹⁸ Ableism refers to a way of thinking that sees disabled people as being less worthy of respect, of less value and less able to contribute and participate in society compared to non-disabled people (Ontario Human Rights Commission, 2016). This way of thinking can be both conscious or unconscious and can lead to discrimination, social exclusion, and limited opportunities for disabled people.

work professionals (Pohl et al., 2020). As an example, Autistic mothers were less likely to report that the birthing process was effectively explained to them compared to non-autistic mothers.

Summary Point

Autistic parents may experience a complex combination of challenges, such as limited personal supports and economic disadvantages as Autistic adults, stigma and prejudices regarding their parenting skills, and similar difficulties all parents face in seeking care for their Autistic children. These negative experiences may lead Autistic parents to avoid seeking out needed supports.

Stigma about Autistic people's parenting abilities was also described as a key barrier to accessing appropriate care and support across different sectors (Rogers et al., 2017; Pohl et al., 2020; McDonnell & DeLucia, 2021). Four times as many Autistic parents had their parenting abilities questioned by a professional compared to non-autistic parents (Griffiths et al., 2019). Autistic mothers often reported feeling judged and many were reluctant to disclose their autism diagnosis (Rogers et al., 2017; Pohl et al., 2020). A fear of judgement can lead Autistic mothers to avoid seeking out needed support (Pohl et al., 2020). This stigma may also contribute to higher rates of involvement with child protective services (McDonnell & DeLucia, 2021).

This emerging body of literature identifies the need for population-specific parenting supports (Winnard et al., 2021). More information about possible program and service approaches are described in Chapter 4. In addition to particular challenges accessing services, a recent study by Crane, Lui and colleagues (2021) discussed the experiences of Autistic parents with Autistic children. The Autistic parents in this study discussed the benefits of their own experiential expertise, which they felt resulted in heightened understanding and empathy with their Autistic children.

2.5.2 Families that include Autistic People

Stigma has been suggested as a critical factor for parental stress and social isolation (Mitter et al., 2019; Papadopoulous et al., 2019). For instance, parents or siblings may experience stigma if others react negatively to their Autistic family member's ways of expressing themselves (Mitter et al., 2019). Further, parents have reported feeling shame, and being blamed and stigmatized for their family member's condition as well as their competence as a parent (Milacic-Vildojevic et al., 2012). Having to face public stigma and discrimination can negatively influence family members' ability to cope with adversity (Jahoda & Markova, 2004; Meyers et al., 2009), and lead to negative and distorted self and social perceptions, (Corrigan & Watson, 2002),

concealment of their experiences from others, and social withdrawal (Mak & Cheung, 2008). Because of the transactional and interdependent relationships amongst family members, family perspectives are described in several sections of this report.

2.6 Complexity of Support Needs

In addition to the forms of intersectionality described above, an autistic self-identity can be influenced by the extent to which autism and co-occurring conditions impact the individual. Some Autistic people may require more complex (e.g., in terms of duration, intensity, and frequency) supports and services across the lifespan to experience wellbeing and social inclusion. *Complex support needs* involve needs that are varied, ongoing, and/or extensive. Some Autistic people require specialized supports across multiple areas of daily life due to such needs. Autistic people with complex support needs typically have co-occurring conditions such as intellectual disabilities, significant mental health conditions, and/or serious physical or medical conditions. This increased need for supports and services may be episodic, spiking at or around certain life events (e.g., diagnosis, illness, grief, marriage, birth), or transitions (e.g., into post-secondary education, employment, moving away from the family home). However, for many, the need for supports and services remains consistently high across the lifespan.

Most Autistic individuals have at least one chronic condition. In one study, more than 95% of Autistic children had at least one co-occurring condition, and more than half of the children (at age four and eight) had four or more co-occurring conditions (Soke et al., 2018). There is wide heterogeneity in the type of co-occurring conditions, but intellectual disability (with or without known genetic syndromes) can have significant implications on the form and intensity of supports and services required across the lifespan. Estimating the incidence of autism with co-occurring intellectual disability is complex. On one hand, changes to the diagnostic criteria, such as the merging of autism and Asperger's, as well as an increased number of diagnoses in children without co-occurring intellectual disability, have influenced the rates over time. On the other hand, research on autism has been shown to have a selection bias towards excluding Autistic individuals with co-occurring intellectual disabilities. In a meta-analysis, Russell and colleagues (2019) found that 94% of all Autistic participants in studies in high impact autism journals did not have a co-occurring intellectual disability, which can impact our understanding and knowledge of how to best serve this sub-group.

In a recent systematic review of global autism prevalence, rates of co-occurring intellectual disability ranged from 0 to 70%, with a median of 33% (Zeidan et al., 2021). Recent estimates of intellectual disability among Autistic children from the US Autism and Developmental Disabilities Monitoring Network since 2014 were 31 - 33% (Chiaratti and Venerosi, 2020). Canadian autism prevalence data published by the Public Health Agency of Canada (2018; 2022) do not include data on co-occurring intellectual abilities.

As an Autistic person experiences more co-occurring conditions and challenges in and across multiple life domains, they may require more support from multiple persons and across multiple services (e.g., respite, transportation, day supports, primary, mental, and specialist health) and sectors (e.g., education, health, disability); (Rivard et al., 2021). As such, there is an added need to advocate for, coordinate, and navigate these multiple and often complex systems of supports and services (Calleja et al., 2020). This is often the role of parents or other family members (Murphy et al., 2016; Lubetsky et al., 2014).

The need for specialized supports does not only come from co-occurring intellectual disability. Severe mental health challenges, as well as a consistent lack of effective supports and stigma over time may trigger complex support needs, which may not be well understood or met through current service provision. These individuals may often struggle to be served in mental health, health, and developmental sectors due to eligibility requirements and misunderstanding of autism. When systems are not equipped to understand the fluctuating and/or constant needs of Autistic individuals and their families, promoting optimal person-environment fit can become an elusive outcome. In this report, we have described these individuals as Autistic people with complex support needs.

“ ... Now that he is a teenager. He is much bigger and stronger and many of his outbursts can get violent. He doesn't try to hurt his family; however, he aggressively punches his bed, or the wall and it does get very tense at times.”

- Family Member of an Autistic person

2.7 Autism and Rural and Remote Communities

Living in rural or remote communities can lead to limited access to diagnosis, services and supports (Antezana et al., 2017). This is relevant to the Canadian context where segments of the population live rurally or remotely. For many Autistic people and their families, access to services involves increased travel costs, distance, time, and often poor quality travel options (e.g., wintery roads; unavailability of public transport services, etc.) (de Leeuw et al., 2020). Living rurally could thus amount to driving long distances or choosing to relocate to be closer to supports and services (DePape & Lindsay, 2016).

Summary Point



There is less access to diagnosis, services, and supports for Autistic people and their families in rural and remote Canadian communities. Challenges in access contribute to emotional strain, stress, and additional costs.

Parents of disabled children in Canadian rural communities have described experiencing emotional strain and stress due to these challenges, as well as additional financial burden (Hoogsteen & Woodgate, 2013). Indeed, parents of Autistic children living in rural areas faced 14% higher annual additional costs than those in urban settings (Liao & Li, 2020). Unequal geographic distribution of specialists also creates further structural barriers for families, particularly those from minority groups (Broder-Fingert et al., 2020).

Socioeconomic disparities of neighbourhoods may offer an analytic snapshot of the differences in autism prevalence across the country. The Early Development Instrument (Janus & Offord, 2007), implemented in most Canadian provinces and territories, has been used to collect data on childhood diagnoses by neighbourhood. Merging autism diagnosis with neighbourhood and socioeconomic variables has helped identify some differences in autism diagnosis across the country (Siddiqua et al., 2020). However, to date, the existing data is very limited. Intersections with and experiences of community safety and neighbourhood violence will be further described in Chapter 4.

2.8 Autism and Socioeconomic Status

By and large, autism research has been limited by non-representative population samples that have over-sampled families who have higher income, are more educated, and are more likely to be white than national averages. Despite this over-representation within autism research, a subset of studies demonstrate the role family characteristics, such as socioeconomic status, intersect with and may contribute to economic and service disparities (Smith et al., 2020). For example, although diagnosed autism prevalence has increased around the globe, those of lower socioeconomic status are less likely to be diagnosed with autism regardless of their clinical presentation (Dickerson et al., 2017). Families of Autistic children with lower socioeconomic status typically report lower access to and use of healthcare and autism services in comparison to families with higher socioeconomic status (Smith et al., 2020). Thus, there are intersectional forms of inequity that exist largely in the economic domain amongst families. These inequities include (Singh & Bunyak, 2019; Anderson, Roux et al., 2018):

-
- Having more limited resources (e.g., financial, health insurance),
 - Living in rural and/or disadvantaged communities,
 - Working in jobs with limited flexibility, and
 - Being a female caregiver.
-

In contrast, families with more disposable income may be more able to pay for educational enrichment activities, services, and tuition without needing public funding (Anderson, Roux et al., 2018).

Furthermore, low socioeconomic status often overlaps with racialized and immigrant experiences. When low socioeconomic status intersects with race, there is even greater disadvantage (Caton et al., 2019) and discrimination. In the United Kingdom, vast differences were found amongst the diagnostic outcomes of Autistic children based on race and social disadvantage. These differences were suggested to be due to referral bias and also differences in detection and phenotypic prevalence for members of these racialized communities (Roman-Urrestarazu et al., 2021). Chapter 5 provides a deeper investigation of the effects of financial stability on Autistic individuals, families, and society.

2.9 Addressing the Needs of Equity-Seeking Groups

Throughout the remainder of the report, best and promising practices to address these issues are provided. For example, in *Equitable Access* (Chapter 4), *capacity building* to develop a more skilled and diverse workforce, addressing the unique challenges of Autistic parents, and access to culturally-responsive, *trauma-informed* services are described. In Chapters 1 and 6 the best practice of including and involving Autistic people and their families from diverse backgrounds is suggested for both governance and research. As a final example, in *Pathways to Post-Secondary Education* (Chapter 5), expanding campus Equity, Diversity, and Inclusion (EDI) frameworks to include neurodiversity has the potential to promote acceptance, mitigate stigma and discrimination, and ensure more proportional representation of Autistic people in post-secondary settings.

While exemplified in post-secondary institutions, there are wider EDI applications. Consciously considering the particular needs of Autistic individuals within EDI frameworks and related analysis tools (such as the [Gender-Based Analysis+](#) strategy implemented across pan-Canadian departments of the Government of Canada) offers a concrete way to support the inclusion and participation of Autistic individuals across multiple settings and institutions. Furthermore, a number of health equity and intersectionality policy analysis tools now exist (for example, see Canadian Public Health Association, 2020; Dover & Belon, 2019; Hankivsky et al., 2019; Povall et al., 2018; World Health Organization Regional Office for Europe, 2019), which may be layered upon analysis of autism policy to address health inequities experienced by particular sub-groups of Autistic people.

Multiple examples of potential solutions relevant to supports and services for Autistic people are described in this report. However, system-wide strategies to improve systemic issues of the Canadian health, social, and education systems are needed to fully address some of the challenges faced by *equity-seeking groups* in Canada.

Key Finding - Autism and Intersectionality

Applying a lens of intersectionality and broadening Equity, Diversity, and Inclusion measures and Gender-Based Analysis+ practices to include autism helps to prioritize and develop actions to mitigate stigma and discrimination and address inequities within services and supports, for example through the expansion of:

- Service provider workforce capacity and diversity,
- Culturally-responsive, trauma-informed service provision,
- Educational and employment opportunities accepting of Autistic people,
- Shared governance and citizen engagement, and
- Research inclusive of equity-seeking groups.

2.10 Chapter Summary

This chapter considered some of the unique challenges and needs faced by Autistic individuals and their families from a range of intersecting identities, such as:

- Race, ethnicity, and language,
- Gender, gender identity, and sexual orientation,
- Diversity of family structure, including the experiences of Autistic parents,
- Complexity of support needs,
- Living in rural and remote communities, and
- Low socioeconomic status.

Though preliminary and limited by being a non-Indigenous-led assessment, the experiences of First Nations, Métis, and Inuit Peoples in Canada in relation to autism were also highlighted. In support of truth and reconciliation and guided by the input of Indigenous representatives on the assessment committee, this assessment sought to hear and amplify the voices of Indigenous Autistic individuals and their families.



Chapter 3: Social Inclusion

Summary Points

Social inclusion represents an integral aspect of wellbeing and quality of life for all, including Autistic people.

Inclusive communities for Autistic people consist of a sense of belonging and acceptance, active participation and meaningful involvement, emotional and physical safety in environments, as well as equitable access to resources and opportunities across multiple life domains.

3.0 Elements of Inclusive Communities

Social inclusion represents an integral aspect of wellbeing and quality of life for all, including disabled people (Brown et al., 2015; Lai et al., 2020; Schalock & Gardner, 2007). The value of social inclusion is underscored by the United Nations' Convention on the Rights of Persons with Disabilities which was ratified by Canada in 2010 to facilitate the full *inclusion* and participation of disabled peoples, including Autistic people, in the community (United Nations, 2006, Article 19).

As a 'flagship concept' within Canadian disability policy (Prince, 2009), inclusion has been a challenging and often contested concept to define or operationalize. It has been critiqued by some as promoting dominant societal values and 'normative' activities such as employment and *independent living*, rather than activities based on personal preferences or needs (Cobigo et al., 2012). While employment and independent living can be desired goals of inclusion for many Autistic people, social inclusion also represents opportunities and life activities beyond these economic domains.

“In many ways, society as a whole, needs to relearn core values [that] we all want our children [to learn in] kindergarten: To be kind, to be understanding, to not be so quick to judge, to accept others for who they are and where they are at in this world. To appreciate that every life has value and from every life a lesson in humility, patience and wisdom can be gained.”

- Family member of an Autistic person

After drawing upon a synthesis of critical and disability literature, we suggest that social and community inclusion has multiple dimensions, which have applicability for Autistic people. Inclusion is:

- Linked to a sense of belonging, safety, reciprocity, and acceptance in communities and places (Renwick et al., 2019; Simplican et al., 2015; Power, 2013; Hall, 2010),
- Associated with active participation and involvement of Autistic people in all life domains, including civic, research, and policy spheres (Prince, 2009; Frankena, et al., 2015),
- The result of complex interactions between a person and their environment that promotes opportunities and dignity (Cobigo et al., 2012; Pereira, 2017; Whiteford et al., 2018; Whiteford & Townsend, 2011),
- Affected by the intersection of individual, interpersonal, organizational, community, and socio-political conditions (Simplican et al., 2015),

- Involving equitable relationships and resource distribution amongst Autistic and non-autistic Canadians (United Nations, 2006; Amado et al, 2013; Hall, 2009), and
 - Centred on the goal of enabling meaningful and expected roles, which should be self-determined through the perspectives, choices, and needs of Autistic people themselves (Cobigo et al., 2016; Wehmeyer, 2004; Wehmeyer & Abery, 2013).
-
-

“Autism is a difference in neurology ... We need accommodations to live in a world not built for us, but that doesn’t mean we don’t belong in that world as we are!”

- Autistic adult

Key elements of inclusive communities, therefore, include a sense of belonging and acceptance, active participation and meaningful involvement, emotional and physical safety in environments, as well as equitable access to resources and opportunities across multiple life domains. From both an ecological and social disability standpoint, promoting social inclusion for Autistic people can thus occur through optimizing person-environment fit, minimizing barriers to personally-meaningful participation, and maximizing opportunities across the lifespan (Henninger & Taylor, 2013; Hutchings & Chaplin, 2017; Lai et al., 2020). Framed by this understanding of inclusive communities, this chapter explores the following areas:

- Addressing stigma and ensuring human rights,
 - Promoting safety at home and in the community,
 - Enhancing community participation and accessibility, and
 - Social inclusion through technology.
-

3.1 Addressing Stigma and Ensuring Human Rights

3.1.1 Background

Under the Canadian Charter of Rights and Freedoms (1982), as well as the United Nations’ Declaration of Human Rights (1948), Convention on the Rights of Persons with Disabilities (2006), and the Convention on the Rights of the Child (1989), Autistic people should enjoy equal rights, protection, and the full benefit of the law without discrimination. Like all people, they have the right to enjoy a high standard of physical and mental health.

Summary Points

Autistic people are often subjected to stigma and discrimination of their rights to education, employment, housing, healthcare, safety, dignity, and *self-determination* which have been associated with poor mental health and higher rates of suicidality.

Discrimination is the behavioural outcomes of negative attitudes, which can include avoidance of particular groups, and withholding help, being denied opportunities and equal rights, and being avoided in social situations.

Stigma and discrimination are major public health issues that produce social inequalities and reduce the quality of life of Autistic people, *family members*, and *supporters*. Policies and measures are needed to fight stigma and discrimination towards Autistic people.

Traditional legal decision-making processes emphasize independent decision-making. While typically well-intentioned, assignments of guardians can also restrict autonomy, self-determination, and dignity, and at times can make Autistic people more vulnerable to financial and other forms of victimization.

Stigma and Attitudes

Despite these legislative frameworks, Autistic people are often subjected to stigma and discrimination of their rights to education, employment, housing, healthcare, safety, dignity, and self-determination (World Health Organization, 2022; Roleska et al., 2018). The violation of these human rights has been associated with poorer mental health and higher rates of suicidality in Autistic people (Cassidy et al., 2021).

Stigma can occur when people form negative attitudes towards a particular group (Cremin et al., 2021). Attitudes, which can be implicit or explicit, are comprised of beliefs, feelings, and behaviours (Engel & Sheppard, 2020; Huskin et al., 2018). *Beliefs* focus on people's knowledge of *autism*, including problematic or inaccurate knowledge or not knowing about autism at all (Cremin et al., 2021). *Feelings* reflect the affective component of attitudes, which may include anxiety or nervousness about interacting with Autistic or other disabled people (Engel & Sheppard, 2020). *Behaviours* involve actions or the intention to act and can include discriminatory acts (Huskin et al., 2018).

When negative attitudes lead to stigma, Autistic individuals may be labelled, stereotyped, and/or experience prejudice, which can produce status loss and discrimination (Scior & Werner, 2015). Discrimination can include avoidance of Autistic people, and withholding help, opportunities, and access to healthcare, employment, and housing from them. For example, the United Kingdom’s Learning Disabilities Mortality Review has consistently shown that Autistic people and those with other *developmental disabilities* are more likely to have preventable, treatable, and avoidable medical causes of death compared to the general population. These avoidable deaths have been associated with a need for better training and awareness in healthcare and social service providers (Department of Health and Social Care, 2019a; National Development Team for Inclusion, 2021).

Attitudes are shaped by direct experiences, modelling, values, and exposure to other people (Fisher & Purcal, 2017). People can also be influenced by their social environment and networks, through organizational practices, as well as community and social norms (Dekoninck, 2017). At a societal level, attitudes may also be influenced by governments where legislation and policies are enacted, as these institutions influence the possibilities for people to work, live, and learn. Negative attitudes are one of the major barriers to participation and inclusion of disabled people outlined by the World Health Organization (Dekoninck, 2017; Fisher & Purcal, 2017). While all disabled people may experience others’ negative attitudes, some conditions, such as autism, are associated with higher rates of stigma than others (Huskin et al., 2018).

The double empathy problem suggests that interactions between people with different experiences and ways of thinking can lead to challenges in understanding and empathy (Milton, 2012), which then influence attitudes and behaviours. In line with this thinking, the social challenges that Autistic people experience are not inherently a problem within the Autistic individual (such as social deficit or lack of empathy), but rather, reflect a breakdown in understanding between Autistic people and non-autistic people who experience the world differently.

Autistic people with co-occurring *intellectual disability* face multiple barriers to social inclusion (Ali et al., 2012; Jones et al., 2021). Furthermore, Autistic people who also identify with other *equity-seeking groups* may experience multiple layers of stigma (Duke, 2011) or discrimination (Dekoninck, 2017). The stigma associated with autism can also be experienced by family members, which can lead to emotional distress and social isolation (Mitter et al., 2019). Sometimes parents are incorrectly blamed for passing on “defective” genes or bad parenting, while Autistic individuals may be mistakenly viewed as paying for “past sins” in some cultures (Ali et al., 2012).

Some of the major reasons for negative attitudes towards Autistic people have been linked to (Dekoninck, 2017; Department of Health and Social Care, 2019a; Hamrick et al., 2021; Holton et al., 2014; Catala et al., 2021; McGuire, 2016):

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- A lack of targeted, long-term, and systematic **autism acceptance** and **awareness**-raising campaigns and strategies,
 - The potential and historical negative framing of media messages about autism,
 - A lack of skill, knowledge, and understanding by the public and in the health and social service workforce,
 - A lack of positive and realistic images of Autistic persons in all sectors and strata of society, including the media, and
 - Narratives and perspectives of Autistic people being historically devalued.
-

Broadly, discussions about autism in the media and in research have tended to use negative social narratives (i.e., tragedy, epidemic, and pity) that stigmatize Autistic people (Dosch, 2019). For example, it was challenging during this evidence review to find examples of positive family or parenting experiences (see King et al. 2012 for a notable exception), and yet, stakeholder consultation repeatedly demonstrated the gifts and strengths that Autistic people bring to family situations. A deficit approach to autism frames Autistic people as ‘problems’ to be fixed or ‘puzzles’ to be solved rather than normalizing autistic ways of being and affirming Autistic people as valued and diverse community members (Bagatell, 2010).

“Present the positives, strengths, accomplishments, not just all the negative points. Stop presenting it as a “problematic”, “devastating”, “burdensome” condition for parents and communities to “have to” live with ... It’s devastating for any solid sense of self-worth.”

- Autistic adult

Present in all sectors of life, stigma and discrimination of Autistic people is a major barrier to housing, employment, good economic income, and optimal access to healthcare and social services (Hemm et al., 2015). Stigma is a major public health issue that produces social inequalities and reduces the quality of life of Autistic people, family members, and other supporters. Policies and measures are needed to fight stigma and discrimination towards Autistic people (Scior & Werner, 2015).

Decision-Making

Autistic people experience systemic discrimination in decisions about their lives. With knowledge, and, where relevant, supports, Autistic people can make informed choices. Yet,

traditional legal processes emphasize independent decision-making (Stainton, 2016). In many Canadian jurisdictions, another person or guardian may assume power and control over a person's decision-making if they are viewed as requiring *any* support to make decisions (Bach & Kerzner, 2020). While typically well-intentioned – to protect people and safeguard their interests – such relationships can also restrict autonomy, self-determination, and can unfortunately be a means by which Autistic people become a victim to financial and other forms of abuse or neglect. Their legal status is also more likely to be diminished in the eyes of those around them, including health and social *service providers*, which can contribute to stereotypes, objectification, and negative attitudes (Bach & Kerzner, 2020). In turn, these Autistic individuals may feel powerless and become unnecessarily vulnerable to abuse, neglect, and exploitation. As an example, a study on the guardianship system in Ontario pointed out issues with the lack of safeguards, due process, and barriers people under guardianship face in revoking guardianship orders and restoration of rights (Joffe & Montigny, 2014). As per these authors, there is evidence of lack of monitoring and supervision of persons in guardianship roles. They also provided examples of the Public Guardian and Trust refusing to pay for a requested capacity assessment despite this being outlined as part of their role if requested and the person is unable to pay.

3.1.2 Best and Promising Practices

In this section, strategies for addressing stigma and discrimination and for promoting the self-determination of Autistic people are discussed. These strategies culminate around the importance of collaborative decision-making and leadership by Autistic people (Boyce et al., 2001) and include:

-
- Promoting wider public understanding, acceptance, and inclusion of Autistic people and *neurodiversity*, and
 - Respecting within health, social, and legal systems the ethical advantage of and evidence for supported decision-making.
-

Acceptance and Understanding of Neurodiversity

Combatting stigma and promoting public acceptance of autism requires an understanding of neurodiversity, as described in Chapter 2. *Neuro-affirming* practices and places can promote comfort and affirm neurodiverse ways of being. This was an important concept emerging from those with lived experience and involves the ways in which physical spaces are set up, as well as the relationships, respect, and sense of belonging experienced within those spaces by Autistic people. It is important that the knowledge provided to learners about autism within educational or training programs reflect a current understanding of autism, with the goal of autism acceptance.

Autism acceptance involves promoting public acceptance of diversity and reducing stigma related to neuro- and developmental differences across the lifespan and across settings, including but not limited to early childcare and learning centres, schools, community centres, businesses, workplaces, college campuses, and other public spaces. It moves beyond the provision of individually-based autism supports and services, to also consider population-level approaches to improving inclusion, and building on strengths. This often involves training and education for individuals who work in these settings, as well as peers and the general public. Public campaigns have the potential to increase public understanding and acceptance of Autistic people if they are done with an understanding of autistic culture and neurodiversity (Kras, 2009; Milton, 2014). Adopting a neurodiversity lens in public campaigns can enable recognition of autism as a dimension of difference. It can showcase the diversity that exists among Autistic people in terms of strengths and areas where supports or **accommodations** may be required (Ortega, 2009; Raz et al., 2018).

Research has shown that direct interactions with Autistic people is a key factor in improving people’s attitudes about autism (Kuzminski et al., 2019). As such, increasing representation of a diversity of Autistic people in popular media and prioritizing strong, diverse leadership by Autistic people who are comfortable with and knowledgeable about communicating with the public about autism, can enhance public understanding and acceptance.

Targeted training or professional development could also lead to improved understanding and, subsequently, better accommodations and services to support Autistic people (Dillenburger et al., 2016). It is critical that these trainings promote the use of a **trauma-informed** (Benevides, Shore, Palmer et al., 2020) and neuro-affirming (Chun & Fisher, 2014) approach. This will encourage professionals to shift away from a deficit approach, towards respecting and validating autistic perspectives and ways of being, while also supporting them in their self-defined areas of need (Chun & Fisher, 2014; Kapp, 2019). These suggested solutions, and the existing evidence for each, are described in more detail in the following sections.

“It all starts with education ... We have to be open and curious to learn ... to acknowledge our own beliefs ... to be open to others’ experiences. We have to want to establish a society that can be truly inclusive – this only starts within and takes personal work. Then we can create a framework for education where all people are reflected and represented.”

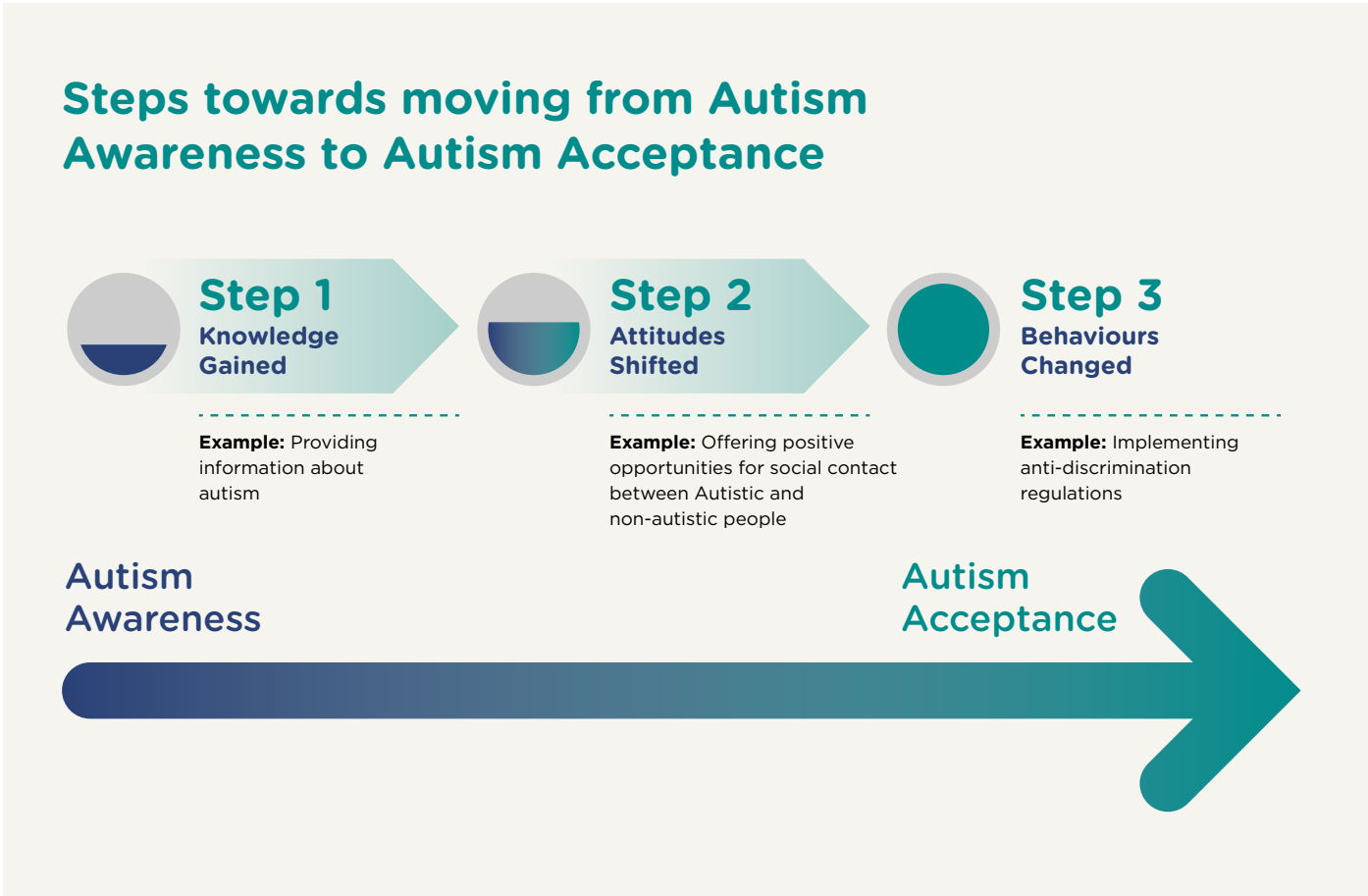
- Service provider

Autism Acceptance and Awareness Campaigns and Training

A first step in changing attitudes towards autism acceptance is to increase public knowledge through awareness (see Figure 5). Education and training, awareness raising campaigns, and

personal contact with Autistic people are powerful tools to change the mindsets of non-autistic people in the long term (Dekoninck, 2017; Fisher & Purcal, 2017). For example, improving knowledge about autism has been associated with more positive attitudes and reduced stigma (Cremin et al., 2021). Furthermore, increased contact with disabled people has been consistently shown to improve attitudes, increase social inclusion, and diminish discrimination (Anthony et al., 2020). However, for personal contact to be most effective, it should occur in a supportive environment and involve positive interactions with Autistic people, as well as provision of additional information that promotes equity and discourages stereotypes (Fisher & Purcal, 2017; Huskin et al., 2018).

Figure 5. Steps towards moving from Autism Awareness to Autism Acceptance.



Changing attitudes within society can be motivated through a range of push and pull approaches (Dekoninck, 2017). *Pull* approaches aim to motivate individuals and organizations through increased knowledge, self-awareness, empathy, and perspective taking to change their attitudes and behaviours. An example would be a social media campaign to promote acceptance and awareness of autism. In the case of *push* approaches, people and organizations are told what to do or not to do. It requires repeated messaging and sanctions to be installed.

An example would be government legislation outlining mandatory training practices for service providers. International research and policy exemplars (see Table 2) demonstrate that to make lasting societal change in terms of disability acceptance and awareness, a combination of push and pull approaches are typically required and implemented (Dekoninck, 2017; Fisher & Purcal, 2017; Scior & Werner, 2015; Thompson et al., 2012).

As laid out by Fisher and Purcal (2017), policy approaches to improve disability awareness, change attitudes towards acceptance, and decrease stigma can be grouped into:

-
- **Personal-level approaches.** Typically from a pull approach, these attempt to change the attitudes of individuals, by increasing knowledge and understanding about the experiences of disability. Such policies can be widespread or tailored to a specific setting (e.g., school, municipality, country) or audience (e.g., students, educators).
 - **Organizational-level approaches.** Often using a mixture of push and pull approaches, these attempt to change the attitudes of a particular group of people (e.g., employees, employers) in various social and economic life domains, such as work, education, health, leisure, or transport, with the goal to increase participation, quality of life, and access for disabled persons.
 - **Government-level approaches.** Generally using a push approach, these mandate behaviour change. While these policies originate from governments and regulatory bodies, they may need other organizations to implement and tailor them to local requirements.
-

All three approaches interact and reinforce each other.

Personal-Level Policy Approaches

Examples of personal-level approaches, each of which will be described in turn, include:

-
- Peer-focused disability acceptance and awareness programs,
 - Acceptance and awareness raising campaigns using mass media, and
 - The positive portrayal of Autistic persons in the media, sports, and the arts.
-

The majority of the limited literature on autism acceptance and awareness has primarily focused on children and youth in educational settings. Furthermore, most research has focused on autism awareness strategies, despite a growing push for autism acceptance. There is some emerging evidence for the effectiveness of these approaches in changing knowledge, attitudes, and intentional behaviours of non-autistic students (Cremin et al., 2021). Peer-focused programs typically include one or more of the following: social contact, simulation, and structured in-person and/or multimedia curriculum (Lindsay & Edwards, 2013).

The duration and format of peer programs has varied widely in the research; however, some emerging best practices have come to light. To affect attitude or intentional behavioural change, programs need to run across multiple sessions (Cremin et al., 2021; Lindsay & Edwards, 2013). Smaller group sizes have also been noted to have a higher impact on social interactions. Combining multiple components such as social contact and different forms of information (e.g., descriptive, explanatory, and directive) can also improve effectiveness.

Explanatory information about autism, through books, cartoons, or targeted educational programmes, can elicit an improvement in attitudes and behavioural intentions, aid moral development, and reduce stereotyping in non-autistic children (Engel & Sheppard, 2020). Facilitating directive communication strategies about the differences in how Autistic students may communicate may be also helpful prior to social contact (Cremin et al., 2021). Social contact (e.g., first-person experiences with an Autistic person) has been found to be the most effective approach to improve stigma-related knowledge and attitudes in the short term (Anthony et al., 2020). There is also emerging evidence that program delivery is more impactful when delivered by an individual with first-hand experience with autism (Cremin et al., 2021). Furthermore, in line with the principles of *co-creation*, input from Autistic people and supporters can promote programs and materials that are positive, respectful, and foster understanding and acceptance of Autistic people (Anthony et al., 2020).

While less direct, educational television and online resources can also be effective (Anthony et al., 2020; Engel & Sheppard, 2020). For example, in 2017, Sesame Street added a four-year-old autistic muppet, Julia. The introduction of this character aimed to educate children about the differences and similarities they share with an Autistic peer (Engel & Sheppard, 2020). Young non-autistic children who watched a short clip of Julia knew significantly more about autism after watching the cartoon.

In addition to the Julia character on Sesame Street (the outcomes of which have not yet been evaluated, but have been suggested to be forthcoming), the Sesame Workshop developed the [See the Amazing](#) online initiative aimed at promoting knowledge and acceptance of autism. The multiple components of this website include general information about autism and links to resources such as “The Amazing Song” music video, 19 narrated videos for children and parents, an electronic storybook that features Julia, a provider’s guide to autism-friendly spaces, and eight daily routine card sets.

A national (US) pre-post survey evaluation of this online initiative demonstrated small, but significant increases in autism knowledge and acceptance in parents of non-autistic children, and enhanced perceived community inclusion and parenting competence, as well as decreased parenting strain in parents of Autistic children (Anthony et al., 2020). The results of this recent study have important implications for best practices.

Many parents and newly diagnosed individuals turn to the Internet to obtain information about autism; however, the quality of available information varies considerably. An evaluation of autism websites found that less than 50% of sites provided up-to-date information and only a third contained references (Reichow et al., 2012). Additionally, they often offered products or services for sale and 17% promoted supports and services that were not considered evidence-based.

In contrast, Anthony and colleagues (2020) demonstrated how researchers, clinicians, and Autistic people can partner to develop a website with easy navigation, delivery of evidence-based, up-to-date content, and elements of experiential learning. A notable finding of their evaluation was that those parents of non-autistic children, who reported low baseline knowledge, and those parents of Autistic children, who reported high levels of parental strain, demonstrated the greatest positive change. These findings demonstrate the potential benefit of measuring baseline knowledge and attitudes when evaluating large-scale public acceptance and awareness campaigns.

Mass media have a powerful role in shaping people's attitudes, as does portrayal and participation of disabled people in the arts (Fisher & Purcal, 2017). Some recent examples of autism-related campaigns include the UK's [It's Everyone's Journey](#) campaign, which encourages the public to be more mindful of the challenges some passengers, including those who are autistic, may experience while using public transportation (It's Everyone's Journey, 2022; HM Government, n.d.). Specifically, in the context of the COVID-19 pandemic, the campaign informed the public about how individuals, who may not be able to follow public health measures (such as the wearing of face coverings or social distancing), can be supported.

Australia's [Change Your Reactions](#) campaign, which launched in 2018, was developed in response to research indicating that while almost all (98%) Australians know what autism is, only 29% have an understanding of how to support Autistic people and only 4% of Autistic people and their families feel that their community knows how to support them (Amaze, 2018; 2021a). The campaign uses a combination of media platforms to improve public understanding of autism and how to support Autistic people, dispel myths and misconceptions, and foster greater inclusion. The campaign was developed in consultation with Autistic people, families, and other supporters and many of the campaign resources, such as videos, feature Autistic people.

In comparison to general disability acceptance and awareness campaigns, there has been less research regarding the use of mass media campaigns to change attitudes specifically about autism and other developmental disabilities (Scior & Werner, 2015). However, a review of both autism-specific and more general disability acceptance and awareness research provides some promising guidance for those interested in developing future autism-specific campaigns.

For example, campaigns that have successfully influenced public attitudes towards persons with mental health conditions (e.g., in Scotland and New Zealand) have used a combination of strategies, including information, training, and positive media portrayal (Thompson et al., 2012). These campaigns were typically well-funded, intense, lasted for some time, included persons with *lived experience* in the design and implementation, and used more than one communication method.

Many specific examples of successful disability acceptance and awareness campaigns can be found in the report *Awareness Raising on the Rights of Persons with Disabilities* by the Council of Europe (Dekoninck, 2017). Some of these have been included in Table 2. This report provides a range of evidence-informed suggestions for developing campaigns and provides a checklist for developers. The Council aligned their approach to the recommendations laid out in Article 8 of the United Nations' Convention on the Rights of Persons with Disabilities for initiating and maintaining effective public acceptance and awareness campaigns. In addition to the best practices described above, they also suggest:

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- Both a vertical (bottom-up) and horizontal (across sectors) approach developed through shared values and resourcing from community organizations and governments,
 - Convening issue-specific task forces across the country,
 - Adapting and/or learning from acceptance and awareness raising practices of other disadvantaged groups, and
 - Use of innovative technologies.
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Organizational-Level Policy Approaches

These approaches involve disability acceptance and awareness campaigns and training initiatives targeted to specific sectors, such as health, employment, police, education, and housing. Often the aim of organizational-level approaches is to support service providers to achieve better outcomes when working with Autistic people (Marriott & Hartflett, 2020). Service provider training as well as acceptance and awareness building can take multiple forms, specific to the sector and desired goals. Different approaches include service learning within university training (Case et al., 2021). Service learning is an educational approach where students apply classroom learning while volunteering at an agency, for example, that serves Autistic people.

The majority of research in this area has focused on the health and education sector, whereas few studies have focused on changing attitudes among employers or co-workers (Scior & Werner, 2015). In education, there is strong evidence to support inclusion training for teachers-in-training and ongoing professional development for existing teachers (Fisher & Purcal, 2017). In health and social services, there is evidence supporting partnerships amongst day

cares, schools, or supported employment centres and universities for creating and providing professional development and practice opportunities (Hamrick et al., 2021), on-the-job training programs to teach and monitor frontline service providers' foundational skills to work with Autistic people (Gormley et al., 2019), as well as one-time workshops or e-learning (Scior & Werner, 2015). Recommendations for sector-specific training and *capacity building* are made throughout this report in the relevant sections (e.g., in relation to education, public safety, health, and employment).

Government-Level Policy Approaches

In combination with personal- and organizational-level approaches, government-level approaches may be required. As such, in order to meet the desired goal of widespread autism acceptance and awareness, as well as improved quality of care and patient safety, some countries implement strategies such as providing:

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- Regulatory and statutory guidance,
 - Improvement standards, and
 - Mandatory training.
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For example, a key responsibility of England's Autism Act (2009) statutory guidance was the development of autism training for all frontline public service providers, in line with their job role, as well as specialist training for service providers in health and social services (Department of Health and Social Care, 2019b). Further, in response to England's annual 2017 Learning Disability Mortality Review, mandatory learning disability¹⁹ acceptance and awareness training was recommended to be provided to all healthcare providers and be delivered in conjunction with Autistic people or people with intellectual disabilities and their families (National Development Team for Inclusion, 2021). This report highlighted that there was a lack of training, knowledge, and understanding within mainstream healthcare services on how to tailor care for Autistic patients. Beginning in 2019, [Understanding Autism](#) sessions have been delivered to England's Members of Parliament to improve their understanding of autism and how to make environments more enabling for Autistic people (National Autistic Society, 2019; National Autistic Society, 2021a). These training courses were developed by the National Autistic Society in partnership with the All-Party Parliamentary Group on Autism and delivered in partnership with Autistic people.

Overseen by a multidisciplinary oversight group, this wide-scale mandatory training program is currently being scaled up in England. The goal is to provide a phased approach to providing a combination of e-learning and face-to-face training to more than 1.2 million National Health Service staff, and 1.5 million adult social service staff on understanding learning disability and

¹⁹ In the United Kingdom, the term learning disability is often used to refer to lifelong impairments in intellectual abilities and difficulty with carrying out daily activities (Mencap, n.d.).

autism, the legislative context, and making reasonable adjustments (Marriott & Hartflett, 2020; National Development Team for Inclusion, 2021). The content of the training is based on the [Capabilities Framework for Supporting Autistic People](#), which outlines 19 capabilities across five domains, with increasing levels of skill, knowledge, and behaviour expected across three staff groups, or tiers (Department of Health and Social Care, 2019a, 2019b; Skills for Health, 2021):

- **Tier 1** is for people who require a general understanding of autism and the support Autistic people may need, such as those working in public services, commercial or charitable organizations providing health, social services, education, policing, legal, housing, transport, careers, employment or benefit services, inclusive of reception and administrative staff.
 - **Tier 2** is for people with a responsibility for providing direct care and support to Autistic people, such as frontline service providers who are not autism specialists and those in other roles such as education and housing services that are providing care and support for Autistic people.
 - **Tier 3** is for service providers working intensively with Autistic people, including those in management, specialized healthcare, and leadership roles such as psychologists, psychiatrists, physicians with special interest, developmental disability nurses, counsellors, psychotherapists, allied health professionals, social workers, and educators.
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At Tier 1, capabilities focus on broad and general autism acceptance and awareness, while Tiers 2 and 3 are relevant to fewer people, who require increased levels of knowledge and skill (Department of Health and Social Care, 2019b). Preliminary evaluations of this tiered training approach are framed by the Kirkpatrick Four-Level Training Evaluation Model, which focuses on results, behaviours, learning, and reactions (Marriott & Hartflett, 2020). Using this framework, independent evaluators have found encouraging results that Tier 1 training alone is improving staffs' knowledge, skills, and confidence (National Development Team for Inclusion, 2021). Broader, large-scale evaluation results are expected to be published over the next few years.

England has also developed National Learning Disability Improvement Standards, which apply to Autistic people. These standards are currently being implemented and apply to all services funded by the National Health Service (Department of Health and Social Care, 2019a). The future objective is to ensure that all healthcare professionals (Tier 3) will, during their training and/or through ongoing professional development, undertake a common and consistent core curriculum for learning disability and autism (Department of Health and Social Care, 2019a). Regulations for these standards are supported by the work of health professional regulatory bodies and education settings. Through government consultation, there was very strong overall support for using secondary legislation to mandate such training for regulated health

professionals within the Health and Social Care Act 2008, however, as of April 2022, the [Mandatory Training on Learning Disabilities and Autism Bill](#) had still not passed, likely due to COVID-19 slowdowns.

Research on the effects of autism acceptance and awareness campaigns and training is relatively limited in comparison to research on other aspects of autism-related needs (such as diagnosis and early intervention services). However, several emerging best practices can be synthesized. To promote positive and effective program experiences, increase knowledge and skills, as well as encourage attitude change, the following strategies may be useful (Bottema-Beutel et al., 2021; Cremin et al., 2021; Dekoninck, 2017; Department of Health and Social Care, 2019a; Fisher & Purcal, 2017; Lindsay & Edwards, 2013; Marriott & Hartflett, 2020; National Development Team for Inclusion, 2021; Thompson et al., 2012):

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- Reinforcement and adequate resourcing for interlinked programs across all three levels (personal, organizational, and governmental),
 - Content based on evidence-informed practices, sensitively attends to language, and developed in partnership with Autistic people, their families, and the intended audience. In addition to the benefits of *co-production* and co-involvement, including Autistic people in training can also provide new opportunities for paid employment, increased self-esteem, wellbeing, and personal development,
 - Programs should be developed and provided to multidisciplinary and cross-sector audiences,
 - As much and as often as possible, programs should include direct contact and face-to-face training,
 - Programs are multi-faceted, prolonged, but with shorter duration sessions, and
 - Programs are combined with a planned, formal, and independent evaluation from the outset.
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Finally, ongoing national surveillance of public attitudes towards disabled and autistic groups can also provide a broader understanding of trends over time (Thompson et al., 2012). International examples of data collection from England and Ireland (e.g., the British Social Attitudes survey) could be used to inform similar survey development in Canada.

Table 2. International Examples of Awareness and Education Campaigns and Training.

This table provides some examples of previous campaigns and training from across the globe. It is not an exhaustive list.

ACCEPTANCE AND AWARENESS CAMPAIGNS					
Autism-specific					
Campaign (Organizer)	Country / Region	Year / Duration	Description	Target Audience	Approach / Strategy
It's everyone's journey (Department for Transport)	United Kingdom	<i>Started:</i> May 25, 2021 <i>Duration:</i> Ongoing	To raise awareness about the challenges experienced by disabled travellers.	General public (with particular focus on transport operators, disability groups and technology companies)	Social media, digital resources (stories, case studies, videos)
Change Your Reactions (Amaze)	Victoria, Australia	<i>Started:</i> 2018 <i>Duration:</i> Ongoing	To improve public understanding of autism and foster greater inclusion.	General public	Social media, digital resources (info sheets, videos), change your reactions pledge
Think Differently About Autism - I Exist (National Autistic Society)	United Kingdom	<i>Started:</i> 2008 <i>Duration:</i> 1 year	To raise awareness around the lack of supports for Autistic adults.	Government and local authorities	Surveys and interviews with Autistic adults and their families, podcast, website, video
Different Minds. One Scotland. (Scottish Government)	Scotland	<i>Started:</i> 2020 <i>Duration:</i> Ongoing	To help people understand more about autism – what it is and what it is not.	General public	Website, video, informational content, positive media portrayals
World Autism Awareness Day (United Nations)	Worldwide (officially adopted by Canada in 2012)	<i>Started:</i> April 2, 2008 <i>Duration:</i> Ongoing	To highlight the need to help improve the quality of life of Autistic people so they can lead full and meaningful lives as an integral part of society.	General public	Social media, virtual themed events, full day conference, film screening
Autism Awareness Month (Government of Canada and promoted by organizations such as Autism Canada)	Canada	<i>Started:</i> 1993 <i>Duration:</i> Ongoing	To provide an opportunity for Canadians to learn more about autism and how to support Autistic people, their families, and supporters.	General public	Social media, digital resources from autism organizations, Facebook Live roundtable from the 2017 Autism Awareness Day on Parliament Hill

Disability-general					
Campaign (Organizer)	Country / Region	Year / Duration	Description	Target Audience	Approach / Strategy
#MelanieCanDolt (Federation of associations for persons with developmental disabilities and their families)	France	2017	To highlight the capabilities of persons with developmental disabilities by encouraging the general public to show its support to Mélanie in her wish to present the weather forecast on national television.	General public, News media	Social and news media campaign
See the True Me (National Council of Social Services)	Singapore	<i>Started:</i> 2016 <i>Duration:</i> 5 years	To celebrate the strengths and abilities of disabled persons, educate the public on communication tips and support strategies for disabled persons, and encourage inclusion.	General public	Multi-pronged campaign, videos, digital resources, positive media portrayals, interaction tips, broadcast and print media, inclusivity guides
Like Minds Like Mine National Plan (New Zealand Government)	New Zealand	<i>Started:</i> 2014 <i>Duration:</i> 5 years	A multi-pronged plan underpinned by human rights, social model of disability, and social contact to decrease exclusion of disabled people in the workplace and community.	General Public	Like Minds, Like Mine includes a wide range of activities, such as TV campaigns , community workshops, internet resources and disability provider training
We Can Tell and We Will (DisAbled Women's Network [DAWN] Canada)	Canada	2014	To encourage disabled persons to report sexual assault and abuse, spurred by a Supreme Court of Canada case (R. v. D.A.I.)	General public, Disabled persons	Public service announcement
Disability Rights Movement (German Government)	Germany	1997	To educate the public about disability rights.	General public	Multi-pronged mass media campaign, billboards, advertisements, swag, street theatre, conferences, public demonstrations, positive media portrayal

TRAINING AND EDUCATION					
Autism-specific					
Campaign (Organizer)	Country / Region	Year / Duration	Description	Target Audience	Approach / Strategy
I can LEARN. I can WORK (Autism Europe)	European Union	<i>Started:</i> 2021 <i>Duration:</i> 2 years	To promote access to education and employment for Autistic people.	General Public	Webinar and toolkit
Oliver McGowan Mandatory Training in Learning Disability and Autism (Department of Health and Social Care; Health Education England; Skills for Care)	England	<i>Started:</i> 2019	To ensure staff working in health and social care receive autism training, at the right level for their role.	Health and social care providers	Mandatory training
One of the Neighbours (Service Foundation for People with an Intellectual Disability)	Finland	<i>Started:</i> 2011 <i>Duration:</i> 3 years	To make public aware about the process of deinstitutionalization	Housing industry, Service Providers	Positive media portrayals; training; developing organization partnerships; community of practice
Disability-general					
Campaign	Country / Region	Year/ Duration	Description	Target Audience	Approach
I'mPOSSIBLE (International Paralympic Committee)	Germany / worldwide	<i>Started:</i> 2017	To spread the values and vision of the Paralympic Movement to young people throughout the world	Educators	Training
Training in Sexual Education for Persons with Disabilities (Erasmus+ Programme of the European Union)	European Union	Not available	To develop a training course for parents and professionals, about providing sexual education for disabled people	Service providers/ supporters	7-day training curriculum, training toolkit , organizational partnerships

Informed, Interdependent and Supported Decision-Making and Consent Processes

In recent years, there has been an increased focus on legally recognized supported decision-making. With the passage of the United Nations' Convention on the Rights of Persons with Disabilities (2006), particularly Article 12, supported decision-making now has a stronger legal base and new urgency. It is legally authorized in different forms in British Columbia, Alberta, Manitoba, Prince Edward Island, and the Yukon (Sullivan et al., 2019). Recently, Québec also amended their civil code to abolish guardianship (National Assembly of Québec, 2020). However, other jurisdictions in Canada and elsewhere lack even basic legislative frameworks for supported decision-making, and guardianship or substitute decision-making laws and practice still predominate (Stainton, 2016).

Promoting awareness of pertinent legal mechanisms and practices through pan-Canadian standards or guidelines, may encourage provinces/territories to consider reforms. There is a small but growing body of research on the uptake of supported decision-making mechanisms in Canada (Browning et al., 2021). Guidance on the implementation of supported decision-making²⁰ and consent provisions may offer provinces/territories relevant information as they move towards system transformation (Demer, 2018). There are models of supported decision-making in practice in Canada. For example, a microboard is “a small (micro) group of committed family and friends (a minimum of five people), who join with the individual to create a non-profit society (board). They support planning, decision-making, setting up and monitoring supports, advocacy, and act as ambassadors to connect the individual with their community” (Stainton, 2016, p. 7). However, such models are not yet broadly utilized in Canada. Often, families are simply advised they should become legal guardians (Bach & Kerzner, 2020).

To prevent the loss of legal capacity, practice-based frameworks are needed that guide the creation of systems of supports for decision-making (Shogren et al., 2017). A recent publication, *Supported Decision Making: A Roadmap for Reform in Newfoundland & Labrador* (Bach & Kerzner, 2020), offers an up-to-date inventory of tools and resources for supported decision-making.

The notion of interdependence recognizes that people both contribute and require support from their communities (Grills, 2015) and contrasts the idea of independence, which often positions Autistic and/or disabled people as being dependent on others and lacking self-agency (Raghavan, 2020; Kelm, 2013). Networks of informal supporters are critical for supported decision-making and yet most jurisdictions lack policy, funding, and community capacity for developing these interdependent support networks. Without maintaining clear

²⁰ A series of trusted relationships, arrangements, and agreements, that provide disabled people with support to make important decisions about their lives and communicate them to others such that they are able to exercise their legal capacity and personhood to the fullest extent possible in accordance with Article 12 of the United Nations' Convention on the Rights of Persons with Disabilities (McGill Centre for Human Rights and Legal Pluralism, 2017; Stainton, 2016).

roles within an interdependent decision-making process, it can still be difficult to disentangle the voice of the Autistic person from that of their supporters, particularly in complex situations (Lashewicz et al., 2014; Browning et al., 2021). As described by Stainton (2016), this speaks to the need for education on what it means to be a supported decision-maker, and also for a system of safeguards to ensure that the Autistic person's views are not misrepresented or suppressed.

Additionally, and particular to health and research settings, informed consent best practices, legislation, and ethical frameworks should be followed at all times. Provision of accessible approaches (e.g., plain language, easy-to-read, multiple formats) adapted for Autistic people may improve understanding during informed consent processes (Autistica, n.d.).

Key Findings - Addressing Stigma and Ensuring Human Rights

Promoting autism acceptance and inclusion by the Canadian public can be motivated and reinforced through pan-Canadian, multi-pronged strategies such as knowledge-raising campaigns, positive media portrayals, education and training, and lasting peer engagements with Autistic people.

Standardized, mandatory autism training (professional development) tailored to the full range of service providers, including those in healthcare, social services, public safety, and other community sectors, is a key enabler towards the provision of quality care and service for Autistic individuals and their families. Successful training programs:

- Are developed and implemented in partnerships with Autistic people, their families, and end users,
- Focus on evidence-based content,
- Have multiple components and sessions commensurate to the roles of the service providers, and their interactions with Autistic people,
- Incorporate independent evaluation and quality assurance, and
- Involve partnerships amongst organizations and governments, for example, across health, education, and social sectors

Autistic individuals can participate in decisions about their lives and may benefit from formal mechanisms for supported decision-making.

3.2 Promoting Physical and Emotional Safety

3.2.1 Background

All Canadians have the right to security and safety (Section 7, Charter of Rights and Freedoms, 1982). However, in our pan-Canadian opinion survey, most Autistic adults (85%) described fearing for their safety compared to 24% of the general public.

Summary Points

Risks to personal and family safety can involve Autistic individuals:

- Getting lost or wandering away,
- Coming into contact with community members who have violent or fraudulent intent, and
- Being triggered by sensory, mental health, or behavioural stressors.

Negative and preventable outcomes of discrimination, stigma, and ongoing safety risks experienced by Autistic people in the community include abuse, neglect, legal system involvement, hospitalization, poor mental health, and suicidality.

Abuse and Neglect

Unfortunately, maltreatment is an all-too-common occurrence in the lives of Autistic people. Maltreatment may occur in both intentional and unintentional ways. For example, Autistic children are at higher risk of adverse childhood events, including experiences of neglect, abuse, bullying, and neighbourhood violence (Berg et al., 2016). A Canadian study revealed that Autistic individuals reported more experiences of victimization compared to non-autistic individuals including property crime and maltreatment by peers in childhood and more teasing/emotional bullying and sexual assault in both childhood and adulthood (Weiss & Fardella, 2018). Further, Autistic individuals, especially those with co-occurring intellectual disability are also more likely to suffer physical and sexual abuse (Coorg & Tournay, 2013), and their perpetrators are rarely brought to justice (Taylor et al., 2009). In a survey carried out by the United Kingdom's National Autistic Society in 2011, almost half (49%) of Autistic respondents indicated they had been abused by someone they knew (McVeigh, 2014). In extreme instances, some parents have murdered their Autistic child (Coorg & Tournay, 2013; Palermo, 2003; Brown et al., 2018). While extremely rare, the implications of filicide are devastating.

Previous adverse childhood experiences may contribute to poorer adult outcomes (Zimmerman et al., 2018). With age, physical bullying and intimidation may give way to cyber bullying, verbal victimization, and other forms of social exclusion (Volkmar et al., 2017). The use of seclusion and restraint also carry significant risks to an Autistic individual’s physical and mental safety, integrity, and dignity. There is evidence that these practices continue to occur across Canada, ostensibly to prevent an Autistic individual from harming themselves or others (e.g., in schools: Kumble & Sherry, 2010; Bartlett & Floyd Ellis, 2021).

School-Based Risks

As touched upon above, Autistic children are more likely to have multiple experiences with bullying, which can increase their risk of depression and other mental health concerns (O’Sullivan, 2018). Autistic youth who were bullied or teased in high school had higher odds of mental health service use later in life (Anderson, Roux et al., 2018). Autistic stakeholders repeatedly described their experiences of bullying within the education system by both peers and teachers.

“My entire childhood I was abused and bullied and blamed for my behaviour, and made to feel ashamed and guilty and stupid. Not supported, no access to accommodations, no services, just told that I was bad and that there was something wrong with me and teachers yelled at me ...”

- Autistic adult

While the majority of literature on bullying has focused on Autistic students’ experiences with peers, Autistic students tend to have lower quality student-teacher relationships characterized by less closeness and more conflict compared to non-autistic and other disabled students (Eisenhower et al., 2015). This can have negative impacts on the Autistic students’ academic and social outcomes. Further, Autistic students have also expressed feeling judged, abandoned, or isolated at times by their teachers, which can exacerbate feelings of loneliness (Goodall, 2018).

Additionally, certain students, including those who are autistic, are more likely to be pushed out of the public education system, which can lead to further isolation and increase risk of negative outcomes in adulthood, including incarceration (Nelson, 2014). Zero tolerance policies and disciplinary exclusion may systematically and disproportionately exclude students who are already socially disadvantaged (Salole & Abdulle, 2015). **Racialized youth** as well as those with developmental disabilities may be at greater risk of being targeted by these exclusionary measures, contributing to poorer academic achievement, and higher rates of suspension, expulsion, dropout, and incarceration (Salole & Abdulle, 2015; Nelson, 2014).

Home and Community-Based Risks

Stigma, social isolation, financial instability, and a lack of proactive and responsive community-based services and supports may erode the capacity of some Autistic people and their families to remain safe. In addition to the risks of abuse and neglect that were discussed above, some other risks to personal and family safety in the home and community can involve Autistic individuals:

- Getting lost or wandering away,
- Encountering community members who have violent or fraudulent intent, and
- Being triggered by sensory, environmental, mental health, or behavioural stressors.

“... Our daughter used to run away from us or noises, and constantly had to be monitored when she was younger because her old school was located on a highway, which made us incredibly anxious.”

- Family member of an Autistic person

Getting lost. More than 50% of Canadian parents of Autistic children described worrying about their child wandering away (McLaughlin et al., 2018). Research from the United States has suggested that one-third of Autistic children (aged six to 17) had become lost in the previous year, most often in public places (Kiely et al., 2016; Rice et al., 2016). Wandering or becoming lost can place an Autistic individual at risk, particularly if they live in a community with few mechanisms in place for reporting, supporting, and locating a lost person (Kiely et al., 2016). When a person is lost, they may be vulnerable to violence or victimization, including personal injury and abuse (McLaughlin et al., 2020). Due to the lack of community safety mechanisms in many jurisdictions, parents may attempt to address these safety concerns through curtailing with whom their child can spend time (McLaughlin et al., 2018). Some have also requested changes to their child’s Individual Education Plan (IEP) to address wandering. Yet, only a third of parents reported receiving counselling or external support about managing wandering or community safety (McLaughlin et al., 2018).

“We kept him out of school after that. The school asked us to keep him home because they could not provide a safe environment for him until they rearranged their existing [educational assistants] to cover him 100% of the time, because he had taken off from their building twice and they didn’t know either time until way later.”

- Family member of an Autistic Person

Triggered by environmental stressors. Many parents and other family members also described ongoing fear and worry about complex sensory, emotional regulation, and/or mental health responses by their Autistic family members that placed both the Autistic individual and family members at risk. For example, serious self-injury occurs at a very high rate amongst Autistic people, particularly for individuals with co-occurring intellectual disability (Steenfeldt-Kristensen et al., 2020; Murphy et al., 2005). As Autistic young people with **complex support needs** physically mature, their supporters may find it more difficult to support their self-regulation in response to strong reactions from sensory, emotional, and environmental stimuli (Jacobs et al., 2018).

As such, due to a lack of adequate community-based supports and services as they age out of the pediatric system (Dubé, 2016), Autistic people may be at increasing risk of neglect or abuse in community settings, including the family home. Aging supporters may no longer be able to meet the needs of their adult child contributing to additional challenges (Dudley & Nakane, 2017; Foley et al., 2012; Hewitt et al., 2013; Innes et al., 2012; Schepens et al., 2019).

Ongoing safety concerns may lead parents to seek out other residential options (Dubé, 2016; Marin, 2005), but many Canadian jurisdictions are experiencing extreme. To complicate matters, many jurisdictions lack regulations or policies to ensure that Autistic persons with the highest or most pressing needs on residential waitlists are served first (Office of the Auditor General of Ontario, 2016). As such, families can wait years for a well-matched residential setting. See Chapter 5 for more information about housing.

An investigation by the Ontario Ombudsman (Dubé, 2016) of more than 1400 complaints, uncovered concerning outcomes linked to the lack of suitable publicly-funded residential options, including abandonment, abuse, neglect, and inappropriate placements of persons with developmental disabilities, including Autistic people. Many complaints in the Ombudsman's report involved Autistic individuals with co-occurring intellectual disability. In desperation, some families instead turned to hospitalization, long-term care, or attempted to fund and design other accommodations, which may include overly-restrictive measures.

Other Autistic people lose connection with their families and fall through the cracks within the foster care, prison, and shelter systems (Allely, 2015; Davies et al., 2002; Mercier & Picard, 2011). According to an Ontario Ombudsman report, in order to obtain appropriate residential care for their Autistic or disabled child, some parents felt they had no other choice but to relinquish custody (Marin, 2005). An update in 2020 on this investigation confirmed that these practices continue today, although data is not publicly available (Ombudsman Ontario, 2021).

Autistic parents face additional challenges. Due to the lack of knowledge and awareness about Autistic parents within family law, they may be at risk of being misunderstood or their actions

misinterpreted by social workers, Children’s Aid Societies, family lawyers, or court judges (George et al., 2018), putting the rights of Autistic parents at risk in family court scenarios.

Hospitalization and Emergency Services

Autistic individuals with complex support needs may be admitted to hospital for behavioural, psychiatric, or forensic issues (Taylor et al., 2017) when they require more intensive supports than can be provided by the family or community mental health services. Specialized healthcare settings for Autistic adults in Canada are few and far between. Few adult hospital systems or settings have the capacity to implement evidence-informed assessments and services for Autistic patients with complex support needs (Vogan et al., 2017; Lai, Klag, & Shikako-Thomas, 2019). In Canada, there are no specific care pathways for Autistic people who are detained within hospitals because of forensic mental health challenges (Alexander et al., 2016). In lieu of providing evidence-informed supports and services within a safe environment and with an individualized service and discharge plan, Autistic individuals may instead be detained in acute mental health or forensic settings that are designed to address other forms of mental health or substance use concerns (Taylor et al., 2017).

Public Safety and Criminal Justice Interactions

Autistic people may at times come into contact with public safety, criminal justice, and/or correctional sectors. Often in these interactions, the Autistic individual is the victim, as research suggests that Autistic people may be less likely than others to commit violent crimes (Allely, 2015). However, there is a growing body of literature that suggests that interactions and outcomes for those Autistic individuals who do come into contact with these sectors can be unnecessarily distressing and discriminatory. Specific members of equity-seeking groups who are also autistic, such as visible minorities, are at especially high risk for negative interactions with the criminal justice system (Khanlou et al., 2017).

Due to some of the safety and mental health risks described in the sections above, interactions with police and other public safety personnel may occur more frequently for Autistic people. For example, more than 80% of Autistic people in a Canadian study had at least one lifetime interaction with the police, with 53% reporting four or more interactions (Salerno & Schuller, 2019). Unfortunately, many public safety personnel and lawyers may not have formal training in interacting with Autistic offenders (Chester, 2018; O’Sullivan, 2018).

“My son is a black 14-year-old taller than I am ... [He is] non-speaking and can sometimes have meltdowns when he is nervous or scared. It terrifies me that this will be taken the wrong way in public and even more so by police. It’s terrifying ... [I don’t want them to see him as] a danger just because they aren’t acting as you expect.”

- Family member of an Autistic person

There are many processes in the public safety and criminal justice system that can contribute to negative experiences for Autistic people. These include (Salerno & Schuller, 2019; Demer, 2018; King & Murphy, 2014; O’Sullivan, 2018; Woodbury-Smith & Dein, 2014):

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- Crisis responders misidentifying autism, for example, as substance use concerns,
 - Common emergency procedures which may result in negative and often misunderstood sensory reactions,
 - A lack of **augmentative and alternative communication** (AAC) approaches, including ensuring a supporter or communication partner is present during interviews,
 - Autistic individuals may be incorrectly assumed to be capable (or not) to make healthcare decisions or to stand trial without proper consideration of needs, supports, and accommodations,
 - Autistic people may not be offered sufficient supports to fully understand their rights, and
 - Communication differences may put some Autistic people at risk of misunderstanding and/or agreeing to certain statements leading to increased false confession rates.
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“Education for law enforcement, specifically that we may not understand rapid questions/ commands, we may have tics/stims that make us appear to be on drugs when we’re not, we may not make eye contact and this does not mean that we’re guilty/hiding something, we may have sensory ... meltdowns and this is not non-compliance.”

- Autistic adult

There is scant data on prevalence rates of Autistic people in the Canadian prison systems. However, previous studies have found higher rates of neurodevelopmental conditions, including autism, in prison populations (McCarthy et al., 2015). The existing literature also suggests that Autistic people are more vulnerable to bullying, social isolation, victimization, and exploitation in prisons (Allely, 2015; Robertson & McGillivray, 2015). Interpersonal difficulties with prison staff and fellow inmates and distress in these environments are also commonly reported (O’Sullivan, 2018). Persistent and significant inequalities in service access may lead to an over-representation of Black Autistic people in the criminal justice system due to unmet mental health needs (Anthony & Bills, 2021).

Suicide Risks and Prevalence

When Autistic children, youth, or adults experience ongoing feelings and experiences of social exclusion, they may experience suicidality which encompasses contemplating or attempting suicide, or death by suicide. Autistic individuals are at heightened risk for experiencing suicidality compared to those who are not autistic (Howe et al., 2020). Rates of suicidality in Autistic youth and adults are as high as 19 – 66%, significantly greater than the general

population (Dow et al., 2021; Hedley & Uljarević, 2018). Autistic women are 13 times more likely to die by suicide compared to non-autistic women, while Autistic men are six times more likely to die by suicide compared to non-autistic men (Hirvikoski et al., 2016). Overall, a recent meta-analysis found that Autistic people have a three-fold increased likelihood of suicidality compared to non-autistic people (Blanchard et al., 2021). Further, Autistic individuals make up between 7 – 15% of the suicidal population, a substantial subgroup (Segers & Rawana, 2014).

Specifically, Autistic individuals without co-occurring intellectual disability have been shown to be more likely to experience suicidality than the general public (McDonnell et al., 2020; Richa et al., 2014). Feelings of loneliness, being a burden, not belonging, and dissatisfaction with social relationships/life has also been associated with suicidality (Dow et al., 2021; Pelton et al., 2020) for Autistic people. The potentially harmful effects of these emotions were exemplified in a broader study of youth suicidality (Mérelle et al., 2020). This study found a trend of suicidality in Autistic boys who felt rejected after being transferred to special needs education.

Risk factors for suicidality in Autistic individuals include, but are not limited to (McDonnell et al., 2020; Pelton et al., 2020; Richa et al., 2014; Segers & Rawana, 2014):

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- Adverse childhood events such as peer victimization and (cyber) bullying, or sexual abuse,
 - Lifetime trauma,
 - Major changes in routine,
 - Co-occurring mental health diagnoses, including depression,
 - Medication use, and
 - Pain.
-

Depression is among the strongest predictors of self-harm and suicide in Autistic people (Cybulski et al., 2021). Rates of depression are estimated to be four times higher in Autistic individuals compared to non-autistic individuals (Hudson et al., 2018). The degree of engagement in recreational, educational, and/or vocational activities, as well as a family history of depression/anxiety have been shown to be associated with severity of depressive symptoms and likelihood of suicidal ideation (Radoeva et al., 2021).

3.2.2 Best and Promising Practices

Evidence-informed strategies for promoting personal safety and security of Autistic people and their supporters, include ways to:

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- Eliminate abuse and neglect,
 - Improve home and community safety through improved knowledge, amenities, and support systems,
 - Avoid unnecessary pathways into forensic mental health and the criminal justice sectors,
-

and

- Offer autism professional development and training to public safety personnel and legal professionals.
-

Eliminating Abuse and Neglect

Safeguards within communities are needed to protect Autistic people who are at increased risk of abuse and neglect (Autism Canada, 2018; Autism United Canada, 2019; Dubé, 2016). The risk of abuse is greatest in situations where Autistic individuals are under the absolute power of a family member or guardian including at home, at school, in healthcare, or in residential settings. Therefore, having protection and accountability measures are particularly important (Demer, 2018).

A 2016 report by Ontario's Special Ombudsman Response Team included several recommendations to the Ministry of Community and Social Services for preventing and responding to incidents of abuse involving adults with developmental disabilities, including Autistic adults:

- Regular monitoring and auditing of agencies serving adults with developmental disabilities, as well as providing them education and training,
 - Providing service agencies with more direction so that victims of abuse are placed in safe and secure housing and not sent back into the care of their abusers,
 - Allocation of sufficient resources to ensure the availability and accessibility of crisis beds and crisis workers as well as 24-hour, seven-day-a-week urgent support, and
 - Establishing specialty police units to address situations involving abuse of adults with developmental disabilities.
-

These recommendations are consistent with the emerging consensus on measures to prevent, identify, and respond to sexual abuse within institutions and facilities (Matthews, 2017). Regularly gathering statistical information about incidents of abuse by guardians and in institutions, as well as the use of community shelters by adults with developmental disabilities can also allow for more effective community planning.

A least restrictive approach should always be followed when considering the use of seclusion and restraints. Further, these approaches should only be used to promote safety of the person and those around them in that environment. According to a review by Sturmey (2018), large-scale, safe restraint reduction is possible in a variety of settings using varied methods. In line with this review, Kumble & McSherry (2010) emphasize that if seclusion and restraints are used, it should only be as a last resort and not merely because the institution lacks adequate resources to appropriately support the inclusion of Autistic people.

Regulating these practices through guidelines, codes of practice/policy directives, and legislation are some ways to promote the safety of Autistic students in schools and other institutions (Sturmey, 2018; Kumble & McSherry, 2010). In the UK, the Mental Health Units (Use of Force) Act 2018 will come into effect in 2022. It aims to reduce the use of force (e.g., restraint, seclusion, and segregation) and ensure accountability within mental health units (Department of Health and Social Care, 2021). Statutory guidance for the Act was published in December 2021 for National Health Service organizations in England and police forces in England and Wales. The guidance also acknowledges that the use of force has often disproportionately targeted certain groups including Autistic people and those with developmental disabilities.

To mitigate abuse and neglect in community settings, all service providers, either publicly or privately hired to work with high-risk Autistic residents (in any residential, hospital or long-term care environment), should receive specific training (Hewitt et al., 2017) as well as orientation to additional sources of support, including appropriate referral pathways and access to intensive supports for individuals with complex support needs.

Autistic people also need to be formally taught about their legal rights (Paradiž, 2009; Ward & Meyer, 1999; Cone, 2000). Mentoring on *self-advocacy* skills (described in Chapter 1) (Paradiž et al., 2018) and safety issues should be provided, including how to interact with police and legal authorities (New Zealand Ministries of Health and Education, 2016). Information on safe and healthy relationships (Curtiss & Ebata, 2016; Hannah & Stagg, 2016) is also important so that individuals are able to identify situations of potential harm and are aware of the steps they can take to protect themselves. For the broadest reach, such information could be built into education and *life skills* pathways. In the US, every state has a [Protection and Advocacy System](#) that provides legal support and self-advocacy training to disabled people to enable them to exercise their rights (Administration for Community Living, 2021). They also provide training and technical assistance to service providers and policymakers and carry out public acceptance and awareness initiatives.

Improving Home and Community Safety

Home and community safety is often impacted by access, or lack thereof, to community-based supports and services. Some services (e.g., respite) act as proactive supports to increase the resiliency of family members. Other services (e.g., mental health crisis supports) are urgent supports to avoid escalation that could compromise safety.

Autism-specific home and design modifications can help promote safety and comfort. A synthesis of 10 autism-specific housing guidelines (Brand, 2010; Chan, 2018; Dalton, 2016; Gaines et al., 2016a, 2016b; Kinnaer et al., 2016; Lowe et al., 2014; Mostafa, 2010; Nagib & Williams, 2017; Owen & McCann, 2018) suggests considering the following design elements to

promote safety and functionality in the family home and in community residences, particularly for Autistic persons with complex support needs:

- **Acoustics.** Implement sufficient soundproofing, avoid echo and sound reverberation, minimize background sounds, and use sound absorbent materials.
 - **Control of environmental stimuli.** Offer person-controlled/calibrated temperature, lighting, and white noise where possible. Offer access to low and higher arousal spaces, and implement smart home options such as dimmers.
 - **Durability and cleanliness.** If necessary, choose durable materials tolerant of unintended use that are non-toxic. Custom-made (i.e., soft, tamper proof) furniture and hardware are also available.
 - **Fixtures and objects.** Aim for typical furnishings where possible, implement technology and sensors to maximize person-environment fit and minimize risks, consider angled windows for privacy, promote communication through chalkboards, mounted tablet/iPads, and/or signage.
 - **Organization and order.** Create ample storage space, reduce environmental triggers, conceal non-essential fixtures, and avoid clutter.
 - **Personal space calculations.** Design spaces with wider entrances, higher ceilings, more space per person, and multiple exits. Be cognizant of staffing needs and count these individuals into design calculations.
 - **Safety and supervision.** Decrease/contain risks and triggers (i.e., burns, toxin ingestion, sharps, falls, drowning, wandering, violence, property destruction, access to food/television), offer secure zones to decrease risks through protective object cases, locks, or alerts, and embed unobtrusive monitoring and supervision mechanisms through mechanisms such as wall cut outs, angled windows, etc.
 - **Spatial sequencing, zones, and compartmentalization.** Build in escape/retreat spaces, offer interest/activity/sensory-themed rooms or spaces, provide transition/buffer zones between different (e.g., high and low) arousal spaces.
 - **Visual and aesthetics.** Choose soft/neutral and/or preferred colours and avoid strong patterns, promote natural light and avoid fluorescent light, provide visual cues for activities/routines, and promote wayfinding through colours and signage.
-

When families cannot provide a safe home or can no longer cope, they may need to find alternative housing (Dubé, 2016; Marin, 2005). Other countries, such as England, Germany, and Denmark have regulated residential matching processes and provide interdisciplinary community healthcare teams to ensure adequate community care (Office of the Auditor General of Ontario, 2016; Dudley & Nakane, 2017; Walsh & Hall, 2012).

Wandering. Regarding safety concerns related to wandering, simple environmental modifications such as secure windows, door locks, and fencing can be cost-effective solutions (Anderson et al., 2012). Electronic tracking devices have also been shown to contribute to decreased frequency and duration of wandering and reduced risk of serious injury (McLaughlin et al., 2020). The development of smaller and more comfortable tracking devices (e.g., Apple Watch) could improve uptake among children with sensory sensitivities, and also offer more ‘normalized’ and stylish options. Pediatricians and other service providers may have a key role to play in proactively informing families about strategies for preventing and managing the risks of wandering (McLaughlin et al., 2020). Amber Alerts and Child Abduction Response Teams, which are designed to assist local law enforcement agencies when they respond to incidents of missing and abducted children, could also be expanded to locate Autistic individuals who become lost (Hillman & Anderson, 2019).

Communication differences. Another safety consideration is related to communication differences, which can lead to miscommunication and possibly negative interactions between Autistic people and other community members. Tools such as autism passports, alert cards, or mobile Apps that hold information about the Autistic individual can improve the safety in various community settings (Social Care, Local Government and Care Partnership Directorate, Department of Health, 2016a). For example, [Autism Passport](#), developed in the UK, is a communication tool that Autistic people can fill out and carry with them to communicate basic information about themselves, including accommodations needs, to others (Autism Anglia, 2021). Such tools may be particularly useful in emergency or medical situations, when interacting with law enforcement, healthcare providers, and other public safety personnel. In these scenarios, communication challenges may be more likely to occur due to the stressful nature of the situation. They may also enable Autistic people to disclose their diagnosis as well as other important information about themselves, so that community members can better understand and support them. For instance, the Autism Alert Card used in the UK includes information about areas where Autistic people may require support as well as emergency contact information (National Autistic Society, 2021b). In Ontario, the Health Care Access Research and Developmental Disabilities team developed a series of tools that can be used in healthcare settings to improve communication (Heifetz & Lunsky, 2018).

Preventing Suicide

Given the existing knowledge related to depressive symptoms (Radoeva et al., 2021) and previous adverse events, preventing suicide for Autistic people should involve upstream efforts to promote self-worth and social inclusion (Pelton et al., 2020). This approach would involve many of the strategies outlined in this chapter, particularly those related to human rights, self-advocacy, and community participation. Further approaches to building safe and inclusive school environments are discussed in Chapter 4. Access to appropriate mental health services is also essential and

is described in greater detail in Chapter 4 (Cybulski et al., 2021). It is also extremely important that healthcare providers and other supporters acknowledge and recognize early mental health concerns and suicidal signs in Autistic people, rather than potentially viewing these as “inherent” aspects of the condition (Dow et al., 2021). More autism training and better clinical tools for assessing suicidal risk in Autistic individuals can improve practice (Hannon & Taylor, 2013; Hedley & Uljarević, 2018; Howe et al., 2020).

Currently, the healthcare system lacks the necessary number of autism-knowledgeable service providers who can provide adapted evidence-informed mental health and suicide prevention supports (Hedley & Uljarević, 2018). While general mental health practitioners may have resources and expertise to support Autistic people, greater collaboration with autism or developmental service agencies can help to strengthen general mental health practitioners’ knowledge, skills, and confidence to adapt their care to better support the mental health of this population (Lake et al., 2014).

Peer-mediated or *autistic-led* monitoring of popular social media or chat sites used by Autistic individuals might be promoted through the implementation of manualized gatekeeper or suicide intervenor training of Autistic leaders/communicators in these communities. Community or government-sponsored websites or social media platforms developed for use by Autistic people should also be regularly monitored for suicidal content, with safety plans (e.g., reaching out and offering crisis supports) in place if a suicidal risk occurs. These practices were built into the stakeholder consultation process of the Assessment of Autism and were utilized by some stakeholders. Pan-Canadian hotlines, such as the Kids Help Phone or the Canada Suicide Prevention Service, would also benefit from having autism-knowledgeable staff, who, where relevant, can screen for autism and provide adjusted communication techniques and/or counselling as needed. As an example, the American Association of Suicidology published a crisis support toolkit for crisis workers in identifying and supporting Autistic callers/texters who are in crisis (Morgan, 2018).

Preventing Unwarranted Criminalization and Incarceration

Providing Autistic people with access to secure and supportive housing in the community is a proactive measure to reduce interactions with the criminal justice and correctional systems (Dubé, 2016). For individuals who have been charged with minor offenses, court diversion programs, which are typically reserved for individuals with mental health conditions, could be expanded and tailored to support Autistic people (Dubé, 2016). These programs can be made available before or after a conviction to link individuals to community supports and services. This could be done, for example, through a specialized liaison who could help with the securing and planning of supportive resources such as supervised residential placements within the community as an alternative to incarceration.

Targeted outreach and education of officials in the criminal justice system is needed to improve their understanding of autism and to encourage implementation of best practices for interacting with Autistic people (Dubé, 2016). Strengthening police curriculum to include strategies for responding to sensory-emotional reactions and for interacting with individuals who may communicate and process information differently can enable better communication and provision of accommodations (Social Care, Local Government and Care Partnership, Department of Health, 2016a; Taylor et al., 2009). Further, having specialized case management and court support services, who are experienced in supporting Autistic people (Dubé, 2016), as well as a Forensic Medical Officer, who can assess the suitability of people for detention or interview (Department of Health, Social Services and Public Safety, 2015) can help mitigate the unwarranted criminalization and incarceration of Autistic people. Finally, collecting statistical information on the number of Autistic adults who enter the criminal justice and correctional systems can enable better planning to ensure that adequate resources are available within the community as an alternative to incarceration (Dubé, 2016)

Autism Training for Public Safety and Legal Systems

The Mental Health Commission of Canada released a report in 2014 targeted at improving the interactions between police and people living with mental health conditions, which broadly included people with developmental disabilities and autism (Coleman & Cotton, 2014). The report concluded that police academies lack sufficient training in developmental disabilities, with only half of police services providing some form of training. The report recommended the establishment of policing standards that include provision for mandatory training for police personnel to develop competencies such as verbal communication, de-escalation techniques, patience, and relationship building.

“... We were so lucky, fortunate ... the police officer we ended up with ... had a psychiatric nurse background ... he talked to the people that were going to charge him ... he managed to talk them out of it ... that was really good.”

- Family member of an Autistic person

There is emerging consensus that police training about autism should be developed in partnership with Autistic people and their families and standardized across departments, with regular refresher sessions (Ball & Jeffrey-Wilensky, 2020). Several training courses have recently been developed in collaboration with Autistic people and public safety personnel. For example, in Canada several localized services or networks have developed curriculum and knowledge tools in partnerships with autism agencies, such as the [Canadian Police Knowledge Network](#), [Canucks Autism Network](#), and the [City of Laval](#) (Canadian Police Knowledge Network, 2022; Canucks Autism Network, n.d.; City of Laval, n.d.; Giant Steps School, 2020). There are also notable

examples from the UK, such as [Autism and the Police](#) and [Criminal Justice: A Guide for Police Officers and Professionals](#) (National Autistic Society, 2021c; National Autistic Society, 2021d).

In the UK, the National Autistic Society has also developed prison standards and an autism accreditation process in collaboration with the Feltham Young Offenders Institution, which became the first prison in the world to receive an autism accreditation in 2015 (Ministry of Justice, 2018). Since then, several other prisons have received accreditation following an intensive inspection process and hundreds of hours of training. Some key features of accredited prisons include offering autism-specific support for education and physical activity, having a dedicated unit for individuals with learning disabilities, providing Autistic offenders with mentorship during their sentence, and translation of documents into accessible, easy read formats. Accredited prisons are monitored and re-assessed every three years.

While providing police with appropriate training can mitigate negative interactions, some suggest that a better solution would be to minimize interactions between police and Autistic people overall through the provision of mental health support (Ball & Jeffrey-Wilensky, 2020). The [Integrated Mobile Police and Crisis Team](#) initiative in the Waterloo and Guelph regions of Ontario provides an example of how police services can collaborate with mental health professionals to provide more supportive and comprehensive mental health crisis care to community members in times of need (Guelph Police Service, 2019).

Key Findings - Promoting Physical and Emotional Safety

Enhanced safety and accountability mechanisms, such as autism-specific building design and tracking of adverse events, help prevent injury and maltreatment of Autistic people.

Community-based risk prevention strategies, such as autism passports or alert cards and anti-bullying campaigns that consider the unique needs of Autistic children and adults, can promote safer communities.

Best practices for suicide prevention, such as early recognition and support for mental health concerns, access to crisis lines, websites, intervenor training, and clinical assessments can be adapted to better meet the needs of Autistic individuals who are experiencing suicidality.

First responders and justice system personnel benefit from access to specialized supports and guidance on how to engage with Autistic people and their families.

3.3 Enhancing Community Participation and Accessibility

Summary Points

Environmental modifications and adjustments can improve accessibility of public spaces for Autistic people.

Community recreation and leisure programs that are inclusive and neuro-affirming provide a sense of belonging, and promote inclusion, engagement, acceptance, and positive perceptions of self.

3.3.1 Background

In line with the United Nations' Convention on the Rights of Persons with Disabilities, Autistic individuals and their families have the right to equal participation in education, technology, transportation, sports and recreation, employment, healthcare service, and cultural life (Coussens et al., 2019). Yet, in many Canadian communities, they face physical, attitudinal, informational, and systemic (McColl, 2019), as well as sensory and cognitive, barriers in doing so. Accessibility is achieved when environments, services, and processes are understandable and usable by the broadest range of people, regardless of their capabilities, and enables the full participation of everyone in society without barriers (Valencia et al., 2019; Employment and Social Development Canada, 2022). Participation is closely linked to environmental factors, such as social support, opportunities, available activities, the *built environment*, and people's attitudes, rather than type of disability (Coussens et al., 2019). Accordingly, the greatest barriers to participation are related to support and relationships, attitudes of services, systems, and policies, as well as accessibility (Coussens et al., 2019; Krieger et al., 2018).

“In practice, any useful strategy will need to adopt a model of difference: where Autistic people are not seen as flawed people ... but rather one that advises systemic and systematic change to make Canada more welcoming and accommodating to Autistic people as they are.”
- Autistic adult

Autistic people can live fulfilling lives and contribute to society within a supportive system and environment (Ripat et al., 2019). However, due to inaccessible environments, some Autistic individuals are not able to fully participate in their communities, resulting in lower quality of life (Tint et al., 2017).

Accessibility and Universal Design

Universal design, with its goal of making “all products, buildings, and exterior spaces ... usable by all people to the greatest extent possible” (Mace et al., 1991, p. 2), has made many inroads in the physical accessibility of public and residential spaces. However, currently applied strategies may not be ‘universal enough’ to meet the distinct needs of all Autistic people (Brand, 2010; Lowe et al., 2014; Mostafa, 2010). Even environments that have been categorized in policy as accessible may do little to improve the common mismatches between an Autistic person and the built environment, which can give rise to states of chronic and acute anxiety (Dalton, 2016).

Over the past decade, a number of disability architects and researchers have called to extend the boundaries of universal design and accessibility to include the needs of Autistic people (Chan, 2018; Dalton, 2016; Lowe et al., 2014; Mostafa, 2010; Nagib & Williams, 2017). For example, Kinnaer et al. (2016) offered two novel forms of accessibility that apply to Autistic people: sensory and cognitive accessibility.

Sensory and Cognitive Accessibility

Many Autistic people experience sensory differences, which may be exacerbated in public spaces, due to the high variability and variety of sensory stimuli that are often out of their control (Heffernan, 2016). For example, a grocery store may expose an individual to the combined sensory stimuli of fluorescent lights, background music, changes in temperature, unfamiliar smells, and close human contact through line-ups. In COVID-times there is also the need to wear masks, which may create uncomfortable tactile input. *Sensory accessibility* refers to designing, developing, or modifying spaces to provide a neutral and consistent sensory environment.

“The (x-ray) technician became very upset when my son needed to see where the door out was ... to know he was safe ... [The] hospital was great in Emergency when he was screaming and I didn’t know what was wrong. They got him into a private room quickly, turned down the lights, and helped him to be comfortable. So appreciated.”

- Family member of an Autistic person

Autistic people may process cognitive information in different ways. These neurological differences can impact, to differing extents, perception, memory, language, attention, and problem solving (Mahdi et al., 2018, de Schipper et al., 2015, de Schipper et al., 2016). *Cognitive accessibility* refers to developing, designing, or modifying environments to be used by the widest diversity of individuals with differing cognitive characteristics and capabilities (Johansson, 2016).

Transportation

Community mobility involves a person's ability to get around their community. Lack of access, comfort, and independence in community mobility has been shown to limit social participation and autonomy of Autistic people (Lindsay, 2017). Challenges experienced by Autistic people across different modes of transportation include (Kersten et al., 2020; Chan, 2018; Lindsay, 2017):

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- Community and driving safety,
 - Pedestrian wayfinding, and
 - Managing traffic volume.
-

These challenges are compounded by an absence of public/disability transportation options, lack of familiarity with public transportation modes, lower rates of driver licensure, and a high reliance on others to meet transportation needs (Kersten et al., 2020; Chan, 2018; Lindsay, 2017). In one study, the most common travel practice described by Autistic people was receiving rides from other people, typically other members of their household (Deka et al., 2016). In this study, almost three quarters of participants (73%) reported missing activities because rides were unavailable.

In addition to rides, other common modes of transportation for Autistic people include public transportation, walking, and driving (Chee et al., 2015). For each of these transportation methods, however, there are documented barriers. Those who walked, described the absence or poor quality of sidewalks, streetlights, and intersections or street crossings, as well as concerns regarding traffic speed and volume, crime, and the absence of nearby destinations (Deka et al., 2016). Public transportation environments pose sensory difficulties for Autistic users (Lindsay, 2017), particularly if they are required to take transit at peak hours (Falkmer et al., 2015). Parent perspectives also suggested concerns for safety (Kersten et al., 2020, Lindsay, 2017, Deka et al., 2016, Lubin & Feeley, 2016). Yet, these parents also reported a lack of formal transportation skill-building available to their child during the transition to adulthood (Lubin & Freeley, 2016).

Data from several countries suggest that Autistic people do not acquire their driver's license as often as their peers (Kersten et al., 2020, Lindsay, 2017). For example, in the United States, about 33% of Autistic adolescents acquired a driver's license versus 83.5% of non-autistic peers (Curry et al., 2018). While driver training methods may be effective in supporting Autistic individuals in gaining their driver's license (Myers et al., 2021; Myers et al., 2019), such methods may not be available in many Canadian jurisdictions. During our stakeholder consultation, we also heard that in some Canadian jurisdictions medical assessments are required for Autistic people prior to obtaining a license. While potentially necessary, such processes may act as an added barrier.

Recreation and Physical Activity

Recreational and activity-based programs were identified as a high priority need among parents of school-aged Autistic children (Lai & Weiss, 2017). Recreation and leisure encompass a broad range of play, recreational, and leisure activities, such as informal or organized play, sports, physical fitness, and relaxation (Rehadat International Classification of Functioning Guide, 2021). The existing literature on recreation and leisure for Autistic people has primarily focused on the experiences of children and youth in sports and physical activity, with little attention on the needs of adults or recreational pursuits other than sports/physical activity.

Physical activity and sport can bring about physical, social, and personal benefits for disabled persons (Government of Canada, 2020a). The Canadian Policy on Sport for Persons with a Disability was thus intended to facilitate the full and active participation of disabled persons in sport, and to contribute to social inclusion through these activities (McColl et al., 2017). The policy builds on the commitments made under the Canadian Sport Policy and the Physical Activity and Sport Act to foster participation of under-represented groups in sport. This, in part, occurs through partnership work between Sport Canada and other non-profit sports bodies, such as Special Olympics.

Sport and physical activity have been linked to multiple benefits for Autistic people across the lifespan. For example, sport has been described in the literature as an enjoyable, motivating activity that can allow individuals with developmental disabilities to experience several positive outcomes such as belonging, inclusion, engagement, acceptance, and positive perceptions of self (Zhao et al., 2021). Furthermore, physical activity has also been linked to brain health. As laid out in 2018 ParticipACTION Report Card on Physical Activity for Children and Youth, being physically active has been linked to improved memory, attention, focus, concentration, **executive functioning**, and lower rates of anxiety in Autistic children (ParticipACTION, 2018).

Despite this legislative context and the suggested benefits, Autistic children and youth, as well as their families continue to have lower participation rates (i.e., in terms of intensity and frequency) in play, physical activity, and recreation in comparison to non-autistic peers (Hilton et al., 2020; Huang & Kang, 2021). This participation disparity has been demonstrated even when controlling for other intersecting personal and environmental characteristics, such as income and ethnicity (Ratcliff et al., 2018). Furthermore, Autistic adolescents have decreased participation compared to Autistic children (Hilton et al., 2020) and this pattern continues into adulthood (Ratcliff et al., 2018). While families that include Autistic children were found to engage in similar rates of leisure as other families, family members and other supporters reported less satisfaction with these leisure activities, poorer family functioning, and lower overall satisfaction with family life (Reinders et al., 2019). These findings were more pronounced for families of Autistic children with complex support needs (Walton, 2019).

In today's technology-reliant society, and in the era of COVID-19 precautions, most Canadians have become more sedentary, including children (ParticipACTION, 2020). In turn, children are spending less time in outdoor physical activity than in previous generations (Varela et al., 2021; Amini et al., 2021). Preferences for screen time, coupled with increasing parental concerns about community safety and unsupervised outdoor play, have reduced opportunities and desire for such activities in children and youth (Rideout et al., 2010; Vu-Nguyen et al., 2016). In turn, the prevalence of obesity, diabetes, and use of health services for mental health concerns is increasing (ParticipACTION, 2020).

These issues may be more prominent in Autistic individuals for whom physical activity participation can be challenging and social inclusion is more limited. Both in Canada and the United States, Autistic children were far less likely than non-autistic children to meet physical activity guidelines (Bremer et al., 2020; Healy et al., 2019). Autistic youth and adults were also two to three times more likely than other disabled groups to be overweight, obese, or have type 2 diabetes (Young-Southward et al., 2017). Furthermore, Autistic youth who were overweight were four to five times more likely to experience suicidality than other Autistic youth (McDonnell et al., 2020).

Autistic people and their family members have described multiple barriers to participation. For community-based recreation, families described obstacles such as (Kohl & Barnett, 2020; Milgramm et al., 2021):

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- Crowded settings,
 - An incompatibility with the Autistic individual's developmental stage or interests,
 - A lack of structured activities that promote interaction among peers and families, and
 - Geographic distance.
-

Concerns regarding neighbourhood safety were also associated with decreased participation (Fiscella et al., 2021).

In school contexts, physical education classes were viewed as particularly challenging by Autistic adolescents (Arnell et al., 2018). The perceived high level of demands, regulated setting, and low responsiveness to specific needs affected the adolescents' willingness to participate. This finding is particularly relevant, as physical education classes continue to be a common integration point for students in mainstream and special education classes in Canada (Zhao et al., 2021). For Autistic children, in-school physical activities significantly predicted out-of-school physical activities (Bremer et al., 2020). As such, providing enjoyable and motivating activity options to Autistic children in schools may be an integral way to improve leisure and physical activity participation overall. Recent Canadian research also indicates that Autistic youth are more likely to be active when physical activities generate meaning, purpose, and a

sense of identity, emphasizing the importance of considering the broader social context of how such activities are offered and experienced (Jachyra et al., 2021).

3.3.2 Best and Promising Practices

Accessible and inclusive communities in which Autistic people and their supporters can and want to participate, can be promoted through a number of evidence-informed strategies across the areas of:

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- Expanding accessibility and universal design principles to encompass neurodiversity,
 - Promoting the use of *assistive technology* to improve autonomy and community participation,
 - Improving transportation services and supports, and
 - Upholding rights to inclusive recreation and leisure.
-

Expanding Accessibility and Universal Design

The evidence recommends that universal design principles are adjusted and used to promote inclusion, accommodations, and non-segregated opportunities, specifically for augmentative and alternative communication users and others with different communication, sensory, and environmental needs (Coussens et al., 2019; Krieger et al., 2018; Martin & Milton, 2017). Accordingly, Autistic people should be involved as Canada moves forward in operationalizing the Accessible Canada Act into pan-Canadian practices and guidelines (Petri et al., 2017), particularly on how different forms of cognitive and sensory accessibility are recognized and included. For example, the use of plain language that is clear, accessible, and to-the-point is largely seen as best practice in many sectors to effectively communicate with the intended audience and can be used to increase accessibility of public spaces for Autistic people (Communication Disabilities Access Canada, 2014; Stableford & Mettger, 2007).

“If I attend something and it has many loud noises and lots of people in closed spaces ... it can be too overwhelming from a sensory perspective”

- Autistic adult

Promoting *sensory accessibility* could include a range of built environment considerations such as promoting clarity and order, choice of colours and patterns, increasing natural daylight, limiting extraneous noise, echoes, and alerts/alarms, and offering clear exit pathways and low stimulation escape spaces where possible (Kinnaer et al., 2016). Sensory accessibility may also involve developing, designing, or modifying spaces to provide additional sensory stimuli as a mode for increased participation and interaction of Autistic people with the surrounding context. This form of sensory accessibility may be particularly relevant in

the domains of recreation, education, and culture, where opportunities for multi-sensory feedback and experiences can be offered through inclusive playground structures or sensory gardens, sensorimotor rooms in hospitals, community centres, or libraries, or creative sensory installations in museums or parks. Sensory accessibility considerations are specifically mentioned throughout this report in relation to public spaces, transportation, recreation and physical activity (described later in Chapter 3), diagnosis, supports, and services (described in Chapter 4), and post-secondary education, employment, and housing (described in Chapter 5).

Broadly, environments that offer predictability, consistency, comprehensibility, controllability, orientation, and navigation are viewed as promoting *cognitive accessibility* for Autistic and other disabled people. Cognitively accessible spaces would, for example, accommodate a wide range of literacy and language skills, use multiple modes (e.g., pictorial, verbal, tactile) for presenting essential information, and minimize hazards and adverse consequences of accidental or unintended actions (Connell et al., 1997). For example, in the context of an airport, cognitive accessibility features might include large and easy-to-read orientation maps, signage at all doorways, radio frequency and/or text alerts or announcements in addition to those on a loudspeaker, and policies to allow Autistic people to wear noise-cancelling headphones in these busy/loud environments.

The enactment of provincial policies such as the Information and Communications Standards of the Accessibility for Ontarians with Disabilities Act have been an important initial step to promoting more accessible information formats and communication supports (Thomson, 2018). However, efforts are needed to ensure consistent implementation and uptake of standard approaches across the country. This can be promoted, in part, by the development and dissemination of autism-friendly communication and built environment design examples and guidelines. For example, the autism-specific design recommendations summarized in the safety section provide concrete examples of some accessibility considerations that might be useful when developing autism-inclusive and neuro-affirming spaces.

At the municipal level, as well as in provincial/territorial and pan-Canadian services, reviews or audits of accessibility should be undertaken at regular intervals to identify barriers to participation (Coussens et al., 2019; Krieger et al., 2018). These reviews should pay specific attention to built environments, especially shared public spaces, to ensure that they do not create barriers to access and participation among Autistic people (Andrews et al., 2015; Coussens et al., 2019; Krieger et al., 2018).

Creating safe, neuro-affirming spaces (online and in the community) can enable Autistic adults and children to build and contribute to communities in urban, rural, and remote areas (Myers et al., 2015; Saxena et al., 2020). Where specific neuro-affirming or autism-inclusive models do not exist, there may be merit in building off or adapting existing programs/models that have been

developed to promote other identity-affirming practices (e.g., Asniish Naa Gegii: The Children's Health and Wellbeing Measure, 2020).

Identity-affirming spaces reflect environments that are designed and/or safe for specific groups of people, who are defined by a shared identity and likely experience historical and ongoing marginalization (Bizub & Allen, 2020). They allow individuals who share a particular identity to maintain a strong sense of community and require particular consideration for the unique experiences and needs of that group (Carter, 2007; Bizub & Allen, 2020). Neuro-affirming spaces are those designed for accessibility and usability of Autistic people. In these spaces, attention is also paid to support structures and attitudes and openness to social reciprocity. Social reciprocity refers to a willingness and ability to engage in back-and-forth communication and social relationships with others.

“I’d love to see more availability of autistic spaces and programs for Autistic individuals that don’t address therapy goals or skill-building directly but are instead based on creating community and providing accessible opportunities to explore shared interests and leisure activities.”

- Service provider

Improving Transportation Services and Supports

There are many ways in which transport systems can be improved for Autistic people and their families. One approach is to provide needed supports to Autistic youth and adults to gain their driver’s license if this is desired and safe. Autistic youth may have increased difficulty compared with peers as driving demands become more complex, suggesting that they may benefit from a slower and gradual approach to driver training (Patrick et al., 2018). With prolonged training many Autistic people can achieve licensure when supported by specialized instruction that is individualized to their needs and strengths (Myers et al., 2021). Specific recommendations to enhance learning to drive include standardizing instructional approaches and refining clinical assessment tools to determine driver readiness, which, in other jurisdictions, is often implemented by occupational therapists (Myers et al., 2019; Kersten et al., 2020; Lindsay, 2017). However, few such programs are offered in Canada.

Other jurisdictions have also considered ways to improve the accessibility of standard licensure testing procedures for Autistic people. Northern Ireland’s Ministry of Transport now offers theory and practical driving tests that accommodate disabled candidates, including adjustments such as additional time, flexibility in responses (e.g., read/text to voice options), and allowing an accompanying support person (Department of Health, Social Services and Public Safety, 2015).

Driver training manuals could also be updated to include autism-relevant information about addressing anxiety concerns, hazard perception, and navigation challenges (Chee et al., 2015).

Another way to promote community participation for Autistic people is through consideration of and adjustments to public and disability transportation services. Many Autistic people would benefit from better access to adapted transportation options that are safe, accessible, and sensory-friendly so that they can access services and participate in their communities (Kersten et al., 2020). Drivers and other frontline staff working in transportation would benefit from disability acceptance and awareness training, including autism-sensitivity practices (Government of Michigan, 2012; Social Care, Local Government and Care Partnership Directorate, Department of Health, 2016a).

Autistic individuals' use of public transport could be further facilitated through more inclusive transportation policies. For example, in the United Kingdom, Autistic individuals have been offered free off-peak transportation (Social Care, Local Government and Care Partnership Directorate, Department of Health, 2016a). While some changes have been made to improve the accessibility of public transportation services, these efforts have largely focused on the needs of physically disabled people and may not be inclusive of Autistic people (Dudley & Zwicker, 2016a). Needs assessment and eligibility processes may thus benefit from being updated to include cognitive or sensory needs. Shining an autism lens on transportation and urban planning policies has wider implications than just improving service access for Autistic people – it may also have universal benefits for other groups (e.g., children, seniors, other disabled people) in regards to community safety, pedestrian wayfinding, traffic volume, and public/disabled transportation access (Kersten et al., 2020).

Strategies that help prepare Autistic people to use public transit can also facilitate its uptake. In British Columbia, the [TransLink Mobility Guide and Accessible Transit Tool](#) was developed to provide transit users with a detailed visual layout of what they can expect to see and experience when boarding a bus, which can be particularly helpful for Autistic people who may feel anxious when entering new environments (Autism BC, 2020). Further, the Canucks Autism Network hosts airport accessibility tours, which walk Autistic people and their families through the entire process from check-in to boarding and provides them with a resource kit that can be used to help prepare Autistic people for their journey (Kelowna International Airport, 2022). In New Zealand, the [Have a Go Day](#) initiative in Wellington and Hamilton provided community members, particularly those who experience mobility challenges, with a free and accessible opportunity to try out different transportation options (Altogether Autism, 2017). This also served as an opportunity for transport service providers to consider the range of challenges different people can experience when using public transportation.

Upholding Rights to Leisure and Recreation

Facilitators of participation culminate around inclusive *places, attitudes, and programs*. The ultimate goal of inclusive participation is promoting experiences of safety and belonging in physical activity, sport, and recreation for everyone regardless of ability and background (Higgs et al., 2019).

“It would help if I knew what was going to happen before it happened ... Get pictures of the venue, have all of the activities explained to me and also how I should act and what I should wear ... It would also help if I knew approximately how many people were coming.”

- Autistic adult

Inclusive Places

Communities rich in environmental resources, such as sidewalks, equipment and supplies, swimming pools, parks, playgrounds, physical activity programs, and transportation facilitate participation of Autistic children in community-based recreation (Obrusnikova & Cavalier, 2011). For individuals of all ages, outdoor parks have been found to play an integral role in promoting physical activity and maintenance of healthy body weights in urban centres (Messiah et al., 2019). These environments should be safe with space that is suitable, clean, well-lit, and well-maintained. To be inclusive, access to these environments should be affordable and accessible to individuals of all abilities and provide clear navigation, both by staff and with signage (Higgs et al., 2019). In Australia, [Autism Friendly Visits](#), a collaborative initiative between Parks Victoria and Amaze, a non-governmental organization that supports Autistic people, developed social scripts to increase access to local parks (Parks Victoria, n.d.). These scripts use pictures and simple text to show Autistic people what they can expect to see and experience when visiting a park.

When designing inclusive playgrounds, special consideration regarding entry points, surfacing and paths, features to foster inclusive play, staffing/supervision, and a **co-design** process are recommended (Brown et al., 2021). While inclusive playground design has typically focused on physical access, a collaborative design approach resulted in the development of a multi-purpose fitness playground for free play and physical education for Autistic and non-autistic students (Menear et al., 2006). Expanding the playground components beyond one large play structure, commonly found on most playgrounds, offered more space, and catered to a wider variety of needs and abilities. This approach has been shown to balance developmentally-scaffolded levels of physical challenge and to also support both structured and imaginative play, and peer interactions for Autistic children (Yuill et al., 2007). Furthermore, providing lookout points and places of escape within playgrounds can be neuro-affirming.

Inclusive Attitudes

“I feel more comfortable in events that take time to ensure everyone can participate in the social interaction, so I don’t feel left out as I struggle to follow and participate in the flow of conversation.”

- Autistic adult

Leaders, staff, and users all play a role in promoting inclusive recreational environments that are welcoming and accepting (Higgs et al., 2019; Orr et al., 2021). To create such environments, good social, communication, and leadership skills need to be demonstrated by everyone (Higgs et al., 2019). Leaders can demonstrate respect and knowledge in multiple ways, including (Edwards et al., 2021):

- Using constructive language,
 - Being accountable for decisions, policies, and operational practices, and
 - Involving service users in discussion and feedback.
-

Service providers also play a critical role in implementing inclusive strategies such as facilitating group communication amongst disabled and non-disabled children (Edwards et al., 2021). Coaches must be aware that they may inadvertently socially isolate Autistic individuals and strive to include all participants in ways that are enjoyable and personally meaningful (Orr et al., 2021). Training and skill qualification of coaches and leaders are thus extremely important to consider, particularly when aiming to include disabled groups (Higgs et al., 2019).

Inclusive Programs

Inclusive programming ensures that there is a wide range of programs that meet the diverse needs of a community. The Australian Institute for Sport’s (2015) Wheel of Inclusion encompasses a spectrum of programming strategies for disabled people that offers opportunities for inclusion in programs with no or few modifications through to disability-specific programs. While particular to sport contexts, emerging research suggests that a spectral approach to inclusion is applicable to other contexts, such as housing (DuBois et al., 2021). Offering flexibility promotes person-environment fit, meaningful integration, and choice for a wider range of Autistic persons. Programs (including facilities, equipment, and rules) can be modified, to the extent required, across this spectrum to suit the ability and developmental stage of the participants (Higgs et al., 2019). This approach offers participants the best possible opportunity to be actively engaged and fully included by coaches and teammates.

All children are more likely to experience a greater sense of inclusion when recreation programs adopt a process-oriented and child-driven approach (Edwards et al., 2021). These approaches may include adapting activities to particular needs. Additionally, for Autistic youth, predictability, experiencing success, being challenged, and freedom of choice were found to be important considerations when developing programs (Arnell et al., 2018; Menear et al., 2006). For families that include Autistic youth, leisure programs focused on improving the quality rather than quantity of family leisure time, can be beneficial (Reinders et al., 2019; Walton, 2019).

Developing inclusive places, attitudes, and programs, takes (Brown et al., 2021; Government of Canada, 2006; Higgs et al., 2019; Reinders et al., 2019; Mogo et al., 2020):

-
- **Sufficient and proactive planning and infrastructure.** For example, resources offered to municipalities can be used to build and adjust recreational spaces to be neuro-affirming and inclusive of Autistic people and their families. This process includes the continued investment in developing inclusive and adapted playgrounds.
 - **Improved access and accessibility of public/shared recreation spaces.** For example, co-audits of programs and facilities with Autistic representatives may support a phased approach to improved cognitive and sensory accessibility.
 - **Raise awareness about the benefits of sport and physical activity for all, as well as available programs.** The Government of Canada emphasizes the importance of promoting awareness of early childhood sport and physical literacy, the benefits of sport and physical activity (an especially important message for the healthcare sector), disability-specific sport participation and development models, the contribution of disabled athletes to Canadian sport excellence, and access to sport services and programs. This promotion could be made specific to Autistic people and disseminated to and through service organizations across the country.
 - **Further and ongoing capacity building, program development, and needs assessments.** More person- and family-centred, community-based, and in-school programming is needed. Without the proper planning and infrastructure in place, it is difficult for participation to grow. Programs and services educating Autistic youth about how to engage in physical activity may enhance quality of life through increased community participation and diversified social relationships. As a step forward, municipal recreation departments could partner with social/community agencies that serve Autistic children and adults to identify programming needs and gaps. For example, Sport England's (2021) most recent 10-year strategy includes a commitment to working with key partners to address existing inequalities and barriers within sport and physical activity for Autistic and disabled people.
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“I enjoy swimming but swimming pools are often brightly lit ... and loud (music and people) ... and can have unpredictable children screeching and splashing. Maybe sensory-friendly swim times?”

- Autistic adult

Key Findings - Enhancing Community Participation and Accessibility

Broadening universal design beyond physical accessibility to also encompass safety, sensory, and cognitive barriers better supports equitable community participation and accessibility of public spaces for a diversity of Autistic people.

Safe, accessible, and sensory-friendly transportation and community mobility options for Autistic individuals involve strategies, such as:

- Improving access through eligibility and grants for public and disability transportation,
- Community planning to address existing or potential public transportation barriers, for example, sensory triggers and public or provider attitudes, and
- Skill-building to improve safety, wayfinding, and transit use and offering adaptations to getting a driver’s license.

Community recreation and leisure programs that are inclusive and accepting of Autistic people are created through planning, infrastructure, localized needs assessments, and staff development.

3.4 Social Inclusion through Technology

Summary Point

Assistive technologies have the capacity to improve social inclusion of Autistic people in multiple ways but uptake in community and therapeutic settings has been slow.

3.4.1 Background

Technology can offer innovative strategies for:

- Teaching new skills,
- Facilitating community participation through assistive tools and devices, and
- Promoting social engagement and service delivery through virtual platforms.

Ultimately through these strategies, there is the potential for technology to expand opportunities for the meaningful inclusion of Autistic people across many different settings such as schools, the workplace, at home, online, and within communities more broadly (Benssassi et al., 2018).

Despite the many advantages that technology can offer, there are several barriers including affordability, confidentiality and privacy concerns, individual perceptions about the benefits and harms, and individuals' degree of trust/mistrust of technology (Deng & Rattadilok, 2020; Li et al., 2021). Access to the Internet, which is required to use many assistive technology and virtual platforms, may also be limited for those with lower socioeconomic status and those living in rural and remote areas (see Chapter 4 for more details).

Specific to Autistic people, there is additional concern that technology may intensify and/or narrow focus on particular areas of interest (which may have both positive and negative outcomes), exacerbate stress, or contribute to decreased social engagement (Deng & Rattadilok, 2020). Social stigma, limited confidence and skill to use technology, and lack of technical support have also been cited as key barriers (Ayres et al., 2013; Ghanouni et al., 2020). For instance, lack of public acceptance of augmentative and alternative communication (AAC) along with limited training can hinder service providers from encouraging the use of AAC and serve as a deterrent for Autistic people and their families (Moorcroft et al., 2019).

“I now have access to an AAC device for emergencies on my iPad, but I am embarrassed to use it as I worry that people will think I am being “dramatic” because I can speak verbally when I am not overloaded.”

- Autistic adult

Augmentative and alternative communication (AAC) is an important assistive technology for many Autistic people, which can enable the greater social inclusion of non-speaking or minimally-verbal individuals. These systems range from low-tech (such as pen and paper and picture boards) to high-tech (such as speech generating devices, smartphones and tablet applications, and eye tracking and gaze interaction technology) systems (van Grunsven & Roeser, 2021; Beukelman & Mirenda 2013).

However, improvements to AAC interface design and user experience are needed (Lorah et al., 2015). For instance, AAC devices may prevent users from making direct eye contact and can significantly slow down turn-taking during conversations, which makes it difficult for users to participate in group conversations (van Grunsven & Roeser, 2021). Further, speech generating devices often do not allow for stylistic nuance such as tone of voice, which is important for self-expression (van Grunsven & Roeser, 2021). It is also important that AAC systems reflect diverse languages and cultures (Moorcroft et al., 2019). Given that communication is bidirectional, the extent to which AAC users have opportunities to interact with others is also dependent on community members’ understanding and knowledge about communicating with AAC users (Midtlin et al., 2015).

Finally, while technology-based teaching methods have shown promise, high quality empirical data to support their use remains limited (Wainer & Ingersoll, 2011; Ploog et al., 2013). Research looking at the effectiveness of AAC has often focused on an individual’s ability to make requests as opposed to other forms of communication, such as sharing interests or engaging with others (Lorah et al., 2015; Logan et al., 2017). Further, supports and services that use technology typically have multiple components, which make it difficult to identify what contributes to overall effectiveness (Iacono et al., 2016). Due to heterogeneity among Autistic people, different approaches may be more appropriate for certain individuals (e.g., with or without co-occurring intellectual disability). However, more clarity is needed in differentiating these benefits based on needs and abilities (Pennisi et al., 2016).

3.4.2 Best and Promising Practices

Technology across Multiple Settings

In schools, the use of technology can supplement traditional teaching methods and help teachers provide more individualized support to students by matching instructional materials with students’ preferred learning styles (Ramdoss et al., 2012; Sarrett, 2018; Berrigan et al.,

2020). The use of technology is thought to be particularly advantageous for Autistic students because it offers a standardized, predictable, and controlled environment for learning (Golan & Baron-Cohen, 2006; Silver & Oakes 2001), allows users to work at their own pace and ability level (Golan & Baron-Cohen, 2006; Silver & Oakes 2001), is multi-sensory which can be motivating, engaging, and reinforcing for users (Motti, 2019), and requires minimal social demands (Grynszpan et al. 2014).

In the workplace, the implementation of assistive technology has demonstrated the potential to improve work performance, reduce hours needed for job coaching, and promote on-the-job independence for Autistic employees (Gentry et al., 2015; Weaver, 2015). For instance, the use of personal digital assistants (e.g. Apple iPod Touch, tablet/iPad) have been used within services for Autistic adults to improve employment outcomes (Gentry et al., 2015; Hill et al., 2013; Wehman et al., 2016; Smith et al., 2017).

At home, the use of mobile apps to support planning and completion of daily activities can be supportive through the use of visual schedules, checklists, and the gamification of tasks (see [Brain in Hand](#), 2020). Further, smart home technology such as the situated buttons concept (see Salai et al., 2021), the interactive light system to facilitate task management and mood setting (see Huizen, 2018), and the use of eye tracking and voice interfaces to control home appliances (see Klaib et al., 2019) can offer Autistic people greater comfort and autonomy. Technology can also be used to address the residential support needs of Autistic people such as embedding strategies to allow support workers to monitor residents at a distance (Ontario Developmental Services Housing Task Force, 2018; Brand, 2010).

The emergence of online communities has also created new opportunities and spaces for social engagement, particularly for those who prefer virtual interactions over face-to-face communication (Mazurek & Wenstrup, 2013). It has also contributed to the growth of the neurodiversity movement and the amplification of autistic voices (Davidson, 2008; Brosnan & Gavin, 2015).

Technology as a Communication Assistive Device and Teaching Method

The effective use of augmentative and alternative communication (AAC) can enable greater participation of some individuals with complex communication needs within their communities (Jorgensen et al., 2006; McNaughton & Bryen, 2007; Jorgensen et al., 2009; Sennott & Bowker, 2009). The most common AAC methods that have shown success in improving communication skills and expanding verbal repertoires for Autistic people are manual signs, picture exchange communication system (PECS), and speech-generating devices (Ganz et al. 2012; Lorah et al. 2013; van der Meer, Didden et al. 2012; van der Meer, Kagohara et al., 2012; Alzrayer et al., 2014; Lorah et al., 2015). However, the use of handheld electronic devices with speech-generating apps have been suggested to be more beneficial compared to other AAC systems, such

as manual signing and PECS, due to its social acceptance (Lorah et al. 2013), affordability (McNaughton & Light 2013), portability (Sigafoos et al. 2013), and availability (Shane et al. 2012). Other factors that may contribute to its effectiveness include its ability to provide voice-output feedback (Schlosser et al., 2009; Koul & Schlosser 2004; Schlosser et al., 2014), requiring less cognitive and motor skill demands (van der Meer, Didden et al. 2012), and the use of well-known symbols (Koul et al., 2001).

“... the duty to accept, learn, and understand one another’s unique communication styles, verbal and non-verbal, is always bilateral and never unilateral ... Autistic people as a whole are best served by teaching Autistic and [non-autistic] people together to learn one another’s communication styles without expecting compliance or conformity either way.”

- Autistic adult

Public education to address stigma and foster greater acceptance around the use of AAC is important to enable full participation and inclusion of AAC users (Moorcroft et al., 2019; van Grunsven & Roeser, 2021).

“I think the first step in supporting Autistic people’s communication needs lies in changing public perceptions ... regarding the different ways communication might look, and sending the message that all communication should be honoured.”

- Service provider

The uptake of AAC devices can be further improved by modifications to the prescribing process. These modifications include addressing long waitlists, improving prioritization systems that determine who can be approved for AAC systems, and ensuring service providers have enough time to teach Autistic people and their families how to use AAC systems (Moorcroft et al., 2019; Lindsay, 2010). Further, it is relevant to provide clearer guidelines for determining whether AAC is a good fit for a particular individual, for evaluating the effectiveness of AAC once it has been prescribed, and for following up with the AAC user to ensure that it is being used appropriately (Lindsay, 2010). This process also provides families with more time to test out the devices before committing to them. Professionals (including educators, speech-language pathologists, and other service providers) also need training that includes both theoretical and practical experience with AAC so that they feel comfortable recommending and supporting Autistic people and their families to use AAC devices (Moorcroft et al., 2019).

Technology-based approaches are one of many support strategies that may be applied in the classroom. Other school-based strategies/supports are covered separately in Chapter 4. To strengthen the evidence-base for the use of technology-based approaches in teaching, it has been recommended that future research should include comparisons between technology-based approaches and more traditional approaches to teaching within classroom and therapy settings (Ploog et al., 2013; Wainer & Ingersoll, 2011), collect follow-up data to determine generalization of skills and the social validity of the program (Sansosti et al., 2015), and include well-controlled, large-scale studies with larger sample sizes and with diverse subgroups of Autistic people (Ploog et al., 2013).

Accessibility of Technology

Future development, design, and dissemination of technology also needs to consider the accessibility and usability of technology by Autistic people. Recommendations and guiding principles exist, which can provide developers with suggestions on important considerations for developing more appropriate and inclusive technological solutions for Autistic people (Britto & Pizzolato, 2016).

Further, accessibility policies, standards, and procedures for the use of technology should be developed within academic and employment settings (National Educational Association of Disabled Students, 2018). Updated and reliable information about available evidence-based resources needs to be accessible to Autistic people, families, and services providers to guide them in selecting suitable technology to meet an Autistic person's needs (Gamble et al., 2006; Dobbins et al., 2004; Dunn & Laing, 2017; Scott et al., 2012). Finally, providing users with sufficient training (Moorcroft et al., 2019) and access to technical support (Ghanouni et al., 2020) can facilitate greater uptake of technology.

Key Findings - Social Inclusion through Technology

Supports for the use and uptake of assistive technology by Autistic people as a tool to enhance their communication and other life skills have the potential to enhance their quality of life.

Technology, such as communication devices, can support social inclusion of speaking and non-speaking Autistic people with diverse processing abilities by providing greater options for making connections and communicating.

3.5 Chapter Summary

Social inclusion represents an integral aspect of wellbeing and quality of life for all. Key elements of inclusive communities for Autistic people are a sense of belonging and acceptance, active participation and meaningful involvement, emotional and physical safety, as well as equitable access to resources and opportunities across multiple life domains. However, many barriers prevent Autistic people from being safely and meaningfully included in their communities.

Social inclusion can be fostered through public campaigns and targeted education and training programs that promote autism acceptance and understanding of neurodiversity. Legislative frameworks for supported decision-making and more accessible approaches to informed consent can enable Autistic people to have greater control over decisions about their life and mitigate risk for abuse and neglect. The implementation of safety and accountability mechanisms are important for mitigating and preventing abuse, neglect, bullying, and maltreatment across community settings. Finally, environmental modifications that consider cognitive and sensory accessibility, as well as improvements to the accessibility of transportation, recreational facilities and programs, and technology can facilitate greater community participation of Autistic people and their families.



Chapter 4:

Diagnosis, Supports, and Services

4.0 Introduction

As stated in Chapter 1, Autistic people have neurological and cognitive differences that shape how they experience the world. Their range of strengths, challenges, and needs influences the degree of support required in their daily lives (Happé & Frith, 2020). The recognition of **autism** as an aspect of **neurodiversity** has prompted a shift away from attempting to reduce autism characteristics toward supporting skill development and emotional regulation, removing barriers that impede **inclusion** and participation, supporting areas of need, building on strengths, and providing opportunities for Autistic persons to live fulfilling lives (Ali et al., 2012; Milton et al., 2014; Mottron, 2017; Lai et al., 2020). There may be some autism characteristics, particularly early in life, that may provide a focus for supports and services (e.g., to support the development of communication skills). Yet, it is important to emphasize that cumulative research, including a Canadian study of newly diagnosed preschool children (Szatmari et al., 2015), indicates that measures aligned to symptoms defined by the Diagnostic and Statistical Manual (DSM-5) are only weakly correlated with day-to-day functioning.

This chapter summarizes diagnostic and other supports and services used by Autistic people and their families across the lifespan. It covers the following areas:

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- Equitable access to diagnosis, supports, and services,
 - Identification and diagnosis across the lifespan,
 - A lifespan, family-centred approach,
 - Early childhood supports and services,
 - School-aged child and adolescent supports and services,
 - Adult supports and services, and
 - Advances related to neurobiology and potential contributions to understanding individual needs.
-

Terminology

Throughout this report we have used the term ‘supports and services’ rather than interventions as this better reflects our current understanding of autism. In this chapter, however, we have used the term ‘interventions’ in the following cases:

- In many policy and research contexts, the term ‘early intervention’ is used to describe and compare a range of early childhood supports and services, and
- Some models or approaches have ‘intervention’ as part of their name



4.1 Equitable Access to Diagnosis, Supports, and Services

4.1.1 Background

In Canada, roles and responsibilities for the delivery of healthcare services are shared between provincial and territorial governments and the federal government (Government of Canada, 2016). Consistent with Canadian federalism, the federal government provides funding through health and social transfers to the provinces and territories, who then have jurisdictional control over how health, education, and social supports and services are delivered (Zeidan et al., 2019). Each province or territory has developed its own approach to the provision of diagnostic assessment and services (Shepherd & Waddell, 2015). Most provincial and territorial governments subsidize some form of autism services in childhood; however, the form and intensity of services and supports, as well as funding models, vary greatly across jurisdictions (Tsiplova et al., 2019). This variability has contributed to inequities and regional diagnostic and service shortfalls (Smith et al., 2021; Zeidan et al., 2019), as well as pockets of excellence and promising practices.

Summary Points

Autism services, including pathways to diagnosis and accessing supports and services, are complex and challenging to navigate.

Access to publicly-funded diagnoses, supports, and services for all ages and life stages is inconsistent or insufficient across Canada.

There are substantial disparities in access to diagnostic assessments, supports, and services related to income, geography, race and ethnicity, age, and sex and gender.

Eligibility for services usually requires a formal autism diagnosis, or is dictated by age or intelligence quotient (IQ) cut-offs rather than being needs-based. When adaptations are provided, Autistic people can often benefit from generalist, publicly-funded services.

Autism services and supports offered in each province or territory encompass a broad range of elements, including:

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- Screening,
 - Diagnostic assessment,
 - Information and referrals,
 - Early intervention,
 - Behavioural supports²¹,
 - In-home care for daily living tasks,
 - Skills training,
 - School supports,
 - Parent education, training, and coaching,
 - Respite care,
 - Case management,
 - Service coordination,
 - Self-directed services and person-centred planning processes,
 - Service care planning,
 - Transition supports, and
 - Individualized funding.
-

In many jurisdictions, therapeutic services by health professionals such as speech-language pathologists, occupational therapists, physiotherapists, and psychologists may also be offered or are sought out privately by parents (for example, in New Brunswick and Nova Scotia, as described by Tsiplova and colleagues, 2019).

Complexity of Systems across Multiple Ministries

Autism services span multiple systems, making it a particularly complex area of health and social policy. Although many autism-focused services and supports listed above are provided and/or overseen by regulated health professionals, only diagnostic assessments are managed solely under the mandate of the health ministry (Penner et al., 2019; Smith et al., 2019). Even these such assessments may sometimes be financed through other ministries, particularly when related to eligibility for social or developmental services in adulthood. Other supports and services are implemented in and across complex systems of care generally spanning multiple ministries. Depending on the province or territory, the ministries involved in these services and supports may include health, education, family or children, and community or social services (Penner et al., 2019; Smith et al., 2021). Further, there is variability in where and how services and supports are provided, such as hospitals, children’s rehabilitation centres, preschools and early childhood centres, schools, and the family home (Smith et al., 2021).

²¹ This term is inclusive of all forms of structured behavioural strategies across the lifespan, such as emotional regulation supports.

For example, in Ontario, preschool autism services and funding are provided by the Ministry of Children, Community, and Social Services, whereas in New Brunswick and Prince Edward Island, they are provided through the Department of Education and Early Childhood Development, and in Nova Scotia, they are provided through the Department of Health and Wellness (Tsiplova et al., 2019). In some provinces, for example Québec, in addition to the multiple sectors involved, supports and services are organized by age groups (children, youth, and adults), type of disability (physical, developmental, and mental health), and geographic region (reflected by the different health networks) (Zeidan et al., 2019). Such differences complicate comparisons across the provinces and territories.

Current Systems Challenges related to Autism Services

It has been suggested that an optimal and comprehensive systems approach for autism in childhood in Canada would involve rapid access to high-quality diagnostic assessment and early childhood services, adherence to evidence-informed practice guidelines, supports to enhance parents' skills and self-efficacy, and measures to minimize financial impacts to families (Tsiplova et al., 2019). However, a myriad of systems issues have been documented that challenge the realization of this goal.

Major challenges faced by Autistic individuals and their families within the Canadian health and intersecting systems relate to:

-
- **Variable diagnostic policies and practices** (Coo et al., 2012; Klag & Ouellette-Kuntz, 2018; Penner et al., 2019; Smith et al., 2021; Yuen et al., 2018),
 - **Wait times for diagnosis and other services** (Brian et al., 2019; Croteau et al., 2019; Penner et al., 2018, 2015; Smith et al., 2021; Zwaigenbaum, Duku et al., 2019),
 - **Inconsistent and, at times, insufficient access to therapeutic services** (Penner et al., 2015; Smith et al., 2021; Tsiplova et al., 2019; Zeidan et al., 2019),
 - **Difficulty estimating costs and linking these to long-term outcomes** (Pokhilenko et al., 2021; Tsiplova et al., 2019; Yuen et al., 2018; Zeidan et al., 2019), **including costs, efficiencies, and effectiveness of public versus private *service providers*** (Smith et al., 2021),
 - **Urban and rural differences** (Hoogsteen & Woodgate, 2013; Young et al., 2019),
 - **Out-of-pocket costs and the financial impacts to families** (Lord et al., 2021; Tsiplova et al., 2019),
 - **Rapidly expanding prevalence of autism diagnoses in many Canadian jurisdictions** (Coo et al., 2008; Klag & Ouellette-Kuntz, 2018; Yuen et al., 2018),
 - **A lack of workforce capacity within and beyond health systems to meet the increasing demand for autism services and supports in healthcare, schools, early childcare settings, and the community** (Brian et al., 2019; Penner et al., 2018; Penner et al., 2017; Zeidan et al., 2019), and
 - **A lack of pan-Canadian data across the lifespan** (Klag & Ouellette-Kuntz, 2018).
-

Many of these challenges are intertwined with systems complexity (Gardiner & Iarocci, 2018; Penner et al., 2019; Smith et al., 2019, 2021) and inter-/intra-provincial/territorial variation in autism services (Penner et al., 2019; Shepherd & Waddell, 2015; Smith et al., 2021; Tsiplova et al., 2019; Volden et al., 2015). As such, determining effective ways to address these challenges represents a key gap in Canadian health systems research.

Underserved Groups of Autistic People

As introduced in Chapter 2, there are underserved communities across Canada from different geographic regions, cultural, ethnic, and linguistic backgrounds, and gender identities who face additional challenges in receiving competent autism services (Singh & Bunyak, 2019; Khanlou et al., 2017). In many regions of Canada, there are insufficient services for Autistic people available in languages other than English, including limited French capacity in many areas of the country (Xhaferri, 2020; Nugent, 2017).

Mistrust in the healthcare system among Autistic individuals and their *family members* is significantly higher than in the general public (Hemm et al., 2015). This finding was confirmed by the pan-Canadian opinion survey conducted during this assessment. Many Autistic people experience discrimination and biases when accessing autism services (Calleja et al., 2020; Khanlou et al., 2017).



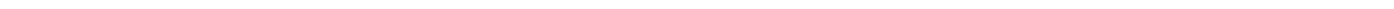
“I don’t trust that I will be given the time and space to communicate my needs and the respect and clear explanations that will enable me to feel comfortable accessing it.”
- Autistic adult



For example, Indigenous Autistic people and their families face additional challenges when they must navigate between different jurisdictions for services and funding (Stavropoulou-Kampoukou, 2019).



“You[‘ve] got to be really mindful of what you are applying for because if you don’t bring it up, they won’t tell you ... They never said once to us you can apply for respite or ... for an OT or ... an SLP, you[‘ve] got to be very up front with what you’re applying for or else they won’t tell you. There’s no service navigator ... to guide you ... same thing with Jordan’s Principle ... you[‘ve] got to go do it yourself.”
- Family member of a First Nations Autistic person



Autistic people are often excluded from publicly-funded physical and mental health programs available to the general public simply because of their autism diagnosis (Maddox et al., 2021; Camm-Crosbie et al., 2019). For example, eligibility based on intellectual quotient (IQ) or adaptive functioning can often prevent Autistic people without co-occurring *intellectual disability* from being eligible for developmental or mental health services (Lorenc et al., 2018).

This discriminatory practice is contrary to evidence that Autistic people can benefit from these programs and highlights the need to address misconceptions among clinicians as well as decision-makers who determine eligibility criteria (Maddox et al., 2021; Zerbo et al., 2015; Crane, Hearst et al., 2021). Experiences of exclusion from essential health and mental healthcare services, for this and other reasons, were frequently identified by Autistic individuals during our stakeholder consultation process. Initial clinical training, continuing education, and service delivery models for all professional disciplines should be aimed at ensuring a full scope of service delivery to all patients, with or without formal autism diagnoses. Appropriate regulatory oversight by professional colleges is also warranted to ensure quality of care (Malik-Soni et al., 2021; Calleja et al., 2020).

4.1.2 Best and Promising Practices

In this section, the following strategies for improving the quality of and access to healthcare services for Autistic people are discussed:

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- Pan-Canadian guidelines and consensus statements,
 - Redesigning and enhancing navigation of autism supports and services,
 - Building the capacity of the autism workforce, and
 - Expansion of telehealth and e-health.
-

Pan-Canadian Guidelines and Consensus

Canadian researchers and professional societies have suggested that pan-Canadian guidelines regarding diagnostic and service pathways could offer more concrete strategies to ensure equitable care to Autistic persons. For example, Smith and colleagues (2021) recently stated: “In the absence of national standards and oversight, the diversity of funding models across Canada creates a patchwork of [autism] services, with potential inequities depending on where children live” (p. 147).

Through pan-Canadian and provincial-territorial collaboration, establishing consensus on early identification and screening, diagnostic, and needs-based early intervention pathways may reduce interprovincial/territorial variability and promote more equitable health service access and utilization (Zwaigenbaum, Duku et al., 2019; Volden et al., 2015). Some examples of how pan-Canadian consensus, standards, and guidelines might enhance equitable access and utilization include, but are not limited to, the efficacy and safety of autism-related therapeutic

products (Tsiplova et al., 2019), universal versus high-risk screening approaches (Yuen et al., 2018), targeted wait times for diagnosis and assessment (Penner et al., 2018, 2019; Tsiplova et al., 2019), and reporting and sharing of comparative data (Smith et al., 2021).

Some jurisdictions, such as New Zealand, the United Kingdom, and the United States, have developed guidelines and minimum standards of care. The New Zealand Autism Spectrum Disorder Guideline, developed in 2008 and updated in 2016, offers a potential approach to the development of national guidelines. These guidelines aim to acknowledge the whole of a person's life – from early intervention and diagnosis to community living for adults to professional learning and development for those who interact with Autistic people (New Zealand Ministries of Health and Education, 2016). The Guideline Development Team had cross-ministerial representation and included consultation with Autistic people and *supporters*. Indigenous input by Māori peoples was overseen by a Māori Advisory group set up by the Ministries of Health and Education. Recommendations in the guideline were graded according to good evidence, fair evidence, expert opinion or consensus, or no recommendation could be made. A recommendation based on the clinical and educational experiences of members of the Guideline Development Team was referred to as a 'good practice point'.

The United Kingdom's National Institute for Health and Care Excellence has also developed several guidelines for the recognition and diagnosis as well as support and management of autism ([Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis](#) [National Institute for Health and Care Excellence, 2017], [Autism Spectrum Disorder in Under 19s: Support and Management](#) [National Institute for Health and Care Excellence, 2021a], and [Autism Spectrum Disorder in Adults: Diagnosis and Management](#) [National Institute for Health and Care Excellence, 2021b]). These guidelines are reviewed periodically by a committee to ensure that recommendations remain up-to-date.

In the United States, the American Academy of Pediatrics developed a clinical report, [Identification, Evaluation and Management of Children with Autism Spectrum Disorder](#), which recommends that developmental surveillance be incorporated during regular health visits and that any concerns raised during these visits should lead to the administration of standardized screening tests (Hyman et al., 2020). Further, the identification of developmental problems should lead to developmental and medical evaluation, diagnosis, and appropriate services. Following diagnosis, it is recommended that there be further medical investigations, including genetic testing (e.g., chromosomal microarray and Fragile X testing) to identify potential factors contributing to developmental delays. Families should be supported in making informed decisions about whether to pursue this testing. In general, there is still low uptake of genetic testing in clinical practice (Moreno-De-luca et al., 2020).

In 2019, The Canadian Paediatric Society issued a series of [Practice Statements on Autism Assessments](#) authored by a multidisciplinary task force. Some key practice recommendations included:

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- All children should be monitored for signs of autism as part of general developmental surveillance,
 - A multi-level (or ‘stepped’) system that includes multiple pathways to diagnosis, based on the complexity of clinical presentation and involving collaboration between community pediatricians, other developmental health professionals, and specialty centres,
 - Comprehensive assessment (similar to that recommended by the American Academy of Pediatrics) including blood work and other testing to identify potential factors contributing to overall presentation (e.g., genetic forms of intellectual disability, treatable metabolic conditions) and other co-occurring conditions (e.g., electroencephalogram or EEG, if epilepsy is suspected).
 - Support for ongoing health needs including attention to physical and mental health conditions, and
 - Ensuring access to services that enhance quality of life for children and families.
-

Updating, expanding, and creating new interdisciplinary guidelines may allow for best practices by health, social, and educational professionals delivering autism services. These quality improvement approaches are best developed by each sector and integrated into existing regulations or new strategic plans.

For example, building on work in other jurisdictions, such as the United Kingdom (Department of Health and Social Care, & Department for Education, 2021a), pan-Canadian occupational and scope of practice guidelines for autism care relevant to various disciplines can influence:

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- Curricula of educational institutions,
 - Regulatory bodies’ professional registration and development requirements,
 - Future regulation of professionals trained to support Autistic individuals, and
 - Consistent delivery of supports and services across jurisdictions.
-

Finally, policies that recognize the implications of *intersectionality* (e.g., culture, language, ethnicity, and gender/sex), and provide service providers with adequate resources (e.g., sensitivity training to address misconceptions about autism and how autism manifests across individual differences), will better support the diverse needs and strengths of Autistic children, adolescents, and adults and may contribute to reducing inequities (Lai & Weiss, 2017).

System Redesign and Enhanced Navigation

System redesign includes improving service access through greater transparency and consistent eligibility as well as reducing service disruptions (Sturmborg, 2018; Wilson et al., 2019). Team-based coordination of diagnostic assessments and support services should be seamless among the healthcare, education, and social care sectors, as well as cross ministerial jurisdictions, sectors, and professions (e.g., physical and mental health, rehabilitation services, education, and social and community service sectors/providers; Hyman et al., 2020).

“ ... the whole model of support is a patchwork ... The paperwork for accessing each service and the reporting from these services is another source of concern. There is no central system where notes can be maintained on a child. The number of consent forms I’ve had to fill in so that his support team can email each other would make up a small novel.”

- Family member of an Autistic person

Ensuring high-quality autism services that are safe, effective, person- and family-centred, timely, efficient, and equitable (Institute of Medicine [US] Committee on Quality of Healthcare in America, 2001; Agency for Healthcare Research and Quality, 2018) requires system-wide improvements. This can be achieved by continuous quality improvement, with re-engineering that evaluates programs and services that align with the priorities of Autistic individuals and their families/supporters. This collaborative evaluation approach is an emerging best practice (Fletcher-Watson et al., 2019).

A learning health systems approach has been used in some provinces to begin to bridge the gap between research and practice (Moat et al., 2020). Collecting and analyzing pan-Canadian disaggregated data on the incidence and prevalence of autism as well as wait times for diagnostic assessments and support services will better inform appropriate health system planning and investments. Other countries such as those in the UK have successfully adopted national standards on wait times to ensure timely and consistent access to diagnosis and needs-based services across jurisdictions (Welsh Government, 2019). Data collection is further discussed in Chapter 6.

Navigation support can also allow for greater continuity of services and enable Autistic people and their families to make informed decisions concerning what supports and services are appropriate for them, especially during times of transition²² (Ministry of Children, Community and Social Services, 2021a; Roth et al., 2016). This navigation includes easy access to current, evidence-based, local information about available supports and services for Autistic individuals, their families, and other supporters (Social Care, Local Government and Care Partnerships,

²² Navigation supports around times of transition are described in later sections.

Mental Health and Disability and Dementia, 2015; State of Victoria, Department of Health and Human Services, 2019).

For example, in the UK, the [Autism Service Directory](#) is a comprehensive directory of services and supports (such as diagnosis, housing, supported living, education, employment, social groups, leisure activities, and advocacy organizations) for Autistic people, their families, and other supporters (National Autistic Society, 2021e). Information should be evidence-based, transparent, and updated regularly. Addressing misinformation and misconceptions of autism, monitoring and regulating autism service providers, and only funding evidence-informed therapies will enable Autistic individuals, their families, and supporters to make informed decisions and receive appropriate individualized, needs-based services (Nicolaidis et al., 2014; Malik-Soni et al., 2021; Hyman et al., 2020).

Autistic individuals, their families, and supporters prefer individualized needs-based supports and services (Maddox et al., 2021; Lai & Weiss, 2017; Doherty et al., 2020). Access to needs-based, as opposed to diagnosis-based services, is more likely to benefit Autistic individuals. However, in many jurisdictions, access to these services is predicated on a formal autism diagnosis, which creates delays in receiving needed support services (Taylor & Henninger, 2015).

Capacity Building of the Autism Workforce

Currently, the number of highly-trained clinicians with specialized autism expertise has not grown in parallel with autism prevalence (Bridgemohan et al., 2018). The situation is more critical for Autistic adults, for whom there is a scarcity of professionals with expertise to deliver high-quality autism diagnostic and support services (Malik-Soni et al., 2021; Calleja et al., 2020; Murphy et al., 2016). To address this shortage, workforce expansion and extensive **capacity building** of clinicians and other service providers, including those who identify as autistic, across the healthcare, education, and social service systems may be warranted.

Capacity building includes planning for sufficient numbers of the needed types of service providers, as well as providing training and professional development along with organizational support for these providers (Bergeron et al., 2017). However, there are currently scant Canadian data about the quality and quantity of autism service providers to guide capacity building (Financial Accountability Office of Ontario, 2020). This is important information to determine the number of well-trained professionals and service providers needed to ensure recognition of autism-related characteristics as well as diagnostic and support services across the lifespan and across different sectors.

Expanding the numbers and types of trained clinicians (e.g., primary healthcare providers with enhanced training as well as specialists from various cultural and linguistic backgrounds) supports timely and equitable access to early recognition, diagnostic assessments, supports, and services for all Autistic persons, particularly in underserved communities (Malik-Soni et al., 2021). This includes increasing educational and professional development training opportunities and establishing communities of practice for diverse groups of clinicians. A framework for such capacity building would be helpful. This is particularly needed to increase the number of clinicians from relevant disciplines with expertise to recognize and diagnose autism in girls and women, adults, the **2SLGBTQIA+** community, and people of diverse cultures, all in the complex context of co-occurring physical and mental health conditions (Bergeron et al., 2017; Cumin et al., 2021).

Approaches to capacity building include providing autism education early in the curriculum of medical, health, education, and social services students and upgrading practicing professionals' competencies to work to their full scope of practice and more effectively with Autistic individuals (Zeidan et al., 2019). With respect to the latter, the Extension for Community Healthcare Outcomes (ECHO) model, which has been implemented in Canada, is one example of an evidence-based telehealth strategy that enables knowledge transfer from autism specialists or centres of excellence to community professionals, including primary service care physicians, particularly those located in rural and remote areas (Mazurek et al., 2020; Giachetto et al., 2019; Dreiling et al., 2021). The ECHO model has also been applied to support the development and enhancement of service delivery models by engaging with clinical and administrative leaders (Vinson et al., 2022).

As a stop-gap measure, it may be possible to expand capacity by increasing scopes of practice and competencies of pediatricians, child psychologists, and child psychiatrists through to early adulthood (i.e., beyond 18 years old). Although not assessed formally in relation to autism, this approach has been used successfully in areas of healthcare for which management of a condition in adulthood is relatively new. For example, over many years, clinicians developed expertise and adapted models of care related to managing congenital heart disease and recognizing clinical issues specific to adults based on their pediatric colleagues' experiences (Thakkar et al., 2018; Webb et al., 2015).

However, the implication would be that pediatric clinicians would need to further divide their time among a larger number of people in need, across a broader age range. As such, capacity building among health providers serving adults (i.e., within primary care, mental health, and the broader health system) would be a more sustainable strategy. This includes training and ongoing professional development for psychologists, physicians (including psychiatrists)

and other health professionals to ensure timely and equitable access to autism diagnostic assessment for adults that meets best practice quality standards (National Institute for Health and Care Excellence, 2021b). In addition, expanding access to existing expertise by removing barriers (e.g., age restrictions on relevant billing codes) and addressing hesitancy of clinicians who work with adults could increase access to diagnostic assessments, supports, and services (Nasmith et al., 2010).

Expansion of Telehealth and e-Health

Remote technology can be used to (Ellison et al., 2021; Sutherland et al., 2018; Alfuraydan et al., 2020):

- Provide some supports and services to Autistic individuals at home where they feel most comfortable,
- Offer family and other supporters assistance without having to travel, and
- Increase timely access to diagnostic services in rural, remote, on reserve, and Northern communities.

The global COVID-19 pandemic and mandatory shut-downs to inpatient and outpatient services, pushed many clinicians and clinical services to adopt telehealth practices for autism assessments (Kryszak et al., 2022). While the pandemic placed a strain on autism diagnostic services and disrupted access, it has also provided the impetus for clinicians to rethink assessment practices and for institutions to accelerate the development of infrastructure needed to support the large-scale implementation of telehealth services (Kryszak et al., 2022).

However, remote technologies require easy access to data-enabled smartphones/tablets or computers with high-speed Internet in a comfortable and private setting. While only 6% of Canadians did not have access to the Internet at home in 2020, one in four of these cited the cost of internet service as the reason, with an additional 13% indicating that the cost of equipment was a barrier (Statistics Canada, 2021b). The digital divide is most apparent in rural and remote areas, where only 46% of Canadians have access to the Internet with the needed broadband speeds, compared to 87% of the general population (Canadian Radio-television and Telecommunications Commission, 2020). Unfortunately, those who need access to such services the most, are also often those who are least likely to afford internet access.

For rural and remote areas in Canada, the use of telehealth technologies can be useful for both developmental surveillance and diagnostic evaluations, provided that the Internet is accessible (Brian et al., 2019). Using telehealth, shared care between a local primary healthcare provider and autism specialist(s) further away can be facilitated through video-conferencing services

and mobile developmental clinics that travel to rural or remote areas on a seasonal schedule. There are many exemplars of this model in Canada, including a collaboration between the Cree Board of Health and Social Services of James Bay, the Montreal Children's Hospital, and the McGill School of Communication Sciences and Disorders to offer speech and language assessment and supports to Autistic children living in remote areas of Québec (McCrum, 2014). In addition to such collaborative models, capacity building (e.g., based on the ECHO model described in health systems) in underserved communities should also be prioritized (Mazurek et al., 2020).

Other supports and services can also be provided through telehealth. In the United States, the [Indian Health Service Telebehavioural Health Center of Excellence](#) provides a range of services including psychiatric and therapeutic services to American Indian and Alaska Native children and adults across the country using televideo (Indian Health Services, n.d.). To improve internet connectivity, services are delivered in local tribal healthcare facilities where there is faster and more stable internet connection compared to individual homes (Hays et al., 2014).

In Australia, the [Aspect Teletherapy Service](#) delivers autism-specific services through video-conferencing to Autistic people and their families in collaboration with their local support network, which can include educators as well as health and community service providers (Autism Spectrum Australia, n.d.). Sessions are delivered by speech-language pathologists, occupational therapists, psychologists, and special educators and can take place within the individual's home or school. A study examining the use of Aspect Teletherapy Services during the COVID-19 pandemic revealed benefits for service users as well as practitioners such as not having to travel, feeling more comfortable compared to face-to-face therapy, and the opportunity for greater family involvement and capacity building (Johnsson & Bulkeley, 2021). Barriers to using telehealth services were also identified such as poor internet connection and other technical difficulties, limited access to technology, and challenges related to balancing multiple responsibilities at home.

In addition to telehealth, online tools can also offer information and navigational supports. Australia also offers a free national autism helpline, [Autism Connect](#), that is funded by the Australian Government and provides supports and expert advice to Autistic people, their families, and other supporters (such as health professionals, researchers, teachers, and employers) related to exploring autistic identity, diagnosis, education, financial aid, employment, behaviour and communication strategies, referrals to services, peer support, finding autism-friendly places and events, and making environments accessible (Amaze, 2021b). These services can be accessed over the phone, through email or web chat, and are offered in over 160 languages.

A notable online tool launched in Canada in 2020 is the [Autism and/or Intellectual Disability Knowledge Exchange Network \(AIDE Canada\)](#), which aims to offer accessible, reliable, and evidence-informed information and resources about autism and *developmental disability* in French and English (AIDE Canada, 2020). The website is funded by the Public Health Agency of Canada and has an important goal of addressing regional disparities in accessing services, supports, and resources for Autistic people and/or people with intellectual disabilities and their families across Canada, particularly in rural and remote areas. A key aspect in developing the website content is the leadership and involvement of Autistic people themselves. About 25% of the AIDE Canada leadership team and 30% of their staff are autistic. Another provincial example is the [Autism Community Training](#) group's website and repository of more than 70 videos on a range of autism-related topics for parents and professionals, funded by the Government of British Columbia.

Parsons and colleagues (2017) conducted a systematic review of parent-mediated programs delivered remotely for Autistic children living outside urban areas and found preliminary evidence that these telehealth services were effective in addressing children's social and communication skills and in improving parent knowledge and program fidelity. A more recent review (Tan-MacNeill et al., 2021) of parent-mediated online programs conducted with parents of Autistic children also found positive effects on children's behaviour as well as improvements in parents' self-efficacy or stress levels. More evidence about the effectiveness of remotely-delivered services and supports is accruing due to the COVID-19 pandemic's restriction of in-person therapy services, but no systematic review has emerged to date.

Key Findings - Equitable Access to Diagnosis, Supports, and Services

Supports and services that are responsive to the needs of Autistic individuals offer programs that build on developmental growth and meet emerging challenges at different life stages, including through adulthood.

Adapting general health services so that Autistic individuals can be included in existing publicly-funded services, such as substance use or anxiety programs, can be improved through systems redesign, reviewing eligibility requirements, and improving general providers' autism knowledge.

Improving timely access to high-quality diagnostic and support services for Autistic people of all ages occurs through an expanded and diverse workforce with more specialized training in autism and ongoing quality assurance mechanisms.

Improving systems design and coordination and providing family-centred navigation supports ensures greater access to and continuity of services for Autistic individuals across the lifespan.

To improve equitable access and evidence-based services and approaches for Autistic persons and their families, other countries have implemented:

- Clinical autism guidelines (for example related to interdisciplinary care and pathways),
- Safety standards (for example oversight of therapeutic products), and
- Increased transparency (for example related to wait times).

Remote technologies, such as tele- and e-health, as well as mobile developmental clinics, and university-service partnerships, offer Autistic individuals and their families with more effective access and opportunities to participate in some assessments and interventions that may otherwise be unavailable, for example, in rural, remote, and northern areas of Canada.

4.2 Recognition and Diagnosis across the Lifespan

4.2.1 Background

Although some children can be diagnosed by two years of age (Brian et al., 2019), most children are diagnosed much later. Nearly half of Canadian children and youth diagnosed by age 17 did not receive a diagnosis until after age six (Public Health Agency of Canada, 2018). Variability in wait times is partly attributed to differences in diagnostic approaches across the provinces and territories (Smith et al., 2021). For example, in some jurisdictions, diagnosis must be carried out by a multidisciplinary team regardless of clinical presentation, which may not always be necessary and may contribute to longer wait times (Penner et al., 2018; Haute Autorité de Santé, 2018). Delayed diagnosis in the early years can result in missed opportunities for early supports and services (Zwaigenbaum, Brian et al., 2019). Furthermore, to capitalize on a period of significant neuroplasticity (Piven et al., 2017), early diagnosis, supports, and services can potentially maximize developmental gains.

Summary Points

Autistic Canadians are not receiving timely diagnosis.

There is inconsistent and insufficient access to publicly-funded autism diagnostic services in Canada, with significant gaps, for example in adolescent and adult diagnostic services, and extensive wait times ranging from months to years for child diagnostic services.

International guidelines recommend a maximum 3- to 6-month interval between referral and diagnosis (National Institute for Health and Care Excellence, 2017; New Zealand Ministry of Health, 2016; The Miriam Foundation, 2008). Only two provinces, British Columbia and Nova Scotia, have specified target wait times for assessment (six weeks and three months, respectively) (Penner et al., 2019). Most provinces/territories do not publish their wait times for assessment; however, in a study representing data from five Canadian jurisdictions from 2005 and 2011, diagnosis of children younger than six years was made an average of 19 months after parents identified initial concerns (Zwaigenbaum, Duku et al., 2019). The global COVID-19 pandemic further strained healthcare systems, which has had added impacts on autism assessment wait times in many jurisdictions (Kryszak et al., 2022). For example, according to the [British Columbia Autism Assessment Network](#), as of December 1, 2021, the autism diagnostic wait times in the province averaged more than 21 months.

As summarized by Penner and colleagues (2019) in a study of pediatricians, diagnostic practices and policies vary greatly across Canada. Some jurisdictions favour multidisciplinary specialist assessment practices and the use of specific standardized diagnostic measures, whereas others allow for diagnosis by single clinicians and do not require specific measures. Mandating specific standardized assessments has not been associated with longer wait times, however, limiting pathways to diagnosis to specialist referrals and the use of multidisciplinary teams has resulted in delays to access early intervention services (Penner et al., 2019). On the other hand, these authors suggested that more lax diagnostic standards have been associated with greater false-positive diagnoses, which in turn impacts wait times and service costs and utilization.

A longitudinal comparative research project in New Brunswick and Nova Scotia exemplified the impact of these service differences (Smith et al., 2021). Autism diagnoses in New Brunswick can be made by individual clinicians on their own without a standardized diagnostic approach. The province also typically serves a larger cohort of Autistic children with less complex presentations more quickly (within four months of diagnosis). On the other hand, in Nova Scotia, autism diagnoses require assessment by multidisciplinary teams using a standardized approach, and yield a smaller, but older (due to wait times) cohort of Autistic children with more compromised adaptive functioning and higher levels of autism characteristics. This finding may suggest that when multidisciplinary teams are used, there may be a narrower spectrum of children diagnosed with autism.

Diagnostic delays are related to a shortage of qualified healthcare professionals (Thomas et al., 2007), requiring multiple appointments to see various healthcare professionals, difficulties with travelling long distances (Oberleitner et al., 2007), and the complexities of working with a multidisciplinary team that may span the healthcare and educational systems (Hurt et al., 2019). Barriers to diagnosis in rural and remote areas include limited access to local diagnostic services and associated costs to see specialists in urban centres (Hoogsteen & Woodgate, 2013).

Biases and sex or gender stereotypes have been recognized as impeding recognition of autism in some girls, women, and people assigned female gender at birth (Saxe, 2017). Many healthcare providers may be unfamiliar with autism presentation in females and standard diagnostic tools may be less sensitive (Lai & Szatmari, 2020). This is because girls and women may exhibit fewer or different behavioural features of autism, and may present with gender-typical intense interests, higher social attention, linguistic abilities, and motivation for friendship, and may be more apt to mask than males. Autistic women who were diagnosed later in life reported health professionals being dismissive of their concerns (Green et al., 2019). It is important, however, to acknowledge the complexities of initial diagnostic assessment for

autism in adulthood, particularly in women (Cumin et al., 2021). It involves distinguishing features of autism from other related or differential conditions, which requires significant clinical skill.

Autistic individuals and their families, especially those from various cultural, ethnic, and linguistic backgrounds have also experienced disappointing, dismissive, or discriminatory encounters with healthcare professionals, especially during the diagnostic assessment (Fong et al., 2021; Lum et al., 2014; Nicolaidis et al., 2015). For example, due to systemic racism, autism is underdiagnosed among Indigenous children (Lindblom, 2014), or may be misdiagnosed as fetal alcohol spectrum disorder or a conduct disorder before an autism diagnosis is considered (Mandell et al., 2007). Characteristics of autism may also be difficult to differentiate from the developmental expression of early life trauma, although published data are primarily related to children with severe environmental deprivation growing up in orphanages (Levin et al., 2015; Rutter et al., 2007) and not from the broader range of contexts experienced in Canada.

“My family doctor ... wiped off my many discussion attempts at visits during my son’s first 18 months of life ... It wasn’t until ... my husband had videotaped my son flapping at supper and showed it to our doctor. She immediately apologized and referred him for testing.”

- Family member of an Indigenous Autistic person

Canadian data are not available on potential racial/ethnic and socioeconomic disparities in autism diagnosis. However, international studies, primarily from the US and the UK have reported disparities in diagnostic status based on ethnicity (Roman-Urrestarazu et al., 2021; Yuan et al., 2021). As described in Chapter 2, this can be linked to biases in diagnostic assessment processes, including standardized assessments.

The needs of individuals who are quiet, passive, and/or do well academically may not be noticed until a later age or be overlooked altogether (Lindsay et al., 2013; Mitchell & Beresford, 2014; Peters & Brooks, 2016). Furthermore, recent changes to diagnostic criteria acknowledge social communication challenges may not manifest until later in adolescence or adulthood, when social situations and relationships become more complex (Fusar-Poli et al., 2020). As such, there is recognition of a “lost generation” of Autistic adults who may not yet be diagnosed (Lai & Baron-Cohen, 2015). Yet, for adults in Canada who are seeking diagnoses, few publicly-funded diagnostic services exist and those that do exist are concentrated in large urban centres. Therefore, most adults seeking an autism diagnosis must pay out-of-pocket for private assessments in order to be eligible for/access these services. Such assessments can range from several hundreds to thousands of dollars (Lai & Baron-Cohen, 2015).

Causes of this service shortage have been linked to the insufficient numbers of healthcare professionals with relevant expertise to diagnose autism in adults (Malik-Soni et al., 2021) and a lack of appropriate diagnostic guidelines, criteria, and tools to support assessment of adults with suspected autism (Edelson et al., 2021; Wigham et al., 2019). Diagnosing autism in adults can be challenging if there is no corroborative developmental history from a childhood informant, such as a parent. Furthermore, many adults have developed coping strategies, such as masking, and their presentation may also be affected by co-occurring mental health, other neurodevelopmental conditions (Lai & Baron-Cohen, 2015), or the manifestations of trauma (Cumin et al., 2021).

“... I have heard of so many ridiculous responses ... you couldn’t possibly be autistic you’re wearing makeup. You drove yourself here, you looked me in the eye, etc., totally discounting a lifetime of masking.”

- Autistic adult

4.2.2 Best and Promising Practices

Improving the identification and diagnosis of autism across the lifespan requires different considerations for children and adults. The following section discusses:

- Approaches to identification and diagnosis of children, and
 - Strategies for addressing the significant gap in the availability of adult diagnostic services.
-

Approaches to Identification and Diagnosis of Autism in Children

The first step towards a diagnosis is detecting behavioural features of autism and other co-occurring conditions. The identification of possible signs of autism may occur in multiple settings such as preschools, day cares, at early wellness checks, and in primary care. Healthcare providers, educators, and family members can be taught to monitor and identify early signs of autism throughout childhood, as some autism presentations may be less apparent during the early years (Zwaigenbaum, Brian et al., 2019). Public education, media acceptance and awareness campaigns, and professional development on characteristic features of autism have been used in other jurisdictions (e.g., US, UK) to promote timely identification and appropriate referrals for further diagnostic assessment (Malik-Soni et al., 2021).

The American Academy of Pediatrics in the United States recommends universal screening for autism at 18 and 24 months. However, there is no direct evidence that universal screening can lead to earlier access to services and supports or improved outcomes for those diagnosed as autistic (Siu et al., 2016). Therefore, although screening instruments can provide useful information, they should not form the sole basis for further assessment and support (Lord et al., 2021).

In the Canadian context, universal screening practices may not be the most cost-effective approach and could lead to false-positive identification, which slows access to diagnostic and support services (Yuen et al., 2018). As a result, the Canadian Pediatric Society recommends autism-focused surveillance, monitoring for early signs of autism at each health maintenance visit, using standardized tools when concerns are identified, but also making referrals that are based on shared decision-making between clinicians and parents/supporters rather than questionnaire scores (Zwaigenbaum, Brian et al., 2019). Targeted screening approaches may be warranted for children who are at increased likelihood for autism, such as siblings of diagnosed individuals, infants born preterm, and those with specific genetic conditions (e.g., tuberous sclerosis).

Early childhood and day care workers who intensively interact with an array of children from a diversity of backgrounds and with many different developmental profiles, may be well-positioned to participate in early identification or screening (Larsen et al., 2018; Zhang et al., 2019). They may also have unique and local access to underserved or at risk populations (Janvier et al., 2016). Findings suggest that care providers can effectively monitor young children for signs of autism in preschool or day care settings (Janvier et al., 2016; Gulrud et al., 2019). It should be noted, however, that to more precisely specify developmental differences that may indicate autism, specialized training and extensive experience are needed (Larsen et al., 2020; Zhang et al., 2019). Currently, autism training, including on early identification, for educators working in preschool or day care settings is uncommon despite these care providers having daily contact with Autistic children (Samadi et al., 2020). Emerging research suggests that advanced training and specialized work experience (including *pratica*) can improve care providers' sensitivity to detecting unexpected features in early development and provision of effective daily monitoring and support (Zhang et al., 2019; Samadi et al., 2020).

To expand diagnostic capacity and reduce wait times, the Canadian Paediatric Society recommends a stepped (multi-tiered) approach. In a stepped approach, the number and types of clinicians involved (i.e., solo practitioner, shared care model, or team-based approach) and what assessment tools are used, depends on the child's complexity of presentation, developmental level, co-occurring conditions, psychosocial history, and other factors (Brian et al., 2019). The Lancet commission also recommends a stepped approach to diagnosis that entails using existing information, starting with a brief evaluation and progressing to a more comprehensive assessment, if needed (Lord et al., 2021). However, as per the recent Lancet Commission report, regardless of the diagnostician(s), the use of at least one standardized diagnostic tool, in addition to clinical expertise, is highly recommended, not only to improve diagnostic accuracy, but to allow for assessment of change (Lord et al., 2021). An earlier study demonstrated that the clinical impression of the team member administering a standardized diagnostic tool, such as the Autism Diagnostic Observation Scale, was critical to the accuracy of the diagnosis (Molloy et al., 2011).

A central aspect of a stepped approach to diagnosis and services involves outcome measurement (Lord et al., 2021). As will be further described in more detail in the stepped approach to care section, monitoring using standardized assessments and goal-based outcome measures provides clinicians and parents with a way to make informed decisions about service pathways. As such, the purpose of diagnostic assessment is “... to inform needs-based treatment planning and service provision, and to provide data for monitoring of progress and anticipation of later needs with the assumption that needs change and improvements can occur” (Lord et al., 2021, p. 23). Such a person-centred approach should also take account of potential variation in the age at which autism can be reliably diagnosed. Thus, when the initial assessment does not lead to an autism diagnosis, functional needs should still be addressed over the course of that individual’s development. Recognizing that some individuals may be diagnosed with autism at a later age despite not being identified as such earlier in childhood (Ozonoff et al., 2018), reassessment can also be beneficial.

Applying a stepped care model, the most accessible and least costly approach to diagnosis is using community clinicians as diagnosticians. As such, general pediatricians, and potentially primary healthcare providers (e.g., family physicians, nurse practitioners) can be trained to diagnose less complex autism cases independently and to refer individuals with more subtle, ambiguous, or complex presentations to a specialist (via a shared care model) or specialized inter- or multidisciplinary teams (Guan et al., 2022). Depending on the complexity of the clinical presentation, standard diagnostic tools may be used (National Institute of Health and Care Excellence, 2017; Whitehouse et al., 2018; Haute Autorité de Santé, 2018; Volkmar et al., 2014; Scottish Intercollegiate Guidelines Network, 2016). Additionally, providing more psychologists and psychiatrists with advanced training on autism, commonly co-occurring/overlapping conditions, and differential diagnosis could also enable them to work to their full scope of practice to support more complex autism diagnostic assessments and post-diagnostic care.

When a child’s diagnostic evaluation is team-based, an assessment for service planning may occur concurrently. Otherwise, in the first two approaches (i.e., solo practitioner or specialist/shared care model), the lead diagnostician would refer for or assess post-diagnostic supports and services planning based on an Autistic individuals’ and their family’s strengths, challenges, and support needs (Lord et al., 2021). They would then provide a referral for additional services as needed, in addition to doing follow-up assessments during transition periods.

Adult Diagnosis

Countering the lack of adult diagnostic services requires an increased pool of healthcare professionals with relevant expertise to diagnose autism in adults (Malik-Soni et al, 2021). As in children and youth, diagnosis is ultimately based on clinical judgement, and principles of best practice in diagnostic assessment can be applied across the life span. Accordingly,

development of appropriate diagnostic guidelines, criteria, and tools can also support the assessment of adults with suspected autism (Edelson et al., 2021; Wigham et al., 2019). These standards and guidelines should be sensitive to gender, language, culture, and intersectionality. The UK National Institute of Health and Care Excellence provides guidelines on when an adult autism diagnostic assessment is warranted – based on autism features, current functioning (e.g., in employment, education, relationships), mental health, co-occurring learning or developmental disabilities, and/or another neurodevelopmental conditions (National Institute of Health and Care Excellence, 2012). A recently published study based on a clinician consensus process suggested that improvements to diagnostic practices for adults in the United Kingdom would involve clear assessment pathways, providing updates to individuals on the waitlist, pre-assessment information gathering/provision, co-occurring condition identification, and training/networking (Wigham et al., 2022). However, to date, studies are insufficient to recommend a particular autism diagnostic tool for adults (Wigham et al., 2019; Baghdadli et al., 2017). Therefore, incorporating diagnostic tools in the assessment process should be tailored to the complexity of clinical presentation, as recommended in pediatric practice (Wigham et al., 2019). Below is a quote from an Autistic adult that illustrates potential problems with using current pediatric assessment tools for an adult population:

“The entire process was horrible. I hated every second of it. They gave me a children’s book. She told me to “explain the book” and was upset when I told her what was going on detail by detail without being able to put together a story. She gave me toys - none of which was stimulating to me - and told me to use them ... I got infantilized during the process. The entire time I was made to feel like a child.”

- Autistic adult

Due to the aforementioned challenges, a collaborative decision-making process is needed to consider all the evidence for and against a diagnosis (Lai & Baron-Cohen, 2015) and potentially contradictory evidence may be resolved by drawing on clinicians’ expertise (Hayes et al., 2021).

Key Findings - Recognition and Diagnosis Across the Lifespan

Efficient and timely access to diagnostic services starts with early recognition of autism characteristics and other co-occurring conditions in multiple settings and by multiple partners, for example, families, educators, and health professionals.

A stepped approach to diagnostic services for individuals suspected of being autistic provides greater flexibility and promotes more timely access. This approach encourages diagnosis by trained community physicians for those with less complex clinical presentations prior to the involvement of more intensive and specialized diagnostic teams or processes.

Supports and services for Autistic children and adolescents are most effective when provided consistently across a range of settings, for example in and across homes, preschools, day cares, schools, and community recreation centres.

4.3 A Lifespan, Family-Centred Approach

4.3.1 Background

Autistic individuals possess strengths and abilities, which can and should be promoted and celebrated by their families, schools, communities, and in society. To capitalize on these strengths, supports and services can promote optimal functioning and help to ameliorate the many social and environmental barriers that Autistic people and their families face (Lai et al., 2020). These supports and services, typically provided through both informal (e.g., family members, friends) and formal (e.g., service providers, clinicians) channels, may address needs related to core autism characteristics, as well as co-occurring conditions. Although described in Chapter 1, we will briefly summarize these needs, as a preface to describing current best practices to supports and services across the lifespan.

As per the DSM-5, core autism characteristics primarily cluster around differences in (Mahdi et al., 2018; de Schipper et al., 2015, de Schipper et al., 2016):

- **Communication**, such as speaking, understanding, reading, and writing messages, communicating using verbal and nonverbal messages, holding conversations, and using communication devices and techniques,

- **Social relationships**, such as formal, family, and informal relationships (e.g., friendships/peer relationships) as well as basic and complex interpersonal interactions,
- **Highly focused and/or intense interests, repetitive activities, and preference for sameness/routines²³**, and
- **Sensory differences**, such as hypersensitivity²⁴ and hyposensitivity²⁵ to sensory stimuli as well as sensory seeking or interests.

There is a wide range of spoken language abilities in Autistic people, and progression of communication skills is often uneven. About 30% of Autistic children are minimally verbal or non-speaking (Brignell et al., 2018), and other Autistic individuals may have some form of language or communication impairment (Parsons, Cordier, Munro et al., 2017). It has been reported that Autistic children and adolescents can experience increased feelings of loneliness and poorer friendship quality compared to non-autistic peers (Parsons, Cordier, Munro et al., 2017). As children develop, they experience increasingly complex peer social demands. These relationships can be particularly challenging for Autistic individuals given some of their core social and communication differences (Montgomery & McCrimmon, 2017).

Diverse responses to sensory stimuli, such as over- or under-reactivity, are highly prevalent in Autistic individuals (Hazen et al., 2014; Keluskar et al., 2021). Sensory processing differences are highly associated with other core and associated features of autism including intense and/or highly focused interests, self-injurious behaviour, anxiety, and attentional differences (Hazen et al., 2014).

Finally, in relation to differences in self-regulation, sensory processing, communication, and/or a form of intense and/or highly focused interests, Autistic individuals may also present with what are often perceived as *behaviours that challenge²⁶*, such as aggressive or self-injurious behaviour, meltdowns (when viewed as uncontrollable), or significant property destruction (Jiujiu et al., 2017; Oliver, 2017; Bottema-Beutel et al., 2021). As was touched upon in Chapter 3, environmental or sensory triggers, as well as internal pain or discomfort, may lead to behaviours such as screaming, crying, hitting, or not reacting, that are perceived by others as challenging but could also be a means of communication.

It is important to think critically about why and how behaviours become labelled as challenging. For example, historically, ‘stimming’ as a form of stereotyped or repetitive motor

²³ As noted in chapter 1, where possible we have modified DSM-5 language. Moving forward in this chapter, we typically use the term intense and/or highly focused interests.

²⁴ Also sometimes referred to as hyper-reactivity or over-responsivity

²⁵ Also sometimes referred to as or hypo-reactivity or under-responsivity

²⁶ Behaviours that challenge have been widely adopted in the United Kingdom in place of challenging behaviour. This term was also preferred by the Autistic committee members.

movements were viewed as non-normative, problematic, and even challenging by some, rather than a useful form of coping or self-regulation (Kapp et al., 2019). Through the perspectives of the Autistic people and the neurodiversity lens, stimming as well as certain other behaviours can be reframed as neuro divergent rather than challenging. From this understanding, stimming may not be considered a behaviour that challenges unless it results in significant functional impairment, personal distress, or bodily injury.

In addition to these core autism characteristics, prevalent co-occurring conditions and associated features can occur across:

-
- Physical health,
 - Mental health,
 - Self-regulation, and
 - Learning and cognitive functions.
-

Some physical conditions, specifically sleep problems, gastrointestinal problems, epilepsy, and immune dysregulation occur more commonly in Autistic children and adolescents than in the general population (Coury et al., 2020). For example, in Ontario, compared to non-autistic children and young adults (aged one to 24 years), Autistic individuals had a higher prevalence of asthma, were more likely to visit a specialist, undergo surgery, and to be hospitalized for psychiatric reasons (Brooks et al., 2021). Food selectivity and reduced variety of foods eaten, as well as difficult mealtime behaviour are also common in young Autistic children (Page et al., 2021) and may persist into adulthood (Peeverill et al., 2019). A large percentage of Autistic children also have attention deficit hyperactivity disorder or anxiety diagnoses (Hyman et al., 2020). Depression also occurs in many older Autistic youth as they experience difficulties in social relationships and/or victimization through bullying (Rai, 2018). Autism characteristics and diagnoses are also over-represented among individuals with anorexia nervosa (Boltri & Sapuppo, 2021, Tchanturia et al., 2013, 2020; Westwood & Tchanturia, 2017).

Autism frequently co-occurs with intellectual disabilities and specific learning differences, which may be associated with a need for **accommodations** (Baio et al., 2018; Ibrahim, 2020). To differing degrees, Autistic individuals may also experience difficulties with **executive functioning**, which involves cognitive flexibility, shifting, inhibition, attention, as well as self-awareness and self-regulation (Benallie et al., 2021). Examples of common difficulties with executive functioning experienced by Autistic individuals include attending to relevant stimuli as well as shifting attention (Keluskar et al., 2021).

Research has shown that Autistic individuals can have difficulties with regulating their emotions (Cai et al., 2018). Emotional (or self-) regulation represents an individual's ability to manage and change their emotional responses by engaging in behavioural strategies and cognitive

processes to regulate their affect in order to reach their goals (Reyes et al., 2019). The core features of autism render Autistic individuals at higher risk for emotional regulation difficulties (Keluskar et al., 2021) and these difficulties can lead to poorer overall adjustment and mental health (Reyes et al., 2019). For example, emotional or self-regulation difficulties in Autistic individuals have been linked to differences in sleep and feeding, understanding and expressing emotions, shifting attention, and other executive functions. Challenges with self-regulation may be triggered when trying to manage transitions or change (Grandisson et al., 2020).

Both core autism characteristics and co-occurring conditions can influence participation in and across life activities, such as learning and academics, play and recreation, self-care and daily routines, interpersonal interactions and relationships, mobility, domestic life, as well as community, social, and civic life (Mahdi et al., 2018; de Schipper et al., 2015; de Schipper et al., 2016), particularly when environments are not sensitive to and accommodating of neurodiverse needs (Coussens et al., 2019).

4.3.2 Lifespan and Chapter Approach

The next three sections of this chapter present the current best and promising practices for promoting health and wellbeing, as well as addressing the challenges (summarized above) experienced at each life stage (ages 0 - 5, 6 - 18, adulthood). While the intent of this report is not to provide clinical guidelines, nor an exhaustive report of therapeutic supports or services, a brief introduction to the research evidence is outlined as a foundation for key findings.

In many instances, supports and services (e.g., for mental health) are relevant to multiple life stages and tailored to the individual's developmental stage or ability. Decisions on what supports, services, or models to describe at each life stage were guided by the literature in terms of the common age group to which particular supports typically apply. For example, Early Intensive Behavioural Interventions involve preschool children, whereas peer-mediated social skills programs more often involve older children and adolescents. However, due to waitlists, later age of diagnosis, and/or ongoing needs, some school-aged children may require programs or services that are typically offered at an earlier age. There are other supports and service models that apply more universally. For example, a stepped model of needs-based care is described in the first life stage, but ultimately should continue across the lifespan. For brevity, we will introduce each type of support or service only once, but will emphasize the potential breadth of application.

4.3.3 Family Wellbeing and Family-Centric Pathways

Autistic people bring unique strengths and resilience to their families, but without appropriate supports, family members may also experience challenges (Cridland et al., 2014). Family wellbeing is a perspective that considers the resources, needs, and physical and emotional health of individual family members, as well as the collective family unit (Tint & Weiss, 2016). It

also attends to the quality of the relationships within the family and how these may be affected by social, political, and economic systems. Accordingly, despite the United Nations (2012) positioning of families as the basis of society, the wellbeing of families of Autistic individuals is rarely centred as a priority in research, practice, or policy (Tint & Weiss, 2016).

Summary Points

The responsibilities of supporting an Autistic family member in a system with inadequate supports may lead to negative impacts on parental and sibling physical and mental health.

Autistic parents who have Autistic children are often unfairly judged and stigmatized and may have their ability to parent questioned. These negative experiences can influence the supports and services they receive and impact trusting relationships with service providers.

Costs from the family or individual perspective involve monetary payments for out-of-pocket and private services and support, and also invested time, transportation requirements, and emotional costs.

Accessing private, out-of-pocket services and supports can decrease the short-term costs to the provincial/territorial public payor, however the long-term costs to parents and other sectors can greatly influence overall societal costs.

Families and other supporters play an important and rewarding role in the lives of many Autistic people — as care providers, advocates, and managers of their social and physical environments (Lai et al., 2020). At the same time, parents of Autistic children can experience greater levels of stress, distress, depression, anxiety, marital issues, and financial hardship than their peers with non-autistic children (Murphy, 2021; Scherer et al., 2019; Hayes & Watson, 2013; Volkmar et al., 2014; Mitter et al., 2019). Many parents also worry about the future of their Autistic adult children (Dudley & Nakane, 2017).

“People not listening and the system not thinking of solutions for adult individuals! They need a safe and supportive environment to be treated with dignity. Parents will age and family isn’t always an option to care for these vulnerable members of our society.”

- Family member of an Autistic person

Most caregiving in Canadian society occurs through informal means — by family members (Statistics Canada, 2020a). Parents of Autistic people often spend more time and a longer duration in caregiving roles compared to others (Sharpe & Baker, 2007). They are also at elevated risk for poorer physical and mental health compared to other parents (Da Paz & Wallander, 2017; Mugno et al., 2007; Isa et al., 2013; Samuel et al., 2012; Zablotzky et al., 2013). Without support, parents' unmet mental health needs risk their psychological, physical, and social wellbeing, jeopardize adaptive functioning of the entire family, and may cause marital strife (Catalano et al., 2019).

Indeed, the health and wellbeing of Autistic people and their parents appear to be closely linked, suggesting that a family-centred approach to service delivery may address and support the needs of the whole family, not just the Autistic person, to ensure the family's wellbeing and quality of life (Ooi et al., 2016; Tint & Weiss, 2016). Such an approach across the lifespan can offer families more opportunities to experience the positive gifts and strengths that having an Autistic family member can provide (Kayfitz et al., 2010; Potter, 2016). For example, a review of couples' relationships amongst parents of Autistic children and youth highlights that general experiences of support from both within and outside the family, and access to autism services and resources, can promote resilience and buffer against marital breakdown (Saini et al., 2015).

Mental health and counselling supports specific to the needs of parents and family members, as well as respite programs, may also ameliorate their ongoing stress (Derguy et al., 2015; Eggleton & Keon, 2007; Shepherd & Waddell, 2015). Family therapy may be one approach to addressing challenges in communication, relationships, mental health, and coping that may occur when parenting an Autistic person (Spain et al., 2017). Family physicians and other primary healthcare providers are uniquely positioned to monitor the physical and mental healthcare needs of the family members of Autistic people and provide or refer them for appropriate care and support (National Institute for Health and Care Excellence, 2017; Hyman et al., 2020).

Peer support has also been shown to reduce parents' stress and negative mood (Clifford & Minnes, 2013). Professional-led workshops on stress management (e.g., mindfulness, biofeedback), problem-solving, and coping skills are also beneficial. Receiving factual and accurate information about autism decreases feelings of stress and anxiety, especially when parents are able to better understand the reasons for their children's behaviour (Catalano et al., 2019) and can better advocate for their children's needs (Siller et al., 2014). These support programs may be more effective when offered in settings where Autistic children receive their own supports and services, for example in childcare and school settings (Catalano et al., 2019).

Autistic parents who have Autistic children face additional and unique challenges, circumstances, and opportunities and may benefit from additional supports that differ from

those suited to their non-autistic peers (e.g., They may benefit from peer support from other Autistic parents or Autistic adults as mentors) (Rogers et al., 2017; Pohl et al., 2020; McDonnell & DeLucia, 2021). For example, Autistic parents of Autistic children are often unfairly judged and stigmatized by society and clinicians, often have their ability to parent questioned, or do not receive the support they need to parent and advocate for their Autistic children (Murphy, 2021).

When non-autistic siblings are supported to understand and accept their Autistic sibling, the sibling experience can be positive and lead to increased family resiliency and deep sibling bonds (Tsai et al., 2018). However, siblings have also reported additional responsibilities at an early age, less attention from their parents, and feeling responsible for supporting and protecting their Autistic sibling, which may negatively affect their mental health and personal development (Watson, 2021; Leedham, Thompson, & Freeth, 2020). As such, the wellbeing and support needs of siblings of Autistic individuals also require attention (Hyman et al., 2020). For example, support groups that teach siblings about autism, create space to share experiences with others, and learn coping and relaxation techniques can be beneficial (Watson, 2021). In the United Kingdom, organizations such as [Connecting Young Carers](#) (n.d.) and [Carers Trust](#) (2022) offer services, resources, and advice to children and young people who support family members due to a chronic illness, disability, or mental health or substance use concerns. These supports include peer and community support groups, provide information about funding options and about the rights of young people in caregiving roles, as well as offer one-on-one advice and guidance, emotional support, and training.

Costs to Families

As described by the Lancet Commission, costs not only include those to the health payor, but also to families. Costs from the family or individual perspective involve monetary payments, and also invested time, transportation requirements, and emotional costs (Tsiplova et al., 2019).

The lack of differentiation within available data regarding use of public versus private services further complicates the Canadian autism care landscape and creates cost disparities for families. Parents often cover any service shortfalls, on top of having to manage funding and service navigation in multiple jurisdictions (Shepherd & Waddell, 2015). Due to the duration of wait times or the availability/quality of services, many families find it necessary to seek out private services while waiting for publicly-funded services or to supplement offered services. For example, even when wait times for an early behavioural intervention program were short, as in New Brunswick, a significant proportion of parents perceived a need for additional health services (e.g., speech-language and occupational therapies) (Tsiplova et al., 2019).

Although accessing private, out-of-pocket services and supports can decrease the short-term costs to the provincial/territorial public payor, the long-term costs to parents and other sectors can greatly influence overall societal costs (Yuen et al., 2018). The type of service model

may also necessitate more parental costs in terms of transportation, loss of productivity, and parent-mediated services and purchases (Penner et al., 2015; Smith et al., 2021; Tsiplova et al., 2019; Young et al., 2019). Other out-of-pocket costs of autism-related materials and products include items such as books, learning aids (e.g., electronic tablets), educational toys, exercise equipment, and safety equipment (Tsiplova et al., 2019).

Furthermore, families that are required to move between provinces/territories, such as military families who experience mandatory relocation, are thus faced with disruptions and discontinuities to service, including delays in diagnosis or support services, and losses or gains in available services determined by the direction of posting (Cramm et al., 2019). The financial impacts of supporting an Autistic family member, often across the lifespan, are covered in more detail in Chapter 5.

Key Findings - A Lifespan, Family-Centred Approach

Family-centred service models ensure that in addition to supports and services for the Autistic individual, parents and other family members also receive support services, such as mental health, navigation, and respite.

Autistic parents who have Autistic children face unique challenges and circumstances that may benefit from additional supports, for example, to overcome stigma they may incur as an Autistic person.

4.4 Preschool and Early Childhood (0 - 5) Supports and Services

4.4.1 Background

Key goals of supports and services for Autistic pre schoolers are to enhance effective communication and social interaction between them and their family members, peers, and others (Lai et al., 2020; Bölte et al., 2019). Supports and services may also focus on building developmentally-appropriate *life skills* (e.g., eating, toileting) when these are delayed, working on sensory and motor development, and/or managing behaviours that challenge (Bölte et al., 2019). As such, supports and services may involve family supports, speech-language therapy, occupational therapy, psychological or behavioural therapy, as well as early childhood education and social work services, among others (Hyman et al., 2020; Ip et al., 2019; National Institute for Health and Care Excellence, 2017).

Summary Points

Young Autistic children require timely and appropriate supports and services as this is a period of significant development. And yet, early childhood autism supports are limited and vary across Canada.

Many different regulated service providers can be involved in the provision and oversight of quality early intervention supports and services, such as speech-language pathologists, occupational therapists, and psychologists, among others.

Common Supports and Services

The approaches taken by these professionals were traditionally clustered under two broad categories: behavioural and developmental. Both approaches aim to address the core and related challenges associated with autism; however, the underlying theory and practical applications are different.

Acronyms

In this chapter we have used the following frequently referred to acronyms because, for some, the acronym may be more familiar than the full term:

ABA - Applied Behaviour Analysis

NDBI - Naturalistic Developmental Behavioural Interventions

EIBI - Early Intensive Behavioural Intervention

IEP - Individual Education Plan

Sandbank and colleagues (2020) produced a seminal review and meta-analysis of early interventions. As per this review, behavioural approaches are derived from operant learning theory and characterized by the discrete presentation of information (i.e., a stimulus), the prompted exhibition of a target skill, and positive reinforcement such as edible treats, access to toys, or praise for target responses. Target skills are chosen based on functional areas of child need. Historically, skills tended to be initially targeted in highly structured interactions within isolated clinical contexts, but as the child demonstrated progress, approaches were integrated

into more natural settings, such as mainstream classrooms. The field that entails the application of operant learning theory to real-world behaviour change is Applied Behaviour Analysis (ABA).

Early Intensive Behavioural Intervention (EIBI) incorporates ABA-based teaching techniques into service programs. These programs were initially based on the model reported by Lovaas (1987), but currently include a broader range of ABA-based approaches. The Discrete Trial Training (DTT) model used by Lovaas (1987), has largely been supplanted by more recently developed ABA-based models that adopt a greater focus on functional skill development and incorporating learning opportunities into everyday activities, which are reflected in the current Canadian landscape of provincially/territorially-funded services.

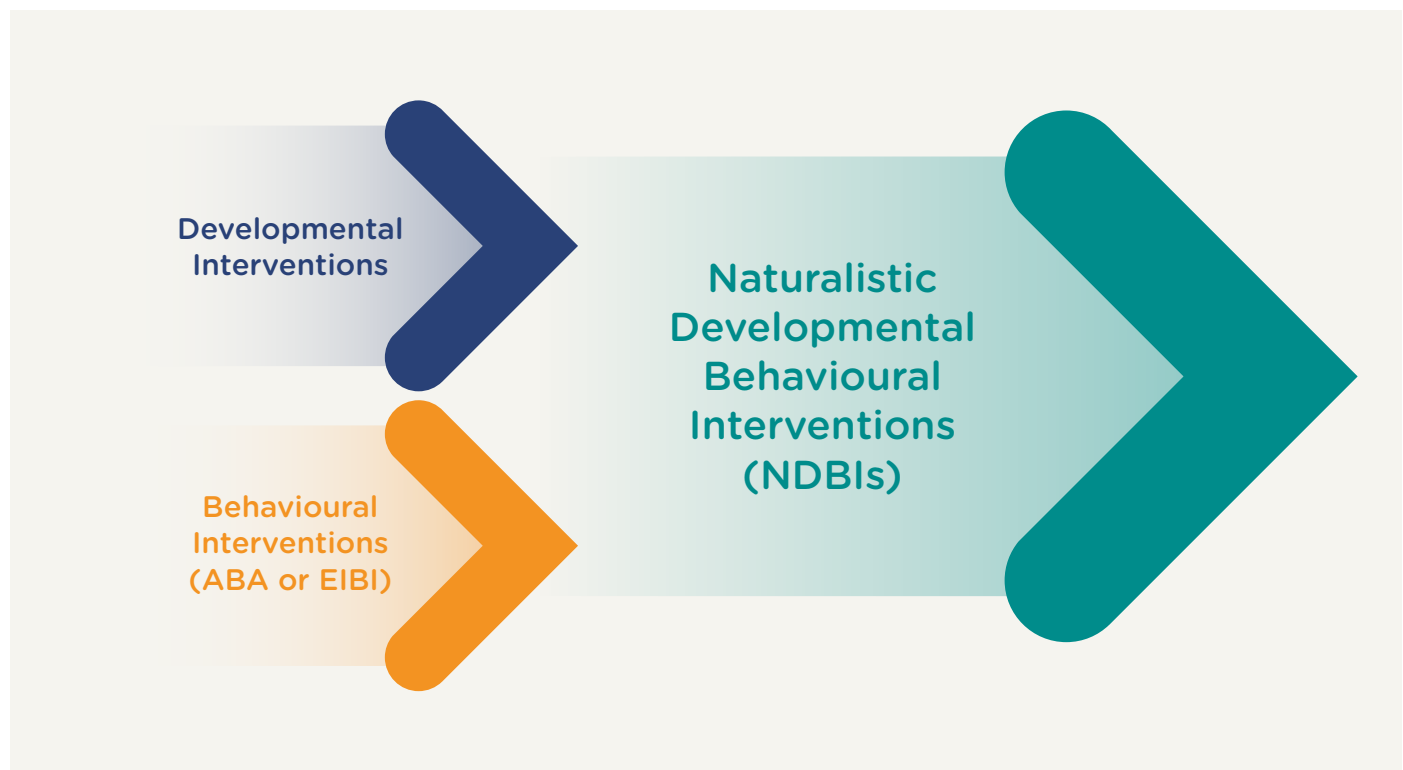
Therapies based on ABA are a primary approach used in many clinical practices. Typically, behavioural therapists or technicians overseen by regulated health professionals, such as psychologists or occupational therapists, implement these approaches. Use of behavioural principles is embedded in the clinical practices of many psychologists. If within their scope of practice, certain methods (e.g., PECS, positive behavioural supports) may be used by other clinicians such as speech-language pathologists, occupational therapists, or early interventionists (Bejnö et al., 2021; Tsiplova et al., 2019).

Developmental approaches were derived from developmental theories of learning and child development and aim to promote children's active exploration of their physical and social surroundings through human interactions as primary means of social and language development (Sandbank et al., 2020). Developmental approaches thus focus on improving parent-child or child-child interactions as a way to address possible deficits in social communication and to promote developmentally-scaffolded skills. These approaches are enacted in everyday routines such as play, with the goals based on typical sequences of child development. Developmental approaches are child-led with the goal of facilitating the development of foundational skills. Examples of developmental approaches include DIR/ Floortime (Greenspan & Wieder, 2007), Responsive Teaching, and Hanen models (Carter et al., 2011). Typically, these approaches are offered and/or overseen by clinicians such as speech-language pathologists, occupational therapists, or psychologists.

Over time, with emerging knowledge of social and cognitive development, leaders in the field have combined behavioural and developmental approaches in practice, with the aim of offering an Autistic child the potential benefits of multiple evidence-informed options. Accordingly, several early intervention approaches for autism are clustered under a third approach with theoretical underpinnings in both behavioural and developmental theories of learning and development (Schreibman et al., 2015).

These Naturalistic Developmental Behavioural Interventions (NDBIs) involve the use of behavioural principles of learning to teach skills chosen from a developmental sequence in naturalistic environments and using natural rewards (Schreibman et al., 2015). Such programs focus on a child’s everyday activities, social interactions, and play skills, which can be readily integrated into family routines (Lai et al., 2020), with the child and adult taking turns to lead the process (Schreibman et al., 2015). Examples of NDBIs include the Early Start Denver Model (Rogers & Dawson, 2010), Enhanced Milieu Teaching (Kaiser, 1993), Pivotal Response Treatment (Koegel et al., 1999), Social ABCs (Brian et al., 2017), and Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER; Kasari et al., 2006). The three common classes of early intervention models are shown in Figure 6.

Figure 6. Common classes of models of early intervention for Autistic children.



Historically, autism services for young children were more singularly aligned with ABA approaches. Early recommendations emphasized delivery of a comprehensive and intensive program of behavioural therapy throughout the child’s early years to enhance functioning and reduce what were considered symptoms or maladaptive behaviour. Considerable research has been conducted on the effects of such EIBI programs, with behavioural approaches showing evidence of effectiveness (Sandbank et al., 2020). However, the methodological rigour of this literature base is weak. For example, only a fraction of studies on EIBI were randomized controlled trials, many outcomes contributing to summary effect sizes were taken from family

member/supporter reports (Sandbank et al., 2020), and generalized long-term maintenance of skills were limited (Reichow et al., 2018). In particular, across studies, evidence is limited to support the notion that greater intervention intensity (e.g., massed trial training, hours per week, long durations) is associated with greater intervention gains (Sandbank et al., 2021; Schuck et al., 2021).

Emerging reports based on the perspectives of some Autistic adults highlight potential negative effects of early EIBI practices, which have been described as traumatizing and unethical (Dawson, 2004; Kupferstein, 2019; McGill & Robinson, 2020; Cumming et al., 2020). These findings should be historically contextualized within the methodological limitations of earlier studies and application of highly-structured behavioural approaches that were commonly utilized at the time. Historically, almost no data were published on possible adverse effects of these approaches and longer-term outcomes were notably missing, with most studies only measuring outcomes up to two years after recruitment (Rodgers et al., 2021). As such, potential adverse outcomes of these approaches could have been missed. Furthermore, while labelled as a particular ABA approach, a lack of fidelity to any clinical approach can also lead to potential and unexpected adverse effects.

Newer forms of interventions implemented with fidelity have stronger evidence of efficacy, with short- and long-term outcomes monitored more rigorously than in the past (Lai et al., 2020; Sandbank et al., 2020; Sandbank et al., 2021). Yet, as we heard during this assessment, due to past negative experiences, some Autistic people and advocacy organizations have been reluctant to support any behavioural approach.

In recent decades, early interventions have increasingly focused on teaching young Autistic children in their natural (i.e., ecologically-valid) environments (e.g., homes, preschools, day care centres) using positive behavioural and developmental approaches (Sandbank et al., 2020). As described earlier, these NDBIs use a combination of developmental and behavioural methods (e.g., prompting, reinforcement), and are typically less intensive, with less structured time with therapists, and involve parents more than traditional EIBI (Odom et al., 2021).

Access to Supports and Services

Although diagnostic delays are a barrier to accessing autism services in Canada (Yuen et al., 2018), wait times for necessary services and supports can be even longer than for diagnosis. For example, wait times in Ontario prevent most toddlers and preschool children from accessing early interventions prior to school entry (Penner et al., 2015). Furthermore, across the country, early intervention and school-based services have variable structure and delivery models (Smith et al., 2019; Volden et al., 2015). For example, Ontario, Québec, and New Brunswick require additional assessments to determine the intensity and duration of early interventions (Penner et al., 2019). In other provinces, such as Alberta, a Multidisciplinary

Team (panel) reviews assessment documentation to determine the funding allocation based on level of need (Government of Alberta, 2021). In one study of Autistic children in Nova Scotia, Québec, Ontario, Alberta, and British Columbia, the majority were receiving some combination of early behavioural and developmental supports, such as speech-language services, although the intensity and duration were highly variable (Volden et al., 2015). Indeed, most were receiving at least one specialized service within a few months of diagnosis, although it was unknown to what extent services were publicly- versus privately-funded by families.

The provinces and territories are also split in how they fund early intervention services (Shepherd & Waddell, 2015). As described in a recent policy analysis (Penner et al., 2019), six provinces/territories (Saskatchewan, Manitoba, Québec, Newfoundland and Labrador, the Northwest Territories, and Nunavut) provide direct services. In contrast, four jurisdictions (British Columbia, New Brunswick, PEI, and the Yukon) historically provided direct funding for families to choose a service provider, although it should be noted that BC has recently chosen to move back towards a direct service model (Ministry of Children and Family Development, 2021a). Ontario had also moved towards providing families with an option between direct services or funding to choose their own service provider. However, their needs-based autism program also remains in flux (Smith et al., 2021), with more than 50,000 children currently registered and waiting to access its services (Ministry of Children, Community and Social Services, 2021b). Eligibility for early childhood supports and services also differs, with seven jurisdictions (Alberta, Saskatchewan, Québec, Nova Scotia, Prince Edward Island, the Yukon, and the Northwest Territories) offering specialized services to children with provisional autism diagnoses (Penner et al., 2019). While funding and service delivery models continue to evolve across Canada, it can be challenging to monitor and evaluate these changes due to limited access to this information within formal government communications and the peer-reviewed literature.

4.4.2 Best and Promising Practices

The following section provides strategies for strengthening supports and services during the early years of Autistic children and their families in the areas of:

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- Timely and early access,
 - Stepped model of care,
 - Use of promising practices, and
 - Family-centred and supportive solutions.
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Timely and Early Access

There is evidence that early childhood supports and services have positive effects on social communication, speech and language, cognition (i.e., reasoning, problem solving), and adaptive behaviour in young Autistic children (Hampton & Kaiser, 2016; Landa, 2018; Wetherby et al., 2018; Lord et al., 2021; Kodak & Bergmann, 2020; Sandbank et al., 2020). Referring young children to supports and services at the earliest opportunity, when developmental delays or differences are detected or autism or other conditions are suspected — even before a formal diagnosis — can support positive developmental outcomes. Early childhood supports and services may also prevent the development of secondary problems, such as behaviours that challenge (Elsabbagh, 2020; Lord et al., 2018). Regardless of when diagnosis occurs, offering follow-up supports and services, including systems navigation and psychoeducation for parents, can be helpful in maximizing potential and minimizing barriers to full participation in life (Lai et al., 2020).

Stepped Model of Care

As recently proposed in The Lancet Commission (Lord et al., 2021), a stepped model of care utilizes multiple modalities and pathways recognizing the heterogeneity of the population, as well as the preferences of Autistic individuals and their families (Lord et al., 2021). A stepped approach to planning should be strengths- and needs-based, as well as child- and family-centred (Hyman et al., 2020; Ip et al., 2019). Child-related factors, such as age, the degree to which autism features interfere with daily living, and whether language and cognitive skills are impaired can influence the extent and form of supports and services needed. Moreover, family-related factors include service preferences, costs, and capacity to collaborate with service providers (McGrew et al., 2016).

No one service pathway will be appropriate for all Autistic children, although there is emerging evidence to support certain early intervention approaches (see Use of Promising Practices) and for concurrently working on multiple goals across life domains (e.g., communication, social, safety, and life skills) (Lord et al., 2021). A stepped approach recognizes that while multiple autism service pathways exist, some services and supports may be more or less appropriate for particular Autistic individuals (e.g., depending on presentation, age, co-occurring conditions, family preferences), and that different intensities and durations may be required to achieve desired outcomes.

The purpose of a stepped model is to build in options for rapidly and flexibly addressing individual needs, while ensuring service and cost efficiencies for both public and family payors. Access to needs-based, as opposed to diagnosis-based services, is more likely to benefit Autistic individuals (Lai & Weiss, 2017; Doherty et al., 2020) and is generally preferred by Autistic individuals, families, and supporters. Supports and services should be provided with

consideration of individually assessed patterns of cognitive abilities, rather than solely on the basis of an autism diagnosis (Maddox et al., 2021).

The stepped model is not linear, and children receive services and supports from multiple steps simultaneously if that aligns with their needs. Highly accessible and/or lower cost pathways typically are based in the home (if easier for the family), or occur at school, in day cares, or via telehealth (Lord et al., 2021). In turn, medium accessibility and costs may involve some travel in the local community, some effort and time from family members and other supporters, and may occur in groups. Low accessibility and/or higher cost services and supports involve individualized services with substantial travel, a high investment of family time and effort, involve intensive hours, and are often restricted to clinic or hospital settings.

A stepped approach requires ongoing assessment and use of evidence-based outcome measures to ensure progress and to support healthcare professionals and families to make informed decisions about supports and services that are based on the assessed needs of the child. Supports and services should then be tailored to each child's needs and family situation, adjusted based on the child's progress and focused on building upon the child's strengths. However, core components of specific therapeutic programs (e.g., how service providers are trained and maintain implementation fidelity; how and for how long the program is administered) must be consistent with the original program approach (Trembath et al., 2019; Sandbank et al., 2020).

Early Intervention Supports

Naturalistic developmental behavioural interventions (NDBI) have emerged as the approach most supported by gold-standard evidence (i.e., randomized control trials) for the development of social communication, language, and play skills in Autistic children (Sandbank et al., 2020). As such, a shift in service delivery approaches is occurring. Although the names of many publicly-funded service models continue to adopt an umbrella title of Early Intensive Behavioural Interventions (EIBI) in some jurisdictions, the range of approaches has expanded and also shifted towards NDBIs. For example, since 2005, the EIBI program in Nova Scotia has been based on Pivotal Response Treatment (Koegel et al., 1998) which embeds many NDBI principles. Other ABA-based services offered by the Nova Scotia program include the Picture Exchange Communication System (PECS) and Positive Behaviour Support (PBS), depending on the specific needs of the child and family. In 2021, PEI began offering an NDBI program, the Social ABCs, for toddlers with suspected autism (Brian et al., 2017). Also, Québec's institut national d'excellence en santé et en services sociaux (INESSS) released a report that promoted several rehabilitation approaches, such as NDBIs (Bujold et al., 2021).

Other NDBI models, such as the Early Start Denver model and JASPER are also being positioned as evidence-based approaches in provinces with direct funding, such as British Columbia and

Ontario. It should be noted that with this shift, a greater number of trained regulated and unregulated service providers may be involved in the provision of NDBI, including, but not limited to speech-language pathologists, occupational therapists, behaviour therapists, and psychologists, among others. These providers may work together in a multi- or interdisciplinary format, across multiple settings, and in a range of publicly- or privately-funded models.

Necessary and helpful elements across naturalistic developmental behavioural interventions include (Frost et al., 2020; Schreibman et al., 2015):

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- Face-to-face and on the child's level,
 - Following the child's lead (e.g., child-initiated teaching episodes, individualized goals),
 - Positive affect and animation,
 - Modelling appropriate language,
 - Responding to attempts to communicate and using communicative motivators (e.g., natural reinforcement and enhancing motivation of the child),
 - Frequent direct teaching episodes, and
 - Quality of direct teaching episodes (e.g., use of prompting, fading, and modelling; adult imitation of the child's language, play, or body movements).
-

As per Schuck and colleagues (2021), alignment between NDBIs and neurodiversity can be found due to the focus on the child and the family within the intervention, the use of a strength-based approach, and its implementation within the natural environment. However, randomized controlled trials comparing approaches such as EIBIs to NDBIs are lacking and further empirical analysis is needed to understand the most effective components within any multi component programs (Schreibman et al., 2015). It is also still unknown “how much” and what type of approach is needed to be effective for an individual child.

Finally, task sharing, in which less specialized providers are delegated some of the tasks and responsibilities that are usually performed by more specialized professionals, can redistribute care, and scale up services in a stepped approach (Centers for Disease Control and Prevention, 2020). This requires partnership and systems coordination between different sectors. When task-sharing is implemented, strategies to ensure better outcomes and transparent processes include the use of (Ip et al., 2019; Odom et al., 2021):

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- Well-trained frontline service providers working in supportive environments and supervised by regulated health professionals,
 - Evidence-informed programs that support ongoing childhood development, including social communication, language, as well as emotional and behavioural regulation, and
 - An appropriate child-to-staff ratio based on child needs and safety.
-

Promoting Parent-Mediated Approaches

Most naturalistic developmental behavioural interventions and developmental approaches incorporate parent-mediated elements, although the degree to which the parent versus therapist works directly with the child varies across models. Parent-mediated approaches are training or coaching programs that help parents develop specific skills to enhance their children's communication and play skills in natural settings. Evidence suggests these programs are effective in increasing social skills and communication (Oono et al., 2013; Ratliff-Black & Therrien, 2020). Such parent-mediated approaches (Pickles et al., 2016) have been implemented successfully in diverse (including low-resource) settings by training and supporting non-specialist providers to deliver the programs (Divan et al., 2015). This delivery strategy may increase the scalability and reach of such evidence-based approaches. Evidence has also shown positive outcomes for young Autistic children with fewer hours of direct therapist involvement, when their parents/families are actively engaged in the therapeutic process (Zwaigenbaum et al., 2015; Sandbank et al., 2020, 2021). Behaviourally-based parent training (individually and in groups) has also been shown to decrease behaviours that challenge and hyperactivity of Autistic children, as well as decrease parent stress levels (Tarver et al., 2019; Kaat & Lacavalier, 2013; Ratliff-Black & Therrien, 2020).

Offering Autism Supports in Early Learning and Childcare Settings

Early learning and childcare settings are increasingly becoming a major life setting for children in Canada and internationally. For example, as the number of working mothers continues to climb, the need for public early learning and childcare services has steadily increased (Zhang et al., 2019). Indeed, early childhood educators and day care workers could be considered among the most important care providers for many young children, with whom they have frequent and sustained contact. Furthermore, such care providers often have training and knowledge of early child development as well as considerable hands-on experience in working with children of comparable ages and diverse developmental profiles (Zhang et al., 2019).

The European Union has promoted publicly-funded day care for two decades and in Sweden, public full-time day care has been widely available since the 1980s (Grönlund & Öun, 2020). The recently proposed Early Learning and Child Care Plan (Department of Finance Canada, 2021; Prime Minister of Canada, 2021c) exemplifies an approach by the Canadian government to promote access to high quality and affordable early learning and childcare opportunities for Canadian families.

Accordingly, service providers in early learning and childcare settings may be well-positioned to implement evidence-based strategies and early intervention programs to the Autistic children they support. There is mounting evidence to support several NDBIs for young children (ages 2-5) within inclusive early learning and childcare settings (Maye et al., 2020; Chang et al., 2016).

For example, Chang and colleagues (2016) found that early learning and childcare providers could deliver Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) with high fidelity in a preschool setting. Typically within these settings, ongoing access to a clinical specialist or consultant skilled in NDBI approaches (such as a speech-language pathologist, occupational therapist, or behavioural consultant) promoted ongoing learning, supported adherence to program approaches, and offered frontline providers individual guidance for specific child needs (Samadi et al., 2020; Chang et al., 2016; Maye et al., 2020; Jocelyn et al., 1998).

Community implementation within early learning and childcare settings can improve local access to autism services (Cochrane et al., 2020). Shifting supports to community settings, however, is most effective when accreditation and early education standards align to developmental best practices and promote inclusion of children with diverse abilities within these settings (Maye et al., 2020).

In addition to individually-based supports and services, such settings could also have a key role in promoting early **autism acceptance** and inclusion. In 2019, Sweden released a national early learning and childcare curriculum, which explicitly outlined a responsibility of such settings to accept and support disabled children, including Autistic children (Bejnö et al., 2021). To meet the goal of inclusion of Autistic children, many settings in Sweden thus needed to adjust the structure and set-up of the environment, curriculum and instruction, teams, and service providers' usage of evidence-based practices. In this study, the Autism Program Environment Rating Scale, developed by the US National Professional Development Centre on Autism Spectrum Disorder, was used to measure, and plan for these environmental changes (Bejnö et al., 2021). The findings suggested that the use of this scale, in addition to an EIBI program, improved the quality of the learning environment compared to preschools using EIBI only. This included the generalized use of NDBI strategies by service providers outside of EIBI programming across all the children with which they worked.

Key Findings - Preschool and Early Childhood

Needs-based supports and services have positive effects on social communication, speech and language, cognition, and adaptive skills in young Autistic children.

Timely access to appropriate, strengths-based supports and services can be better provided through a stepped approach, which is not constrained by a formal diagnosis or a single intervention approach, and instead is driven by assessments of the needs of the Autistic child in the context of their family and culture.

A shift in early intervention evidence currently supports the implementation of a range of approaches which:

- Are of needs-based intensity and duration,
- Are provided with fidelity by skilled service providers in and across multiple community settings,
- Promote parent or family member participation and integration into daily life, and
- Are accompanied by continuous and rigorous evaluation of child- and family-oriented outcomes.

Naturalistic developmental behavioural interventions (NDBIs) can exemplify these principles and are supported by a comparatively greater number of and higher quality studies.

With support and training, service providers at early learning and childcare settings are well-positioned to implement screening, inclusive strategies, and current approaches to early intervention to the increasing number of Autistic children they support.

4.5 Supports and Services for School-Aged Children and Adolescents

4.5.1 Background

As described in the previous section on early childhood, ongoing assessment and monitoring of an Autistic child's development and learning as well as existing or new co-occurring conditions, continues to be required throughout the school years. Many children do not receive a diagnosis until they are in school (Public Health Agency of Canada, 2022). The introduction of the school setting and other community-based activities and roles may also expand and/or change the type of goals, approaches, and supports and services a child requires.

Typically, the goals of supports and services for school-aged children and adolescents (aged 6-18 years) are to increase their independence and maximize their potential through the acquisition of life skills and academic skills, improving organization and self-regulation, as well as strengthening social interaction and collaboration (Lai et al., 2020). In adolescence, particular areas of focus may include promoting mental health as well as navigating more complex peer relationships including meaningful and safe intimate and sexual relationships (LeBlanc et al., 2008).

Summary Points

Autistic children and adolescents rely on the school setting for the provision of the majority of supports and services until graduation. As such, if services are limited or unavailable in these settings, Autistic children and adolescents may not receive necessary supports and services.

How school boards use funds to support Autistic students' needs can vary considerably across the country. Few provinces/territories offer specific guidelines to school boards on how funding should be spent, how to conduct needs assessments, or to outline supportive programs, practices, or curricula for Autistic students.

Mental health conditions, such as anxiety, depression, attentional difficulties, and behaviours that challenge, are common among Autistic students, and yet services can be scarce.

There is a need for specific supports and services for Autistic people during times of school transition because of the greater uncertainty that comes with changes in roles or responsibilities, routines, and support structures.

Access to Supports and Services

Given the variability in provincial/territorial and school board policies and funding, there are substantial differences in the type and intensity of school-based services Autistic children and adolescents receive (McCrimmon et al., 2012; McCrimmon et al., 2019). This variation is not only an issue in Canada, but also in the United States despite federal mandates through the Individuals with Disabilities Education Act (Suhreinrich et al., 2021) and elsewhere.

While services and supports for school-aged Autistic individuals can and do involve multiple settings and sectors, such as primary care, community- and home-based services, as well as recreation and leisure, the school setting is where Autistic children and adolescents are provided with the majority of services (Suhreinrich et al., 2021). As children enter school, access to publicly-funded programs, as well as direct funding allocations typically decrease. Instead, government funds are funnelled to school systems for the provision of educational supports and services. For example, in British Columbia, annual direct funding amounts to families of Autistic children decrease by about 66% percent when the child enters school (Ministry of Children and Family Development, 2017). However, in turn, the school district receives supplementary funding of at least \$18,300²⁷ (unadjusted) per full-time Autistic student (McCrimmon et al., 2012). It should be noted that while this funding is tied to the number of Autistic students in the district, it is not necessarily earmarked to the individual child.

Although Canada does not have pan-Canadian inclusive education legislation, most provinces and territories have committed to inclusive educational approaches within their policies and legislation, which specify that children with exceptional needs, such as Autistic children, are to receive classroom supports to address their needs (McCrimmon et al., 2019). Furthermore, although many Autistic students were historically placed in alternative educational settings, Canadian schools tend to adopt inclusive practices with most Autistic children and youth spending all or some of their time in mainstream classrooms (Montgomery & McCrimmon, 2017). Although referred to by different names, each province/territory has also adopted the use of individual education plans (IEPs) for exceptional students (McCrimmon et al., 2012). Broadly, these plans function to outline specific strengths and needs, curriculum accommodations, and overall goals for the child. Funding mechanisms are also similar with provincial or territorial governments providing funding to the school boards, although the amount per Autistic student varies widely.

Once funding is provided to school boards, how the funds are used to support Autistic students' needs can vary considerably (McCrimmon et al., 2012; McCrimmon et al., 2019). Few provinces/territories offer specific guidelines on how funding should be spent, how to conduct needs assessments, or outline supportive programs, practices, or curricula for Autistic students.

²⁷ Unless otherwise specified, all references to currency (\$) in this report are in Canadian Dollars.

The process to determine the amount and type of services necessary for each students' needs is murky, with only British Columbia specifying formal requirements for needs assessment (McCrimmon et al., 2012). In addition, many autism identification processes seem to be based on dated clinical criteria (e.g., DSM IV). Four provinces (Saskatchewan, Prince Edward Island, Nova Scotia, and Newfoundland) have adopted autism consultants or autism planning teams to support programming for Autistic students.

A recent review summarized the common service delivery models within school settings (Anaby et al., 2019). Common models included:

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- **Pull-out services.** Services that require students to be withdrawn from class received individually or in a group format,
 - **Direct service (individual and group).** Direct specialized services, for example, specialized occupational therapy or speech-language services, or ongoing direct support provided daily by various professionals, including individual therapy and one-on-one tutoring,
 - **Ecological Services.** Similar to the naturalistic and developmental approaches described in the previous section, ecological services are those provided in the child's immediate natural environment, such as in the classroom, gymnasium, and playground.
 - **Supports for service providers.** Supports for service providers including provision of mentoring, coaching, consultation, training, and access to resources, and
 - **Family involvement.** Family involvement is a service approach that involves parents and family members/supporters as active team members working alongside various service providers to take on important roles in their child's health and development.
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In this review, services delivered directly to individuals or within a group were most common. However, provincial/territorial-specific information about service delivery models and support types can be challenging to ascertain, with wide variability of models and supports also described in the international literature (Suhrheinrich et al., 2021). For example, one study identified 14 types of services across five broad categories (communication, behavioural health and life skills, learning supports, technology aids, and other), with about three to five services received per Autistic student (Wei et al., 2014).

Evidence is emerging to support many services and supports that can be offered within the above service delivery models. However, the presence of inequities and disparities in terms of what services are offered, where, and at what age continue to be apparent in Canada. A recent international review (Suhrheinrich et al., 2021) found that older Autistic students were less likely to receive services than younger students and had higher unmet service needs and decreased service quality. Furthermore, wait times for services such as occupational therapy can be substantial (e.g., a year or more) in certain provinces (Grandisson et al., 2020; McCrimmon et

al., 2012). Highly consultative service delivery models are also common, whereby assessment and recommendations are expected quickly although the therapist may know very little about the school personnel, their teaching philosophy, the school culture, or the classroom routines (Grandisson et al., 2020).

When services and supports are delayed, unavailable, or ineffectual, service providers in the educational context may struggle to meet the needs of Autistic children and adolescents, despite legislative mandates. In these instances, Autistic students may experience school exclusion (i.e., disruptions or transitions out of mainstream or special education classrooms) (Williams et al., 2019). Due to ongoing systems issues, some Canadian parents also voluntarily remove their Autistic children, temporarily or permanently, from the public education system to home school them because of concerns regarding their children’s development, academic success, or safety (Lord, 2020). Reported reasons for short-term or permanent school exclusions or voluntary removals often include (Brede et al., 2017; Nuske, McGhee et al., 2019; Guldberg et al., 2021; Lord, 2020):

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- Serious and ongoing self-regulation challenges/behaviours that challenge that jeopardize the physical safety of the child, peers, or teachers and staff,
 - Difficulties dealing with the increasingly complex demands of school life,
 - Sensory responses to noisy, chaotic school environments, and
 - Bullying.
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Although from a standpoint of inclusive school policies, schools have a responsibility to meet the needs of all children, including those with **complex support needs**, inadequate environments and/or a poor match between school demands and the child may lead to such exclusions.

“The school was ill-equipped to handle my child ... They had no supports, which meant I was called to the school to come get my child multiple times per week.”

- Family member of an Autistic person

These exclusions represent one of the most serious disruptions that can be experienced by the family of an Autistic child. Although a universal human experience, disruptions and transitions represent particular challenges for Autistic individuals and their families.

Transitions and Disruptions to Supports and Services

Transitions for Autistic people and their families are more than just specific events in time – they are fluid and ongoing processes along a life journey involving interactions with multiple systems, policies, funding structures, and community contexts (Anderson, Sosnowy et al., 2018; Crider et al., 2015). At times of transition, Autistic individuals and families are vulnerable to socioeconomic exclusion and poorer mental and physical health outcomes (Enner et al., 2020; Levy et al., 2020; Young-Southward et al., 2017). School transitions include time points such as autism identification, transitioning into or out of school settings (e.g., kindergarten, secondary school), moving to or from special education to mainstream classes, from school exclusion to a specialized setting, and transition out of high school (Anderson, Sosnowy et al., 2018; Bennett et al., 2018; Nuske, McGhee et al., 2019; Croydon et al., 2019; Brede et al., 2017).

At each life transition, Autistic people and their families face new opportunities, along with barriers, service interruptions, risks (i.e., mental health, safety), and emotional and financial costs (Ally et al., 2018). Transitions also represent times of uncertainty, distress, and disruption in roles and responsibilities, routines, and support structures for Autistic individuals and families. Feelings of grief, fear, confusion, or frustration may accompany the transition (Enner et al., 2020) sometimes related to losing:

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- Educational and pediatric services and supports (McKenzie et al., 2017),
 - Therapy services and familiar environments (Jacobs et al., 2018), and
 - Trusting clinician or educator relationships (Calleja et al., 2020).
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Transition points can be particularly vulnerable times for Autistic students and their families. Transitions, which can involve changes in location, services, and providers, occur across multiple life domains and systems, for example in education and health systems.

School transitions can lead to anxiety and increased social and academic demands (Croydon et al., 2019; Nuske, McGhee et al., 2019). For example, Autistic youth have described being disoriented and challenged by changes in building locations, physical configurations, and everyday routines, such as the organization of materials, lockers, new and multiple teachers, physical education classes, and transportation (Nuske, McGhee et al., 2019). Parents may also be anxious about school placement decisions and the potential for adversarial parent–teacher relationships. There may also be ‘broken bridges’ in terms of communication and consistency between home and school (Croydon et al., 2019; Nuske, McGhee et al., 2019). Transition to adulthood will be described in more detail below.

Sexuality and Sexual Health

Romantic and sexual relationships often become increasingly important during adolescence and yet the social skills of Autistic adolescents may not keep up with accompanying social

demands and intricate societal nuances (Turner et al., 2017). At the same time, Autistic people are much less likely than their non-autistic peers to receive appropriate sex education, either at school or at home (Turner et al., 2017).

Autistic females are at greater risk of negative sexual experiences, including victimization and abuse, than Autistic men and non-autistic females (Pecora et al., 2019). Without suitable education, Autistic people may be at higher risk for victimization in and perpetration of sexual crimes (King & Murphy, 2014).

As discussed in Chapter 2, based on emerging evidence that requires further study, there is greater diversity in sexual orientation and gender identity amongst Autistic people compared to the general population (Hellemans et al., 2007; Barnett & Maticka-Tyndale, 2015; Rudolph et al., 2018), at times subjecting them to *double stigma* and the concurrent risk of bullying (Hannah & Stagg, 2016; van Schalkwyk et al., 2015).

Bullying

Autistic students have been shown to be involved in bullying incidents two to four times as often as non-autistic students (Chen & Schwartz, 2012; Hoover & Kaufman, 2018).

Autistic students who were integrated in inclusive school settings experienced more severe victimization than those who were not (Park et al., 2020). Autistic youth are most often the victims of bullying, but may also be perpetrators (Park et al., 2020; Hoover & Kaufman, 2018; Croydon et al., 2019; Hellström, 2019). Autistic students who have experienced bullying are at increased risk of (Brede et al., 2017; Croydon et al., 2019; Hoover & Kaufman, 2018):

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- Disengaging from educational settings,
 - Negative impacts on their academic attainment,
 - Developing or experiencing exacerbation of mental health conditions, such as anxiety, depression, and self-harm, and
 - Suicidality.
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“Too many stories where children were bullied, including mine ... He almost got suspended because he left the school yard, trying to go home away from the bullies.”

- Family Member of an Autistic person

With the increasing use of electronic devices (e.g., smartphones) and social media platforms by Autistic school-aged children and adolescents, cyber-bullying is an increasing problem. A meta-analysis reported that among Autistic students, the prevalence of cyber-victimization was 15% (Park et al., 2020) and a systematic review reported a prevalence up to 41%, among students with neurodevelopmental conditions, including autism (Beckman et al., 2020).

Bullying prevention programs can be effective in reducing bullying and victimization among school-aged youth (Bradshaw, 2015), but are generally administered at the level of individual schools or school boards with little attention to differential effects for particular subgroups of students, such as those who are autistic. Such programs are not consistently implemented within school systems in Canada and the degree to which they reduce the prevalence of bullying for Autistic students is largely unknown.

Knowledge and Understanding of Autism in Schools

Many students who have specialized educational needs, such as Autistic students, attend mainstream schools for the entire or part of the school day, where they may be offered specialized classes or modified programs (Towle, 2015). Educational systems, however, may only provide a “one size fits all approach” to Autistic children, regardless of needs or preferences (Sandbank et al., 2021).

Broadly, knowledge and understanding of autism is lacking by educators, school staff, as well as other students and their families (Lindsay et al., 2013). The double empathy problem (Milton, 2012), whereby Autistic and non-autistic peers may have very different perceptions of a social interaction, may also contribute to a social disconnect amongst Autistic students and others around them. Many educators contend that creating inclusive classroom environments for Autistic children can be challenging (Towle, 2015; Odom et al., 2021; Lindsay et al., 2013; Vincent, 2019; Lord, 2020) due to:

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- A lack of autism education for those training to be teachers or educational assistants (e.g., understanding and responding to sensory and socio-emotional needs),
 - Few opportunities for professional development regarding evidence-informed educational supports and teaching methods,
 - Limited access to the necessary tools and resources (e.g., education assistants) to effectively support Autistic students in their classrooms,
 - Inadequate individual needs-based support,
 - Reductions in education funding,
 - Policies framed around the *medical model of disability*²⁸, and
 - Restricted parent participation in the iterative planning and implementation of individual education plans.
-

²⁸ The medical model views Autistic people as having deficits that require curing or treatment as opposed to the social model that views individuals as requiring support to participate in a society that may not have been designed with their needs and differences in mind.

“Most teachers jump to sending a child to sit in the hall or go home early because they are overworked [and] underpaid and under-trained in diversity.”

- Family member of an Autistic person

Physical restraints, seclusion, and time-out rooms continue to be used in many educational settings, disproportionately directed at children and youth with developmental disabilities. In fact, the concerning use of isolation and seclusion with Autistic children in special education settings across multiple provinces/territories in Canada was highlighted in the Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health (Pūras, 2019).

4.5.2 Best and Promising Practices

School-aged children and youth often have needs for supports that span medical, psychosocial, educational, and technology-based services, especially prior to, during, and after times of transition. Selection of services should be based on the evidence supporting their use as well as family and youth preferences. It also requires coordination between different sectors and professionals (Hyman et al., 2020). In the past, programs for Autistic children and adolescents focused mainly on their deficits and shortcomings. Supports and services as well as accommodations are now increasingly selected to build on children/adolescents' strengths and competence, while supporting their areas of need (Lai et al., 2020).

The following section describes:

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- Effective service delivery models,
 - Specialized services and supports, and
 - Promotion of safe and supportive schools.
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Effective Service Delivery

In terms of service delivery, a number of best and promising practices have been suggested within the research evidence. In general, provision of assessment guidelines that take into consideration both academic and non-academic needs could improve consistency of processes across provinces/territories (Grandisson et al., 2020; McCrimmon et al., 2019). Service coordination and collaboration as well as knowledge sharing and training for teachers and other educational staff are also highly recommended (Anaby et al., 2019; McCrimmon et al., 2019). Collaboration can occur at individual and organizational levels amongst teachers, principals, professionals, families, and community providers. Services and programs involving extensive collaboration and coaching with school staff can also help develop the school's ability to promote the participation of Autistic children while fostering staff competence (Grandisson et al., 2020). Promoting family involvement, supports for staff, and ecological services are

also recommended (Anaby et al., 2019). For example, evaluative studies of ecological services, typically in collaboration with occupational or physiotherapists, demonstrated improvements in students' cognitive abilities, behaviour, socio-emotional functioning, and the rates of attendance and school suspensions (Anaby et al., 2019)

In general, support strategies that have shown moderate to large effects offered within these service delivery models include (Watkins et al., 2019; Strain & Bovey, 2011; Gardner et al., 2014; Cihak et al., 2014; Steinbrenner et al., 2020):

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- Supports and services to promote social communication skills,
 - Individualized approaches to developing life skills,
 - Promoting regulation of social-emotional responses,
 - Visual supports and strategies,
 - Technology-based instruction, and
 - Peer-mediated programs.
-

It has been suggested that these supports can be feasibly implemented in inclusive education settings and teachers can be trained to deliver them in collaboration with an interdisciplinary team (Watkins et al., 2019).

In line with a stepped or tiered approach, multi-level services, such as a prevention-to-intervention model, may ensure a needs-based approach while improving classroom environments and support strategies for all students (Anaby et al., 2019). Multi-level services include universal strategies or approaches that can benefit all students, targeted supports with benefits for many students with difficulties, and specialized supports for particular subgroups of students, such as Autistic students (Grandisson et al., 2020). Universal programs, for example aimed at classroom management or self-awareness, can have a wide-reaching impact on entire classrooms or school environments (McCrimmon et al., 2012). Examples of effective universal programs include prevention programs to reduce behaviours that challenge by redesigning physical and social environments as well as promoting prevention-based health education (Anaby et al., 2019). School-wide anti-bullying campaigns are another example of a universal approach which are discussed under Safe and Supportive Schools.

Specialized Supports and Services

Most Autistic children and adolescents will require targeted or specialized supports and services to give them opportunities to meet desired goals and address potential needs. These services are typically time-limited with a predetermined number of sessions (Lai et al., 2020; Hyman et al., 2020). There is evidence for supports and services related to:

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- Academic skills,
-

- Social and communication skills,
 - Self-regulation and behaviours that challenge,
 - Physical health, and
 - Mental health.
-

Addressing Academic Needs

Academic programming that is inclusive and strengths-based considers individually assessed patterns of cognitive and academic abilities, rather than basing curriculum on an autism diagnosis (Keen et al., 2016). Common approaches to addressing academic needs include one-on-one tutoring, direct services from an education assistant (Anaby et al., 2019), as well as adapted grade-level curriculum and appropriate placement, which occurs through autism identification and needs assessment processes (including but not limited to the development of an IEP) (McCrimmon et al., 2019). To ensure recognition of student needs is sufficient and comparable across Canada, consideration could be given to the development of specific guidelines for educational supports in schools based on best practices. This might involve conducting observation in the child's natural environment, such as the classroom, the playground, and the gymnasium, in addition to using standardized tools (Anaby et al., 2019).

Developing Social and Communication Skills

To address the inherent differences in social and communication development experienced by Autistic children, some emerging evidence exists for programs to enhance social cognition (i.e., understanding other people's emotions, feelings, beliefs, and thoughts) and social communication (Fletcher-Watson, 2014). Enhancing pragmatic language can aid in improving social contact and thus, minimize the isolating long-term impacts of communication challenges.

Evidence is promising on how best to enhance pragmatic language in Autistic children under 12 years of age (Parsons, Cordier, Munro et al., 2017), but less is known about effective approaches for Autistic adolescents. According to a systematic review and meta-analysis by Parsons and colleagues (2017), 17 evidence-based programs have been shown to have positive, but varying, effects on pragmatic language skills. These programs included individual and group programs that were carried out across multiple settings, were typically child-directed, and sometimes involved parents. However, group programs in clinic settings were more effective than those in school settings. Additionally, communication improvements have been associated with providing structured opportunities amongst Autistic and non-autistic students across activities and contexts within the school environment (Zagona & Mastergeorge, 2018). In some school-aged children with limited spoken language, studies have also shown broader gains in communication skills when programs involve the use of an ***augmentative and alternative communication*** (AAC) device (Koegel et al., 2019) see (Chapter 3 for further details).

Social skills groups are another approach used to support Autistic children and youth without co-occurring intellectual disability to develop social and communication abilities and have been shown to improve social competence (Reichow et al., 2013), self-reported social behaviour, and sense of wellbeing (Wolstencroft et al., 2018; Gates, 2017). For example, a meta-analysis of single-case experimental design studies of peer-mediated social skill programs demonstrated significant benefits for school-aged Autistic children (Whalon et al., 2015).

Social skills programming was identified as a high priority need across the lifespan in a Canada-wide online survey of family members and other supporters (Lai & Weiss, 2017). However, a recent review by Rodda and Estes (2018) described the broad range of evidence-based strategies that can support Autistic children in developing friendships and other positive social relationships, including and beyond social skills programs. Such approaches may also improve outcomes for Autistic children with co-occurring intellectual disability; however, there is a paucity of literature particular to this subgroup. Two systematic reviews show limited evidence for programs promoting spoken language or nonverbal communication in nonspeaking or minimally speaking Autistic children (Brignell et al., 2018; Koegel et al., 2019).

Finally, a large portion of Autistic individuals show a temporal dissociation between reading decoding and comprehension skills. This means that while they gain these skills, they often learn written language before oral language (Henderson et al., 2014). This developmental sequence may not be disadvantageous, but simply different. As such, the use of technology as a therapeutic tool should be clearly distinguished from the availability of literacy-based assistive devices for non- or minimally-verbal individuals (Ostrolenk et al., 2017).

Self-Regulation and Overcoming Sensory Differences or Behaviours that Challenge

For many Autistic individuals, repetitive or stereotyped behaviour may be a means of coping with stress or communicating the presence of a stressor. Therefore, reducing stress or teaching a more effective means of communication would be the appropriate targets of service rather than reducing the repetitive behaviour itself. Functional analysis²⁹ provides a systematic method for determining factors associated with, or that appear to trigger, a particular behaviour (Walker et al., 2021).

Families often seek help for behaviours that challenge from their pediatrician or primary healthcare provider who may consult with a trained behaviour specialist (e.g., psychologist or behaviour therapist) to uncover the reasons for the behaviour and if appropriate, design an individualized approach to address the behaviour (Ip et al., 2019). If non-pharmacologic approaches, such as specific behavioural approaches, parent training, or environmental or

²⁹ A functional analysis is a behavioural assessment approach which is designed to identify events or settings where behaviours occur, what maintains the behaviour in that setting, and what other external or internal factors may influence the behaviour (Newcomb & Hagopian, 2018).

social modifications are not sufficient, medication(s) may be used concurrently (Hyman et al., 2020; Lai et al., 2020; Lord et al., 2018).

Current evidence supports the use of medications for addressing ADHD in some Autistic children and youth (Rodrigues et al., 2021; Maharaj et al., 2012) and for irritability (Fallah et al., 2019). Autism-specific evidence is lacking, however, regarding use of medications for other conditions such as anxiety, schizophrenia and psychosis, and bipolar disorder. Best practice regarding medications remains the use of guidelines developed for the general population.

There has been much debate as to the nature and function of repetitive behaviours in autism. Some repetitive behaviours may interfere with functioning, and some may be amenable to pharmacological approaches. Moderate effects of atypical antipsychotics on stereotypy have been observed, but the risk-to-benefit ratio does not favour their use in most cases (Zhou et al., 2021). Medications that are useful to youth with obsessive compulsive disorder (OCD) have not been shown to be effective in addressing repetitive behaviours in autism (Williams et al., 2013). The distinction between OCD and repetitive behaviour in autism is important. Co-occurring OCD in an Autistic individual should be treated as per current pediatric guidelines for OCD in children and youth.

Supports and services such as behavioural and cognitive behavioural therapy (CBT), parent training, medication management, and multidisciplinary collaboration have been used to address emotional regulation in autism (Keluskar et al., 2021). There is preliminary evidence that personality style (e.g., shyness versus extraversion) may influence how individual children respond to one CBT model versus another (Cho et al., 2021), further emphasizing the importance of a person-centred model to supporting mental health. There is emerging support for CBT and therapeutic approaches based on mindfulness-based principles with older Autistic individuals and those without co-occurring intellectual disability (Reyes et al., 2019). Research on services and programs for improving emotional regulation for young Autistic children is in its infancy with the findings preliminary in nature (Cibralic et al., 2019).

The best-known approaches for sensory processing differences in Autistic individuals involve a program of occupational therapy that is specifically tailored to the needs of the individual. Sensory-based interventions may include sensory integration therapy, a sensory diet, music therapy, massage, and/or environmental modifications (Hazen et al., 2014; Sandbank et al., 2020). While there is some empirical evidence to support these approaches, more research is needed to evaluate their efficacy (Case-Smith et al., 2015; Hazen et al., 2014; Hume et al., 2021; Sandbank et al., 2020; Watling & Hauer, 2015). Although a few small randomized controlled trials have resulted in positive effects, additional rigorous trials using manualized protocols are needed to evaluate effects on sensory processing, as well as other developmental outcomes

such as play and adaptive functioning (Case-Smith et al., 2015; Hume et al., 2021; Sandbank et al., 2020).

Physical Health Supports

Physical health problems such as disrupted sleep (Elrod & Hood, 2015) and gastrointestinal challenges (McElhanon et al., 2014) are common. Behavioural methods have been shown to be effective for improving childhood insomnia, including in Autistic children (Vriend et al., 2011). Parental psychoeducation about healthy sleep practices is the first line of support, followed by explicit use of strategies such as graduated extinction and bedtime fading (Rigney et al., 2018). The Autism Treatment Network care pathway for insomnia management (Malow et al., 2012) incorporates evidence and best clinical practices for addressing sleep problems in Autistic children. Early evidence of effectiveness is promising for parent-led insomnia programs delivered online to parents of children with neurodevelopmental conditions, including autism (Tan-MacNeill et al., 2021). There is also evidence from a systematic review of the literature supporting the use of melatonin for sleep initiation difficulties in Autistic children and adolescents (Parker et al., 2019).

The adoption of established practice guidelines for management of gastrointestinal problems in all children is also effective for the management of such problems in Autistic children (Hyman et al., 2020; Buie et al., 2010). To date, there is little evidence to support the use of nutritional supplements or dietary therapies (including restrictive diets, such as Casein Free or Gluten Free) for Autistic children (Sathe et al., 2017). There is low-level evidence showing effectiveness of behavioural methods in increasing the volume of food eaten by Autistic children and limited evidence of increased variety in the number of foods consumed (Marshall et al., 2015).

A meta-analysis of randomized control trials evaluating effects of physical activity programs reported a variety of positive effects; however, the quality of the trials was low (Huang et al., 2020). Given that increased rates of overweight and obesity have been reported for Autistic individuals (Li et al., 2020), physical activity is to be encouraged for its health promotion value. Please see the recreation section of Chapter 3.

As with the general population, appropriate and informed sexual behaviour is part of a healthy and satisfying life for Autistic people (Turner et al., 2019). A randomized controlled trial found that a psychosexual training program led to significant increases in psychosexual knowledge and self-awareness of interpersonal boundaries as well as significant decreases in problematic sexual behaviours of Autistic adolescents without co-occurring intellectual disability (Visser et al., 2017). The 18-session training program consisted of manualized psycho education and practice of communication skills regarding topics related to puberty, sexuality, and intimate relationships. Additionally, to ensure that Autistic individuals can experience healthy and

fulfilling love and sex lives, it has been suggested that sexual health knowledge can be improved through (Poulin, 2021):

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- Adapting sexual education content in regular classrooms for Autistic students,
 - Hiring sexologists or clinicians with experience in providing sexual supports into school service centres,
 - Providing teachers with training and support, and
 - Developing partnerships between schools, health, and social services.
-

Mental Health Supports

Autistic children and adolescents, especially those without significant intellectual and/or language impairments, can benefit from many existing supports and services designed for the general population (Wood et al., 2015). Cognitive behavioural therapy (CBT) is a structured, practical, and short-term form of psychotherapy that supports individuals to examine how they make sense of what happens in their day-to-day life and seeks to provide them with the skills and strategies to change thoughts, attitudes, and beliefs that contribute to mental health concerns (Centre for Addiction and Mental Health, 2021).

Evidence supports the use of CBT for anxiety in Autistic children and teens, with and without co-occurring intellectual disability (Hunsche & Kerns, 2019; Kreslins et al., 2015; Ung et al., 2015; Blakeley-Smith et al., 2021). Cognitive behavioural therapy may also be useful for addressing OCD, insomnia, and anger management in Autistic children (Weston et al., 2016). There is also preliminary support for school-based CBT programs for Autistic children experiencing anxiety (e.g., Kester & Lucyshyn, 2019; Perihan et al., 2021).

Preliminary evidence also supports the use of mindfulness-based approaches and biofeedback to enhance general wellbeing, emotional regulation, anxiety, and depression in Autistic children and adolescents (Connor & White, 2018; Cachia et al., 2016; Hartley, Dorstyn & Due, 2019; Wallace et al., 2016). Emerging evidence also suggests that behavioural approaches such as desensitization and reinforcement, prompting, modelling, and anti-anxiety stimuli may be useful for Autistic children with co-occurring intellectual disability (Rosen, Connell & Kerns, 2016). Some children may also benefit from pharmacological approaches in addition to or when other approaches are unsuccessful, particularly for mental health symptoms and behaviours that challenge (Persico et al., 2021).

Safe, Supportive, and Inclusive Schools

By adopting an inclusive school model, promoting *self-determination* of Autistic children throughout their schooling, and actively working to mitigate harmful practices and experiences, schools can become safer and more supportive settings for Autistic students. It can also

provide supports for Autistic students as they transition through educational settings (e.g., across grades, classrooms, and from school to school).

Inclusive education means Autistic students are educated in the same learning environment as non-autistic peers (Lüddeckens et al., 2021). Many countries such as the United Kingdom, France, and Spain have inclusive education policies designed specifically for Autistic students to help maximize their potential (Roleska et al., 2018). Inclusive education has been shown to help non-autistic students become more empathetic and accepting of their Autistic peers (Sawchuk, 2019) and has enabled Autistic students to experience social acceptance and participation in mainstream classrooms (Lüddeckens, 2021). Conversely, research suggests that special education for Autistic children may contribute to reduced social participation, as they may be less likely to be called by friends or be invited to social activities (Orsmond et al., 2013; Tanner et al., 2015; Williams et al., 2019).

“I recognize separation is occasionally necessary ... I am in no way suggesting forcing Autistic people into environments [where] they are uncomfortable. I do, however, think that insisting on that division only begets more division. If we’re constantly placed as an ‘other’ that is how everyone sees us.”

- Autistic adult

Merged models of inclusive school and special education may offer a unique pathway to inclusion for some Autistic children. In the United Kingdom, in an emerging model of education students who attended specialized autism schools were transferred to ‘satellite’ classes in local, mainstream partner schools, while continuing to receive a tailored curriculum (Croydon et al., 2019). This merged model offered Autistic children opportunities for social integration, while still addressing their distinct support needs as required. Teachers reported that students responded to higher expectations in the “satellite” classrooms and they displayed better behavioural regulation and more sustained attention (Croydon et al., 2019).

Creating more inclusive classrooms may also include practices such as standardized training programs about autism acceptance and neurodiversity to promote understanding and positive relationships for educators, non-autistic peers, and other school staff (Lüddeckens, 2021; Sawchuk, 2019). Peer-focused autism acceptance and *awareness* programs aim to educate students about autism and/or to tackle negative attitudes towards Autistic peers with the goal to improving the inclusive school experience (Cremin et al., 2021; Scior & Werner, 2015).

Peer-focused programs have been shown to successfully improve children’s knowledge about, attitudes towards, and acceptance of disabled peers, including Autistic people (Lindsay & Edwards, 2013). To be effective, peer-focused programs should incorporate information, peer

training, and interactional (i.e., social contact) opportunities (Cremin et al., 2021). While all children can benefit from peer-focused programs, the appropriate format and goal outcomes may change depending on children's age (Fisher & Purcal, 2017). For example, older participants are better able to grasp more detailed informational content than younger participants. In turn, social contact programs offered over longer periods of time (e.g., months) allow younger students time to develop understanding of disability and possible friendships (Lindsay & Edwards, 2013). The majority of evaluated programs have reported some positive change in knowledge, attitudes, or levels of stigma, despite different delivery methods (e.g., video, online, or in-person) and the age of participants (preschool to college-aged students) (Cremin et al., 2021). However, in these studies, behaviour change was rarely included as an outcome measure. As such, more research on the longer-term behavioural outcomes of such programs is warranted.

The [Learning with Autism](#) scheme (Autism Wales, 2020a), a collaborative initiative between the Welsh Government, the Welsh Local Government Association, and Public Health Wales, offers an example of a whole school program with peer-focused elements. It was launched in 2016 with a goal of promoting understanding and acceptance of Autistic people across entire school communities, as well as fostering a safer and more supportive educational environment (Welsh Local Government Association, 2018). The program has primarily targeted primary schools, but since 2017, has expanded to early years and secondary school settings. Participants are provided with a set of resources, including reading materials, to learn about autism and are asked to sign a pledge. For a school to receive a certificate of completion, all students, teachers, and other school staff are required to complete the program. Within the Canadian education system, such practices are not consistently available. Inclusive education practices and a consistent approach to individual education plans across all provinces and territories could ensure continuous and equitable learning opportunities (Crosland & Dunlap, 2012; Williams et al., 2019).

Other strategies that have been proposed for the successful inclusion of Autistic children into mainstream education include (Crosland & Dunlap, 2012; Williams et al., 2019; Aspiranti et al., 2020; Pūras, 2019):

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- Making environments predictable and sensory-friendly,
 - Individualizing teaching methods, such as allowing students to preview information or activities before engaging in them,
 - Using tablets/iPads instead of pencil and paper, and
 - Incorporating students' interests to increase motivation and engagement.
-

Promoting Self-Determination

Strategies to promote self-determination and active involvement of Autistic students in school settings have been described in the literature. Autistic students who were provided structured opportunities to participate and lead transition planning within their Individual Education Plans have exhibited higher self-determination skills (Chandroo et al., 2018). Furthermore, self-management strategies, such as choosing goals and observing one's own socio-emotional responses have been shown to improve social interactions, skills, and independent engagement in academic work. Some approaches to self-management involve peer mentoring amongst non-autistic and Autistic peers (Crosland & Dunlap, 2012; Williams et al., 2019; Aspiranti et al., 2020; Watkins et al., 2019). In addition, educators can teach and support older Autistic students to voice their opinions and views during individualized education and transition planning. This can empower and support Autistic students in becoming better self-advocates (Chandroo et al., 2018).

Online peer mentorship opportunities amongst Autistic students can also be beneficial, as they enable Autistic students to learn from other individuals who have adapted to similar life experiences, using a platform that is accessible at any time and from any location (Saxena et al., 2020). Further, personal narratives from non-speaking Autistic youth suggest that there are unique advantages to receiving mentorship from Autistic peers, such as learning about navigating unique personal challenges and victories, increasing visibility of Autistic people in settings where Autistic people are generally underrepresented, and fostering a sense of community and hope among Autistic youth (Capozzi et al., 2019).

“Autistic peers and mentors [are] the one thing missing. We need Autistics who have been through systems and experiences to mentor others who are challenged by it, or younger teens who are just learning about themselves and need help with life transition points.”

- Autistic adult

Addressing Harmful School Experiences

Bullying

One important strategy for enhancing safety for Autistic students is reducing rates of bullying in educational settings. A recent meta-analysis demonstrated that anti-bullying programs can significantly reduce bullying perpetration and victimization by approximately 15 – 20% (Gaffney, Ttofi, & Farrington, 2019). Furthermore, programs to combat cyberbullying were effective in reducing perpetration by 9 – 15% and victimization by 14 – 15% (Gaffney, Farrington et al., 2019).

Preventing bullying incidents requires a whole school, public health approach that includes universal, selective, and indicated programs and activities to ensure a targeted and relevant approach (DeSisto & Smith, 2014). The involvement of principals, teachers, and students is required for success (Forrest et al., 2020; Li et al., 2017). Anti-bullying programs at schools should also consider the particular needs of Autistic students in settings where these students are present (Rawlings & Stoddard, 2019). In 2018, Public Safety Canada (DeSisto & Smith, 2014) recommended future research on bullying of children with developmental disabilities as well as evaluating the outcomes of effective programs and initiatives.

Particular to Autistic children and youth, some suggested anti-bullying initiatives include mentorship from older Autistic students or adults regarding key skills and strategies to address bullying and victimization, peer buddy systems, check-ins with trusted adults/educators, and involving parents (Chen & Schwartz, 2012). Contact-based programs (e.g., engagement amongst Autistic and non-autistic students) have also been shown to improve peer attitudes towards Autistic students (Cook et al., 2020). Organizing school-wide extracurricular activities and team sports may influence autism acceptance by peers and staff (Lüddeckens, 2021). Accordingly, the peer-focused autism awareness and acceptance programs described above may be a significant element to addressing bullying of Autistic students.

Seclusion and restraints

There are short- and long-term negative consequences of the use of seclusion and restraint in schools, including traumatic experiences for the Autistic student (Guldberg et al., 2021; Brede et al., 2017; Lüddeckens, 2021). Parents of children with disabilities have advocated for mandatory regulations and protections regarding their use within Canadian schools (Bartlett & Floyd Ellis, 2021). In line with these calls, to mitigate the ongoing use of seclusion and restraints, the United Nations Special Rapporteur suggested the implementation of human rights regulations and enforcements and the use of de-escalation and *trauma-informed* approaches (Pūras, 2019).

It has also been suggested that the most effective approach to protecting individuals when restraints or seclusion are deemed necessary is combining codes of practice and guidelines on how to use restraints or seclusion properly in the event of imminent harm to students or others, with legislation mandating penalties for non-compliance (Kumble & McSherry, 2010). Tracking systems for exclusion, restraint, and seclusion practices are also an important part of a comprehensive approach (Bartlett & Floyd Ellis, 2021; Kumble & McSherry, 2010). Unlike the UK, Canadian provinces and territories do not collect data on school exclusions, nor on the use of restraints and seclusion in educational settings (Bartlett & Ellis, 2021; Guldberg et al, 2021).

When returning following a school exclusion, Autistic children and their families may need enhanced transitional supports (Anderson, Sosnowy et al., 2018; Nuske, McGhee, et al., 2019). Recommendations for reintegration for school-aged children include (Brede et al., 2017; Nuske, McGhee et al., 2019):


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- Making substantial adjustments to the school environment,
 - Promoting strong relationships between staff, students, and their families,
 - Understanding each student's specific needs and capabilities, and
 - Providing targeted efforts to improve student wellbeing (e.g., emotional resilience, life skills)
-

School safety for Autistic students, especially those who tend to wander, may also be improved by outlining appropriate safeguards in students' individual education plans (McLaughlin et al., 2018). Regulated health professionals can also proactively provide guidance and participate in school safety planning, which may include identifying alternative approaches and support the development of strengths-based safety plans (McLaughlin et al., 2018; National Association of School Nurses, 2013).

Key Findings - Supports and Services for School-Aged Children and Adolescents

The development of Canadian autism-informed inclusive educational guidelines and/or evidence-based service delivery practices can promote the adoption of best practices across Canada. Educational systems can improve the academic experiences of Autistic students by:

- Adopting an inclusive, strengths-based approach individualized to meet the needs of the student,
- Offering a broad range of accommodations that include evidence-informed instructional and support strategies,
- Providing safe, predictable, and sensory-friendly environments,
- Offering specialized supports and services,
- Promoting professional development of education staff,
- Actively involving Autistic students and their parents through timely communications and Individual Education Plans (IEPs), and
- Meaningfully integrating Autistic students with non-autistic peers across academic and non-academic activities and environments.



Priority areas for Autistic school-aged children include the development and implementation of evidence-based approaches to develop skills and coping mechanisms in areas such as social, communication, self-regulation, and management of mental and physical health. These are especially critical during times of transition.

Anti-bullying programs delivered through a whole school approach, and adapted to meet the unique needs of Autistic students, can significantly reduce bullying perpetration and victimization and are a key enabler of safe, supportive, and inclusive schools.

4.6 Adulthood

4.6.1 Background

The goals of supports and services for Autistic adults are to increase self-reliance and self-determination through pursuing higher education and meaningful employment, the acquisition of life skills (such as food preparation, personal hygiene, cleaning, paying bills, making appointments), and promoting and managing one's health including mental health (LeBlanc et al., 2008). Key areas of support may include assistance with finding and retaining employment, practical help with daily living tasks, social interaction including mentoring or befriending, peer support, and advice or advocacy related to locating and accessing services, such as housing, welfare services, health services, and navigating the criminal justice system (Lorenc et al., 2018; LeBlanc et al., 2008; Bölte et al., 2019). These goals may be relevant for many, but not all Autistic people. As discussed in Chapter 2, the complexity of support needs can continue or even increase into adulthood, at a time when fewer community and publicly-funded services are available.

As such, Ally and colleagues (2018), in one of very few Canadian reviews, suggested that transition to adult life can be regarded as successful to the extent that the individual's and their family's wishes and hopes for adult life are incorporated into the transition plan and are realized as they envisioned (Ally et al., 2018). In this vein, parents and, to a lesser extent, professionals, have described a tension between recognizing that some youth had different needs and were following different life paths yet were hoping for or working towards the attainment of

normative ‘successful’ outcomes (Jacobs et al., 2018). The areas of financial self-sufficiency, post-secondary education, employment, and housing are described in Chapter 5.

Summary Points

Publicly-funded and locally-available supports and services specifically for Autistic adults are essentially non-existent across Canada.

When unsupported, transitions are vulnerable times for Autistic people and can lead to family and individual crises, an over-utilization of urgent/emergency care, poor quality of life, and financial instability.

There is very little information about parenting by Autistic individuals in the research literature.

Very little is also known about how best to support older Autistic people and yet it is important to plan for future needs.

Transition to Adulthood

The transition period for Autistic youth (ages 16 to 25 years) is a critically important time during which the incidence and severity of some physical and mental health conditions increases (Malik-Soni et al., 2021). Without continuous and appropriate services, mental and physical health concerns may remain undetected or become exacerbated, putting transition-aged youth at further risk of developing preventable secondary complications and co-occurring conditions (Levy et al., 2020). Studies have shown that transition-aged Autistic youth are less likely than youth with other disabilities to receive transition services to adult care (e.g., Cheak-Zamora et al., 2013; Zablotsky et al., 2020). Furthermore, transition services for Autistic youth are even less equipped to meet the needs of those from *racialized communities*, or those with behaviours that challenge (Taylor & Henninger, 2015).

“Autism is a lifelong condition and way of life that needs to be supported, and not fixed, without interruption at points of life transitions.”

- Autistic adult

Due to these challenges, as well as the inherent heterogeneity of autism, there is wide variability in the trajectories of Autistic individuals. About three quarters of children experience a plateau in the intensity of autism features, whereas a quarter demonstrate continued

improvements during childhood (Georgiades et al., 2022). Work by Fein and colleagues (2013) suggested that improvements early in life in social and other skills can occur for some Autistic individuals. On the other hand, a study following a population-based sample of Autistic youth found continued cognitive development across the adolescent period, but these improvements had little impact on autism characteristics that may be impairing (Simonoff et al., 2020). Similar stabilization in intellectual abilities and autism characteristics was demonstrated in a small study of Autistic adults with co-occurring intellectual disability (Howlin & Magiati, 2017).

Many Autistic adults and their families desire *independent living*. Such goals, however, may not be suitable for or preferred by all Autistic people or families. As Autistic individuals age, they may also be socially expected to take on responsibilities in health and financial decision-making, post-secondary education or employment, and social relationships and intimacy (Bennett et al., 2018; Anderson, Roux et al., 2018; Lai et al., 2020). All Autistic individuals have the capacity for learning and adapting across the lifespan (Jacobs et al., 2018). Yet, due to environmental barriers, they may lack skills and/or resources to achieve successful adult outcomes (Bennett et al., 2018). Furthermore, for some Autistic young adults with complex support needs, achieving these ‘normative’ markers of independence may be unrealistic (Young-Southward et al., 2017). As such, there is a clear need to understand the continuing and future needs of Autistic adults across the lifespan and spectrum of needs.

One of the few Canadian studies focused on understanding the changes and disruptions experienced by Autistic individuals and their families across the lifespan is the [CONNECT Project](#) (Jose et al., 2021). Significant gaps in appropriate health and social care and a growing prevalence of the diagnosis have contributed to an adult population that is significantly underserved during and after adulthood transitions (Ally et al., 2018; Hamdani et al., 2011; Levy et al., 2020; McKenzie et al., 2017). Many Canadian parents find themselves in dual caring roles, supporting both their Autistic children and aging parents. These increased responsibilities often coincide with a sudden decrease in formal supports for the Autistic youth when they leave high school (Dudley & Nakane, 2017; McKenzie et al., 2017).

In other jurisdictions, services also drastically decline after high school (Anderson, Sosnowy et al., 2018). The increasing number of Autistic adolescents and adults transferring to adult-based services has not kept up with ever-increasing needs, resulting in this population often being un(der)-supported and socially isolated (Volkmar et al., 2017; Wolgemuth et al., 2016). A significant difficulty cited by parents is the decreased number of adult respite hours despite the stable or increasing needs of their adult child, resulting in the Autistic individual being isolated at home (Jacobs et al., 2018).

Currently, the few existing adult supports and services are fragmented and often complicated to access. Furthermore, those specialized services that do exist are often only available

for Autistic individuals with co-occurring intellectual disability. Screening and assessment processes are not streamlined across ministries (Bennett et al., 2018) and decisions about where and how to intervene are often based on professionals' subjective needs appraisal rather than formal assessments (Anderson, Sosnowy et al., 2018). Furthermore, differential funding of child and adult services, changing and reductive eligibility criteria, and limited awareness amongst physicians and other professionals contribute to mismatched resources (Anderson, Sosnowy et al., 2018; Murphy et al., 2016). It is often overwhelming and difficult to locate relevant and appropriate services (Calleja et al., 2020), requiring significant parent coordination (Lubetsky et al., 2014).

Primary Care Access and Poorer Physical Health

Autistic adults experience higher rates of marginalization and have more concurrent health conditions than their non-autistic peers (Benevides, Shore, Andresen et al., 2020; Weir et al., 2020). They are also more likely to have several linked health conditions, due to shared causes and biological mechanisms or the experiences of living with autism (Lai et al., 2020). For example, compared with non-autistic adults, Autistic adults have higher odds of unmet physical, mental health, and prescription medication needs, as well as higher odds of emergency room use (Bennett et al., 2018), which may be in part due to difficulties navigating the healthcare system and accessing primary and preventative care (Malik-Soni, 2021). Mortality is increased when Autistic adults have a comorbid illness or co-occurring intellectual disability (Hirvikoski et al., 2016). Parents of Autistic adolescents were two to three times more likely than parents of non-autistic adolescents to report that their child was obese or had obesity-related conditions, including diabetes and depression (Young-Southward et al., 2017).

Physical and mental health conditions can exacerbate difficulties in life activities. Many Autistic adults also do not have a family doctor, nor access to dental and mental healthcare services, due to high costs and/or lack of availability (Malik-Soni, 2021). Sexual and reproductive health service needs are also often overlooked (Graham Holmes et al., 2020). Indeed, publicly-funded, locally-available, and culturally-responsive diagnostic, supports and services for Autistic adults are essentially non-existent in Canada (Jose et al., 2021). Compounding the lack of supports and services is the dearth of evidence to guide diagnosis and effective support services for Autistic adults, with most recommendations based on expert opinion (National Institute for Health and Care Excellence, 2021b). Additionally, there are very few professionals, therapists, and service providers with autism expertise across the health, education, and social services sectors (Malik-Soni et al., 2021; Lai et al., 2020).

Yet without continuous and appropriate services, health concerns may remain undetected, putting transition-aged youth at further risk of developing preventable secondary physical and mental health complications and comorbidities (Levy et al., 2020). The more medically complex

the Autistic individual's condition, the less likely they are able to find transition services to meet their needs (Enner et al., 2020). However, US families have described challenges in finding and accessing therapeutic and medical care, even from providers who understand autism (Roux et al., 2021).

Mental Health and Addictions Concerns

Mental health and substance use concerns are common among Autistic individuals (Au-Yeung et al., 2019; Kunreuther, 2021), and can present in various ways and underlie and exacerbate cognitive, social, and academic challenges. For example, in Ontario, Autistic young adults (aged 18 - 24 years) in comparison to young adults with other developmental disabilities, were more likely to have at least one psychiatric diagnosis, and to visit a family physician, pediatrician, psychiatrist, or emergency department for psychiatric reasons (Weiss et al., 2018). Autistic adults may experience anxiety, depression, obsessive compulsive disorder (OCD), irritability, self-injurious behaviour, suicidal risk, bipolar disorder, or psychotic disorders, although the issue of differential diagnosis versus comorbidity remains unsolved (Lai et al., 2020). In turn, in the United States, the use of psychiatric care and prescription medications for Autistic transition-aged youth has significantly increased compared to peers with developmental disabilities (Bennett et al., 2018). In a qualitative research study from the perspective of Autistic people, autistic burnout can lead to preventable mental health challenges (Mantzas et al., 2022). In this study, autistic burnout was linked to life stressors such as continuous masking and barriers to accessing supports. As mentioned in Chapter 3, Autistic individuals are also at heightened risk for experiencing depression and suicidality compared to those who are not autistic (Hudson et al., 2018; Howe et al., 2020).

Autistic adults also experience increased risk of substance abuse and dependence, substance-related crime, and death linked to abuse compared to their non-autistic peers (Howlin & Magiati, 2017; Castellanos et al., 2020). The average age of onset for substance use disorder in Autistic people is approximately 19 years, when social isolation and life demands commonly peak (Volkmar et al., 2017). There is also emerging evidence of increased risk of suicide among Autistic people without co-occurring intellectual disability (Bennett et al., 2018; Segers & Rawana, 2014; Howlin & Magiati, 2017). Mental health concerns also warrant attention and support in Autistic people with co-occurring intellectual disability. However, for Autistic persons with limited communication or introspection skills, physical distress may present as mental health concerns or behaviours that challenge (Hyman et al., 2020).

A lack of societal acceptance of neurodiversity can place pressure on Autistic people to mask their natural autism characteristics and behaviours in favour of those that are considered more socially acceptable (Pearson & Rose, 2021). Growing qualitative evidence implicates masking with the risk of reduced mental health including suicidality and autistic burnout (Cassidy et al.,

2018; Mantzalas et al., 2022). Masking may also contribute to delayed recognition and diagnosis due to its intent of making autism characteristics less evident. Historically, poor quality of some early intervention programs had also led to adverse effects as well as negative or traumatizing experiences for some Autistic people (Kupferstein, 2018).

Despite an awareness of the extent of mental health concerns within the autistic population, research is scant on the efficacy of supports and services to enhance mental health outcomes, such as reducing anxiety, depression, and behaviours that challenge and improving quality of life among Autistic adults. Findings from a recent systematic review (Benevides, Shore, Andresen et al., 2020) only found two therapies met criteria as emerging evidence-based approaches: cognitive behavioural therapy and mindfulness-based therapies for stress reduction.

Relationships and Parenting

Contrary to previously held beliefs, most Autistic people desire close friendships and meaningful relationships (Enner et al., 2020). However, experiences of social isolation often persist after high school in both academic and employment settings (Volkmar et al., 2017). Opportunities for Autistic adults to develop adult friendships and romantic relationships are influenced by factors such as access to employment, housing, financial security, the individual's interests, and the presence of behaviours that challenge (Bennett et al., 2018). Knowledge of how marriage and parenthood is experienced by Autistic people is currently limited. Yet, in our stakeholder consultation we heard from many Autistic parents, indicating an area for further understanding and research. Parenting and intimate relationships, such as marriage, have not been a main focus of research, which may also suggest certain ableist biases or assumptions about the preferences or capabilities of Autistic individuals.

4.6.2 Best and Promising Practices

This section provides strategies for supporting successful life transitions including:

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- Evidence-informed transition policies, processes, and practices,
 - Cross-sectoral bridging and cooperation,
 - Service navigation across and at each life transition, and
 - Supporting transitions through aging.
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Evidence-Informed Transition Policies, Processes, and Practices

There is a sizable body of literature on the transition from pediatric to adult services within the education and health systems. Transitional services in these areas should follow a gradual, stepwise approach that is person-centred, strengths-based, and needs-led, while celebrating variability in opportunities and possibilities across the heterogeneity of Autistic people

(Brown et al., 2019; Calleja et al., 2020; Nuske, McGhee et al., 2019). For example, the Stepped Transition in Education Program for Students with Autism Spectrum Disorder (STEPS) has been associated with greater gains in transition readiness from high school and, among Autistic students enrolled in post-secondary education, in increased levels of student adaptation to college, relative to those receiving services as usual in the community (White et al., 2021).

To ensure a gradual and more standardized process in the United States, educational transition planning for Autistic adolescents is now mandated through the Individuals with Disabilities Education Act to begin at age 14 (Ally et al., 2018; Anderson, Roux, et al., 2018; Enner et al., 2020; Government Accountability Office, 2017). In Wales, the government extended health and social supports to Autistic youth, up to age 25, through the Additional Learning Needs and Education Tribunal Bill (Welsh Government, 2016). Such policy directions support a gradual transition process from early adolescence to emerging adulthood. Existing consensus guidelines and manualized programs (Nuske, McGhee et al., 2019) emphasize that transition planning in both education and health should consider multiple opportunities and life domains as early as age 12 - 14 years old (Ally et al., 2018; Anderson, Roux et al., 2018; Enner et al., 2020; Government Accountability Office, 2017). Some Ontario high schools use a program called the Secondary Social Communication Program (SSCP), which provides ongoing education and support to Autistic students throughout their secondary school years. Active engagement and involvement of the Autistic youth in transition planning is a best practice (Nguyen et al., 2016; Gorter et al., 2015).

Along with proactive and stepwise planning, two key elements found across these consensus guidelines are collaboration and sharing of best practices. In terms of collaboration, they strongly recommend intentional and meaningful inclusion of Autistic individuals, parents, family, school staff, and other current and future service providers in transition planning (Brown et al., 2019; Pilling et al., 2012). Such collaboration can be improved through systematic processes such as student-led, regular review of the individual education plan, pre-transition meetings and visits, peer buddy systems, and ongoing communication and information sharing (Brown et al., 2019; Nuske, McGhee et al., 2019; Pilling et al., 2012). Transition preparations should also include more formal training opportunities for Autistic high school students, including follow-up visits to employment and post-secondary settings (Nicholas et al., 2015; Nicholas et al., 2017; Toor et al., 2016; Department of Health, Social Services and Public Safety, 2015). Mental health supports are especially important during times of academic and developmental transitions (Hyman et al., 2020).

It has also been recommended that transition planning from pediatric to adult health and social services should begin early (Hyman et al., 2020; National Institute for Health and Care Excellence, 2017). Providing healthcare transition planning and ensuring that Autistic youth

continue to receive comprehensive healthcare is critical as they age. Improving healthcare transition processes could involve (Zerbo et al., 2015; Calleja et al., 2020; Malik-Soni et al., 2021):

- Using primary healthcare providers as a central point of care (akin to the ‘medical home’ model adopted in some areas of the United States),
- Primary care physicians who are trained and understand the medical, behavioural, and social care needs of Autistic individuals, through exposure and attention to autism-related issues during medical school and residency training, and
- Developing the physical environments of clinics and hospitals to be more autism-friendly in terms of sensory accommodations and adjustments.

During all transitions, parents may also benefit from expanded access to parent-led, peer support groups to help them prepare for, cope with, and adjust to changes and disruptions (e.g., diagnosis, transition into and out of school/post-secondary, change in living arrangements, retirement) (Munns et al., 2016; Pilling et al., 2012). Promoting family involvement is key, as it continues to be an essential component of the transition process – with parental engagement as the greatest predictor of a ‘successful’ transition (Foley et al., 2012). A pan-Canadian roll-out of transitional policies or programs would benefit from data tracking to ensure fidelity and to evaluate beneficial outcomes. Canadian and international evidence suggests that there is also a desire and need for expanded and meaningful day supports for transition-aged youth, including vocational/employment, educational, social, respite, and recreational services and other civic opportunities (Dudley & Emery, 2014; McLaughlin & Schneider, 2019; State of Victoria, Department of Health and Human Services, 2019; Government Accountability Office, 2017; Alcorn MacKay, 2010).

Cross-Sectoral Bridging and Cooperation

As mentioned above, many jurisdictions have legislated transition processes that embed a coordinated approach to planning and outline clear roles and responsibilities of each agency and key professionals (Enner et al., 2020; Murphy et al., 2016). Consensus guidelines and practices about health transitions to adulthood, such as the National Institute of Health and Care Excellence (NICE) guidelines from the United Kingdom (UK) aim promote continuity of care across the lifespan (Pilling et al., 2012). These guidelines recommend ongoing access to interprofessional, local adult autism teams. Promoting better adult outcomes across multiple domains in addition to health is also suggested in the UK’s Think Autism (2014) national strategy.

The 2018 Canadian consensus guidelines for primary care of adults with developmental disabilities recommends family physicians engage in transition planning and act as a point of responsibility and knowledge for other service providers (Ally et al., 2018), similar to the

American medical home model (Rogers & Zeni, 2015). Such an approach might be best served through community health teams that offer more rapid access to other health professionals, such as social workers, occupational therapists, speech-language pathologists, psychologists, and physiotherapists. Regardless of whether a team-based or individual clinician model is adopted, enhanced youth-to-adult continuity of care must be intentionally fostered through bi-directional and protracted relationships and collaborations amongst service providers across life stages (Bennett et al., 2018; Enner et al., 2020; Levy & Perry, 2011).

Overwhelmingly, both the evidence and stakeholders point toward the necessity of stronger linkages amongst health, education, and disability sectors through inter-ministerial/sectoral engagement and collaboration in designing and coordinating policies, programs, and services (e.g., Scottish Government, 2011; Welsh Government, 2016; Australian Autism Alliance, 2019; Government Accountability Office, 2014; Lemmi et al., 2017; World Health Organization Regional Office for South-East Asia, 2017; Autism Spectrum Disorder in the European Union, 2018; Autism Europe, 2020). Best practices for such planning should include the input of Autistic people and their families (Social Care, Local Government and Care Partnership Directorate, Department of Health, 2016a). In line with provisions set out in the UK, leadership and coordination at pan-Canadian, provincial/territorial, and local levels is required to aid service delivery, offer guidance, and determine progress (Murphy et al., 2016).

Service Navigation across and at each Life Transition

Parents and other family members have consistently voiced their desire for a person or place to turn to for up-to-date, and geographically and developmentally relevant, information and hands-on support, particularly during life transitions. From our stakeholder engagement, both family members and Autistic adults were interested in having access to navigation hubs (e.g., online, phone) with local information about transitional supports and services.

Some provinces and other jurisdictions have created transition liaison or coordinator positions to support the delivery of coordinated, integrated, and seamless care across transitions; (e.g., embedded within local autism lifespan teams) (Government Accountability Office, 2016, 2013, U.S. Department of Health and Human Services, 2017; Government of British Columbia, 2021; Department of Education and Early Childhood Development, 2009; Canadian Autism Spectrum Disorder Alliance, 2020b; McLaughlin & Schneider, 2019). Families of Autistic children often experience challenges navigating multiple systems to access services (Crossman et al., 2020). Family navigation is a model to provide information and support to access appropriate services (Crossman et al., 2020; Feinberg et al., 2021). British Columbia has already implemented this model (Ministry of Social Development and Social Innovation, 2015).

Aging with Autism: Transitions through to Older Age

Retirement and aging may be a significant transition point for Autistic people, but this was not evident in the literature (Autism Canada, 2018; Howlin & Magiati, 2017; Murphy et al., 2016) despite previous acknowledgement of the significance of the needs and extant evidence gaps (Piven et al., 2011). The few available studies suggest further research and development of supports are required to meet the identified needs of aging Autistic people and their families (Autism Canada, 2018; Dudley & Nakane, 2017; Kim, 2019; Levy & Perry, 2011). Programs for aging adults with developmental disabilities may offer some practices that can be adapted for Autistic persons, such as providing autism education and training providers that serve seniors, developing autism-friendly seniors' living models, and engaging in proactive long-term planning regarding finances, housing, and healthcare decisions (van Schalkwyk & Volkmar, 2017; Volkmar et al., 2017). Finally, adopting a family wellbeing approach (Tint & Weiss, 2016) that offers intergenerational, family-centred services for Autistic individuals and their aging parents may facilitate resource sharing through shared community-based staffing supports (i.e., homecare).

Access to General and Autism-Specific Supports

Given the high rates of co-occurring mental health and physical health conditions in Autistic adults (Benevides, Shore, Andresen et al., 2020), service plans should be holistic and consider integrating supports and services across various health domains (National Institute for Health and Care Excellence, 2021b). Capacity building in this area would enhance availability and equitable access to existing general and autism-specific health and community-based supports and services.

“As I have an IQ [intelligence quotient] (which is an ableist construct) over 70, there are no services available to me locally, despite my desperately needing them.”

- Autistic adult

Expanding service eligibility in both general and developmental disability services, as described in the Equitable Access section, could also alleviate some of the service gaps experienced by Autistic individuals without co-occurring intellectual disability (Anderson, Roux, et al., 2018; Murphy et al., 2016). Accordingly, where necessary and appropriate, mental and physical health services for the general public can be adapted for Autistic individuals so that they are not excluded from available services simply because they are autistic.

Helpful adaptations may include providing more structure, using more directive strategies, having more sessions, and adopting more personalized approaches (Helveschou et al., 2019). Education for providers about autism and collaboration among professionals across

different sectors (such as mental health services, developmental services, housing) to enable wraparound services are also recommended to enable sustainable long-term improvements (Kunreuther, 2021).

Expanding Services for Autistic Parents

Existing parenting resources and autism services may not sufficiently address the needs of Autistic parents. Accordingly, there is a need to identify and expand upon existing parenting resources and supports for Autistic parents (State of Victoria, Department of Health and Human Services, 2019; New Zealand Ministries of Health and Education, 2016; Dissanayake et al., 2020; Winnard et al., 2021). This can be done through forums that focus on the needs of Autistic parents (State of Victoria, Department of Health and Human Services) and may also include supports and education for spouses and partners of Autistic parents (New Zealand Ministries of Health and Education, 2016). An example of a co-created autism-specific parenting resource is the [AMAZE parenting skills guide](#). Ideally, expansion and development of such supports would be created in partnership with the end users – Autistic parents.

Some supports that may be helpful include (State of Victoria, Department of Health and Human Services, 2019; Gardner et al., 2016; and McDonnell & DeLucia, 2021):

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- Communication tools (e.g., in relation to prenatal and labour care),
 - Parent education and supports, and
 - The use of peer support models.
-

In addition to developing and expanding resources, health and social care professionals may also require specific training about autism and parenting in order to address the stigma that has been experienced by Autistic parents (Powell, 2002; Gardner et al., 2016; Pohl et al., 2020; Rogers et al., 2017), and to better support and screen Autistic parents in relation to both mental and physical health (Rogers et al., 2017; Sundelin et al., 2018; Hudson et al., 2019).

Mental Health Provision

Based on the evidence gathered from a recent systematic review, cognitive behavioural therapy and mindfulness-based therapies were considered emerging evidence-based therapies for anxiety management and stress reduction, respectively, for Autistic adults without co-occurring intellectual disability (Benevides, Shore, Andresen et al., 2020). These approaches are effective in helping Autistic adults reduce their stress and anxiety levels (Lai et al., 2020). Appropriate investigations for medical conditions (e.g., pain, gastrointestinal complaints, sleep dysfunction) or other challenges (e.g., sensory overload) may be considered as part of the assessment process before or in conjunction with mental health services (National Institute for Health and Care Excellence, 2017; Hyman et al., 2020).

Mental health services that are accessible (e.g., provided virtually, if appropriate and needed), delivered in autism-friendly environments, and adopt trauma-informed, intersectional, and *neuro-affirming* approaches, may reduce mental health crises that many Autistic individuals experience (Benevides, Shore, Palmer et al., 2020; King et al., 2019; Tang, 2020). The delivery of mental health support within schools and post-secondary settings may be one way to improve access to these services. For example, in England, [Mental Health Support Teams](#) were established in education settings aimed at connecting students with local mental health services, delivering evidence-based supports, training mental health leads in schools and colleges, and offering timely advice to school and college staff (NHS England and NHS Improvement, 2021). Furthermore, Autistic people who have experienced adverse childhood events such as bullying, as well as certain *equity-seeking groups*, may require culturally-sensitive, trauma-informed mental health services (Maddox et al., 2021). Approaching autism services with trauma-informed, neuro-affirming principles may promote greater recognition of the possible risks and negative effects experienced by some Autistic people (Baker & Lang, 2017; Pellicano & Stears, 2011). Autistic adults who previously participated in early EIBI and ABA approaches that were experienced as traumatizing may also need trauma-informed mental health services to address these earlier experiences.

“Applied Behaviour Analysis (ABA) was very traumatic (13 years of it). My difficulties are neurological, and behavioural therapies don’t take this into consideration. ABA drills are very repetitive, and this was so stressful and frustrating.”

- Autistic adult

Recently, a [Mental Health Literacy Guide for Autism!](#) was developed in consultation with Autistic adults as well as parents and siblings of Autistic adults with the primary goal of improving mental health literacy of Autistic adults in Canada (Autism Mental Health Literacy Project Group, 2021). The guide provides information about the mental health experiences of Autistic people and highlights the critical role that societal acceptance of autism plays in supporting their mental wellbeing. It is meant to serve as a resource for Autistic adults, their families, and supporters, as well as policymakers and the broader community to better understand how the mental health of Autistic adults can be supported.

Peer Support and Mentorship Models

Peer mentorship refers to receiving support from an individual with shared experiences, such as another Autistic person, parent, or family member/supporter to another Autistic individual (Shaw et al., 2020). There is emerging evidence supporting peer mentorship. For example, in a recent evaluative study of a 10-week *autistic-led* post-identification/-diagnosis peer support program, participants appreciated the autistic-led nature of the program as well as the sense

of group unity. They developed a positive and practical outlook on autism from their shared experiences (Crane, Hearst et al., 2021). As in the area of mental health, involvement of peer mentors could improve care experiences and overall health outcomes, especially when there is support, infrastructure (e.g., training and mentorship), and role validation for the peer mentors.

Self-Advocacy Training

Autistic and disabled people often receive more support from their families and service providers compared to their non-disabled peers, which may lead to greater passivity, dependency, and a lack of opportunity for self-determination (Roberts et al., 2016). Explicitly teaching Autistic people about **self-advocacy** can enable them to better identify their needs, preferences, interests, and rights and to develop effective strategies to communicate these to others (Roberts et al., 2016; Paradiž et al., 2018). Further, self-advocacy can also contribute to personal growth and the formation of a positive identity (Roberts et al., 2016).

“I think autistic voices should be heard more and taken into consideration because so far we just feel dismissed and ignored by people who think they know better than our own experiences.”

- Autistic adult

A self-advocacy framework for disabled people may be a helpful way to consider how self-advocacy can be strengthened among Autistic people. According to Test and colleagues (2005), there are four key components of self-advocacy:

- Knowledge of self,
 - Knowledge of rights,
 - Communication, and
 - Leadership.
-

Knowledge of self and rights are necessary to be able to identify one’s needs and wants. Developing communication skills allows an individual to effectively express these needs and wants to others. Leadership reflects moving beyond individual self-advocacy towards advocating for the collective needs of a group of people sharing similar concerns. Some studies also emphasize the importance of providing individuals with opportunities to practice their self-advocacy skills (Wehmeyer, 2007; Roberts et al., 2016). This includes opportunities for individuals to practice sharing their perspectives, listening to others and being listened to, making decisions and choices, as well as making mistakes and learning from them, all of which can help to strengthen their learning (Ryan & Griffiths, 2015; Wehmeyer, 2007; Roberts et al., 2016).

Encouraging self-advocacy also requires addressing existing barriers that Autistic people experience, including having their perspectives discredited or invalidated and the inaccessibility of advocacy spaces (Waltz et al., 2015; Petri et al., 2017). Supporting Autistic self-advocates thus requires creating environments in which communication differences are embraced and supported, including for non-speaking Autistic people and augmentative and alternative communication (AAC) users (Paradiž et al., 2018).

Several self-advocacy curricula have been developed for and by Autistic people (Paradiž, 2009; The National Autism Resource and Information Centre & The Autistic Self-Advocacy Network, 2013; McManmon, 2015). Key components of a strong self-advocacy curriculum for disabled people have been suggested to include:

- Teaching about self-awareness and self-knowledge (Test et al., 2005),
- Information about laws and human rights (Paradiž, 2009; Ward & Meyer, 1999; Cone, 2000),
- Communication skills that embrace a diverse range of communication strategies (Test et al., 2005; Olney, 2001), and
- Social awareness (Paradiž, 2009; Moyer, 2009).

Key Findings - Adulthood

Provision of adequate, publicly-funded, and locally-available adult autism supports and services can promote better health, and economic and social inclusion of Autistic adults, and the feasibility of families continuing to support an Autistic person at home.

Implementation of evidence-based guidelines and standard practices for health and education transition to adulthood leads to better health as well as social and economic inclusion for Autistic people and their families. Integration and collaboration amongst health, education, and other community sectors and services are key enablers for successful transitions.

Wider availability of autism-specific supports, for example, pertaining to mental health, peer support, and self-advocacy training can promote quality of life and autonomy.

4.7 Advances related to Neurobiology

Understanding the biology of brain and body differences among Autistic people also has the potential to anticipate individual trajectories and needs, as well as future co-occurring conditions that may have an impact on health and quality of life. For example, from the field of genetics, 10 - 20% of Autistic youth are estimated to have rare *de novo* (not found in parents) variations (Sanders et al., 2015; Zarrei et al., 2019). Further, some genetic variations that are more common among Autistic individuals than non-autistic individuals increase the likelihood of specific physical or mental health conditions. Examples include associations between chromosome 16p deletions and severe childhood obesity (Bochukova et al., 2010), PTEN gene deletions and certain types of cancer (National Organization for Rare Disorders, 2021), and chromosome 22q11.2 deletions and psychosis (Fiksinski et al., 2017). Identifying such differences early on allows clinicians to provide anticipatory guidance that may improve health and in some cases, reduce the likelihood of early death. In other cases, rare genetic syndromes associated with autism (often with co-occurring intellectual disability, severe epilepsy, and other health issues), may have clear enough biology that targeted medical treatments may significantly improve quality of life and life expectancy (Duis et al., 2022). The broad array of genetic differences that have been identified in some Autistic individuals appear to converge on a smaller number of biological pathways (e.g., transcriptional regulation, chromatin remodelling, synaptic transmission, neuropeptide signalling, and/or immunological mechanisms) (Sestan and State, 2018). Further understanding these mechanisms may ultimately yield targeted medical approaches that have the potential to improve health and reduce disability (Baribeau & Anagnostou, 2022).

There is also preliminary evidence that studying brain differences in autism may help to anticipate individual needs and tailored support strategies. For example, longitudinal magnetic resonance imaging (MRI) studies have shown promise in predicting language difficulties in siblings of Autistic youth (Lombardo et al., 2015). Combinations of MRI and computational techniques are also starting to identify Autistic children and youth at greater likelihood of developing specific co-occurring conditions (Kushki et al., 2019). These approaches have not yet been evaluated in terms of potential clinical applications, but may hold promise to further individualize support and service strategies in the future.

4.8 Chapter Summary

While each province and territory offers some form of autism diagnostic and support services, there is considerable complexity and variability in the types of services that are offered and how they are delivered across the country. This variability contributes to disparities in access, with many Autistic people unable to receive timely diagnoses and access to needed supports and accommodations. Certain subgroups of Autistic people are particularly disadvantaged such as those living in rural and remote areas, equity-seeking groups, Autistic adults, and Autistic parents.

Developing pan-Canadian guidelines and standards, reducing service disruptions, reviewing eligibility, implementing system redesign, enhancing navigation, building the capacity of the clinical workforce, and adopting remote technologies could contribute to more equitable access to diagnosis and services for Autistic persons. A stepped approach to diagnostic and support services for Autistic people of all ages can offer greater flexibility and potentially reduce wait times. Particular attention is needed to build capacity for diagnosing and supporting Autistic adults.

The recognition of autism as an aspect of neurodiversity has prompted a shift in the goals of supports and services from attempting to reduce autism characteristics to adopting strengths-based approaches to supporting Autistic people. Adopting a lifespan, person- and family-centred service approach promotes the health and wellbeing of the entire family unit, while also empowering family members to be involved in the delivery of supports and services.

Young Autistic children require timely and appropriate supports and services as this is a period of significant development. There is a shift in early intervention evidence towards the implementation of a range of approaches, which:

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- Adhere to naturalistic developmental behavioural intervention principles,
 - Are of needs-based intensity and duration,
 - Are provided with fidelity by skilled service providers in and across multiple community settings,
 - Promote parent or family member participation and integration into daily life, and
 - Are accompanied by continuous and rigorous evaluation of child- and family-oriented outcomes.
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For school-aged children and adolescents, access to supports within school and community settings that focus on a range of life domains can promote academic success, life and social skills, and improve mental health. Further, initiatives in schools that address bullying, school exclusion, and the use of seclusion and restraints can promote autism acceptance and inclusion.

Ensuring continuity of physical and mental healthcare, education, independent living support, service navigation, as well as access to peer support and self-advocacy training can facilitate transitions and influence quality of life for adults.

Advances in genetic and neuroscience research also hold promise for anticipating the likelihood of physical and mental health conditions and further tailoring healthcare and support strategies. Some rare genetic differences more commonly found in Autistic individuals than non-autistic individuals already have known health implications.



Chapter 5:

Economic Inclusion

5.0 Introduction

Autistic individuals and their families face financial barriers that may preclude their full participation in society. *Economic inclusion* entails removing barriers to reaching financial stability (through adequate access to income, savings, and capital), integration into the labour market, managing autism-specific costs, and these elements combined financial impact on individual and family wellbeing. Supports and services that promote financial stability, employment, post-secondary education, and access to autism-friendly housing options can enable the meaningful participation and contribution of Autistic people, as well as their families, in Canadian society. *Financial stability* involves receiving income from labour market participation and/or disability benefits, the purchasing power of that income, and access to savings and credit to buffer unexpected changes in income.

Accordingly, this chapter will cover the following four sub-themes:

- Financial stability for Autistic people and their families,
- Employment pathways for Autistic people,
- Post-secondary education and lifelong learning, and
- Autism-friendly housing options across the life course.

5.1 Financial Stability

5.1.1 Background

The costs associated with *autism* are high – for individuals, families, and society. Lifetime societal costs associated with this condition have been estimated at US\$46 billion (approximately CAN\$51 billion³⁰) per year in the United Kingdom (UK) and US\$196 billion per year (approximately CAN\$216 billion) in the United States (US) (Buescher et al., 2014). Furthermore, these costs are higher than for other disabled and non-disabled children. For example, the average yearly healthcare costs for Autistic children was two to three times greater than the healthcare costs for non-autistic children (Rogge & Janssen, 2019), including those with asthma, diabetes, or mental health conditions (Beecham, 2014).

Data from the US and UK has also shown that average annual costs for an Autistic child with co-occurring *intellectual disability* are considerably higher than those of Autistic children without co-occurring intellectual disabilities (Buescher et al., 2014). While such societal costings are not available for Canada, Canadian economists Dudley and Emery (2014) suggested that the value of time required from *family members* to support an Autistic

³⁰ The approximate Canadian dollar value was determined based on the Bank of Canada currency conversion rates for the year the cited study was published.

individual with co-occurring intellectual disability, alone, is approximately \$5.5 million higher than that of a non-autistic individual. Regardless of co-occurring conditions, there are significant costs for families and the current supports and services are insufficient to offset those costs and ensure the best possible outcomes for their Autistic family member.

The costs associated with autism typically increase over the lifespan (Buescher et al., 2014; Rogge & Janssen, 2019). However, publicly-funded services and supports decrease significantly after secondary school (DePape & Lindsay, 2016). Eligibility criteria based on level of intellectual disability have also left many Autistic people without adequate supports in adulthood; however, even those with intellectual disabilities experience service gaps (Hewitt et al., 2017). Many aging parents may try to fill these gaps themselves, although this approach is neither equitable nor sustainable (Gentles et al., 2019; Dudley & Emery, 2014).

A major source of societal costs is related to fewer Autistic individuals and their family members participating in the workforce (Rogge & Janssen, 2019). In the Canadian Survey on Disability (2017), government transfers were the main source of personal income for 63% of working age Autistic Canadians (Berrigan et al., 2020). Further, the average annual gross personal income of Autistic Canadians was \$13,700 in 2012, mostly made up of social assistance/disability benefits (Zwicker et al., 2017), well below the poverty line of \$23,227 at that time (Statistics Canada, 2021c).

In a recent review, 58% of parents living with Autistic children reported adverse employment impacts – three times that of parents caring for children with another disability (Liao & Li, 2020). The loss of expendable resources associated with caregiving work – including physical and emotional energy, time, and financial resources – can be a source of serious concern for parents (Gentles et al., 2019). The financial impacts (e.g., loss of income, use of capital, debt) over time can lead to increased stress, decreased quality of life, and family breakdown. The current system relies on parental or family *supporters*, and, therefore, it is in society's best interest to ensure that parents and other family members can continue to provide care. A 10% reduction in informal care provision translates to a 40% increase in the need for publicly-funded services (Every Canadian Counts Coalition, 2017).

5.1.2 Best and Promising Practices

This section summarizes potential approaches that could mitigate the economic impacts of autism on the individual, family, and the public payor, which requires consideration of the following areas:

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- Meeting the basic needs of Autistic people and their families,
 - Costs and tax deductions associated with autism,
 - Family-centred perspective on supports and services across the lifespan,
 - The long-term financial stability of Autistic people and their families, and
 - Collaboration and coordination across ministries, sectors, and jurisdictions.
-

Meeting Basic Needs

As described above, many Autistic people and their families rely on government financial assistance to meet their basic needs (Berrigan et al., 2020). There are significant differences in the eligibility provisions and monthly disability income available across Canada resulting in inequitable access to financial supports. Geographically-equitable, needs-based financial supports should be available across jurisdictions (Eggleton & Keon, 2007; Lemmi et al., 2017; Autistics for Autistics, 2019; Australian Autism Alliance, 2019; Autism Europe, 2020).

One way to monitor these financial supports and ultimately reduce poverty among Autistic Canadians may be to develop an autism- or disability-sensitive Market Basket Measure to serve as a standard adequacy marker for the true costs of this condition (Berrigan et al., 2020). Additionally, some governments and advocacy groups have recommended redesigning social assistance plans (Nova Scotia Department of Education, 2010; Houlden, 2015; Office of the High Commissioner for Human Rights, 2018; Spoelstra & Bountrogianni, 2019; Government of Newfoundland and Labrador, 2019; Canadian Autism Spectrum Disorder Alliance, 2020b; McLaughlin & Schneider, 2019; Autism Canada, 2011; Autism Ontario, 2009) to:

-
- Offer flexible disability benefits that provide partial income or other supports (e.g., extended medical, dental) for those working part- or full-time, and
 - Balance clawbacks for high earners with incentives for labour market participation of Autistic adults who can and want to work. A clawback is the amount of money the Canadian and provincial/territorial governments take back for each net dollar earned.
-

Implementing a universal or minimum income for disabled people, including Autistic people, has also been suggested (Duffy & Elderwood, 2019) and was embraced by many stakeholders. Such reforms may benefit not only Autistic people, but other disabled persons. Some jurisdictions, such as Australia, have also implemented a federally-managed, needs-based disability insurance program (Cebulla & Zhu, 2016).

Summary Points

Many Autistic individuals and their families face significant financial instability.

Eligibility and access to income and benefit programs remains challenging for many Autistic people and their families in Canada.

The labour market participation of parents of Autistic people are impacted by their care responsibilities and can influence family quality of life and financial stability.

Disability support programs are essential to the financial security of many Autistic people.

Publicly-funded supports and services significantly decrease when K - 12 education ends, jeopardizing the feasibility of families continuing support an Autistic person at home.

Intersections of socioeconomic status, sex and gender, race, ethnicity, and education further complicate attaining economic inclusion. Despite an over-representation of white and higher socioeconomic status families in autism research, a subset of studies demonstrated how race, ethnicity, and socioeconomic status may contribute to economic and service disparities (Smith et al., 2020). To address such inequities, stakeholders suggested providing grants and tax breaks that specifically address the needs of Autistic people in financial need.

Costs and Tax Deductions associated with Autism

Personal costs associated with autism include, but are not limited to the out-of-pocket expenses, such as respite, home modifications, transportation to receive care, special equipment, cleaning and repairs, training courses, therapeutic activities, and special diets (Beecham, 2014; Rogge & Janssen, 2019). Tax credits and subsidies, such as the Disability Tax Credit, the Registered Disability Saving Plan, the Medical Expense Tax Credit, the Child Disability Benefit, and the Canada Student Grant for Services and Equipment for Students with Permanent Disabilities are options to offset the well-documented extra costs associated with autism (Eggleton et al., 2018; Berrigan et al., 2020). For example, there are medical expense deductions available for “a patient who has severe autism” for specially-trained assistive animals, and GST/HST exemption for specially-designed training and support services, and for autism-specialized childcare services (up to age 14) (Government of Canada, 2022).

“Autism isn’t a [visible] disability and people judge. [But] when they see his service dog, it creates a visual to his disability and most people treat him with much more compassion.”

- Family member of an Autistic person

However, access to any of these deductions or grants requires ongoing eligibility for the Disability Tax Credit. This gateway status is one of several issues that have been flagged with the Disability Tax Credit that directly impacts Autistic people. Other issues include the following (Eggleton et al., 2018; Disability Advisory Committee, 2019; 2021):

- **Low uptake due to the low income status of many disabled people in Canada.** Typically, non-refundable tax measures only benefit people whose incomes are sufficiently large to be taxable, so they have limited impact on alleviating poverty.
- **Autistic people have more difficulty meeting eligibility criteria.** The Disability Tax Credit eligibility processes were designed with physical disabilities in mind, so it does not easily apply to Autistic people. For example, a physically disabled person must only present with one limitation (e.g., to walking), while an Autistic person would have to demonstrate serious restrictions in multiple mental functions.
- **Autistic people are required to re-apply despite autism being a lifelong condition.** The time and financial costs of having the application completed by a medical professional are significant barriers that are not required of persons with conditions such as blindness or paraplegia. In addition to the individual burden, this process places unnecessary strain on public resources for application completion and adjudication.

Additionally, the eligibility process and requirements for the Disability Tax Credit has been criticized as not properly considering cognitive, communication, and functional challenges associated with autism (Eggleton et al., 2018). As such, some stakeholder suggestions for improving the Disability Tax Credit application process include (Disability Advisory Committee, 2021; 2019):

- Providing clear, accessible, and transparent eligibility criteria for Autistic individuals across the needs/ability spectrum,
- Allowing a wider range of healthcare professionals to complete the forms for Autistic applicants, and
- Considering reforms to the renewal processes for Autistic applicants since autism is a lifelong condition.

Likely in part due to eligibility challenges, uptake of the Registered Disability Saving Plan is minimal with few people with any disability using it (Berrigan et al., 2020). While meant to promote financial stability in the long run, the out-of-pocket costs described above may act

as barriers to accessing a Registered Disability Saving Plan for many families. As we heard from stakeholders, families are often faced with a choice: to pay out-of-pocket for therapy, diagnostic services, and respite, or to invest in a Registered Disability Saving Plan. Furthermore, parents are also faced with difficult decisions regarding whether to invest in the Registered Disability Saving Plan or the Registered Education Savings Plan.

Decisions made early on in their child's life trajectory can impact access to funds later on, as neither of these plans are portable to the other. Other Registered Disability Saving Plan-related issues are that grants, bonds, and contributions are only paid to eligible recipients until age 49 and there are limitations on how the funds can be used with penalties for early withdrawal (Government of Canada, 2021d), even if used to promote long-term financial stability, such as investing in education or housing. Furthermore, many Autistic people may not be able to open a Registered Disability Saving Plan due to legal capacity (Eggleton et al., 2018). Family members can be caught between wanting to assure long-term financial stability of the Autistic individual and concerns regarding placing the individual under a guardianship order. Please see Chapter 3 for a discussion on legal capacity. As described in Chapter 2, First Nations people are eligible to apply for products, services, and supports through Jordan's Principle, however, accessing these funds can be challenging for parents.

“As a parent and caregiver, trying to find funds and spend those funds and then find reliable workers ... You have to be well versed on how to get funds spent within the fiscal year ... or ask [service providers] to write more support letters ... where does that leave the parent's life? ... Is there room for the rest of their life?”

- Family member of a First Nations Autistic person

These are a few of the many complex tax issues and financial decisions that are faced by parents of Autistic children and adults. Additionally, as more provinces/territories opt for direct funding models, parents are increasingly becoming employers who are also responsible for managing employment-related expenses (e.g., Canada Pension Plan, Employment Insurance, or Workers' Compensation Board premiums) of respite or behavioural therapy *service providers* (Ministry of Children and Family Development, 2021b).

Family-Centred Perspective on Supports and Services Across the Lifespan

Autism can cause significant financial and emotional ripple effects on the entire family. Parents or other family members often provide a residence, daily living supports, supervision, systems navigation, and advocacy to their Autistic child well into adulthood. As such, taking a family-centred perspective across the lifespan (Tint & Weiss, 2016) that considers family wellbeing may support the residential and financial stability of Autistic individuals and their families.

“Due to my daughter’s high needs I have never been able to work full-time, so I have earned less and I have not been able to gain the seniority at work that I should have.”

- Family member of an Autistic person

Multiple reports concluded that there is an increased need for affordable respite and personal support services for Autistic people who are living within the family home during adulthood (Dudley & Emery, 2014; Eggleton & Keon, 2007; Organisation for Economic Co-operation and Development, 2007; Nova Scotia Department of Education, 2010; Hodgetts et al., 2013; Shepherd & Waddell, 2015, Government Accountability Office, 2016; Department of Education and Early Childhood Development, 2009; Government of Newfoundland and Labrador, 2019; Government of British Columbia, 2021; Autism Europe, 2020; Autism Society, 2020, New Zealand Ministries of Health and Education, 2016; Department of Health, Social Services and Public Safety, 2015; Canadian Autism Spectrum Disorder Alliance, 2014). Needs-based respite services offer parents of an Autistic individual a break from caregiving responsibilities and also increase their own labour market participation.

Separate from respite is the need for equitable access to publicly-funded, community-based, evidence-informed supports and services specific to the mental and physical health, and socioemotional needs of Autistic people across the lifespan (Dudley & Nakane, 2017; Eggleton & Keon, 2007; Nova Scotia Department of Education, 2010; Scottish Government, 2011; Muskat & Manett, 2012; Caputo et al., 2015; Lemmi et al., 2017; Interagency Autism Coordinating Committee, 2017; Spoelstra & Bountrogianni, 2019; Government of Newfoundland and Labrador, 2019; Welsh Government, 2016; New Zealand Ministries of Health and Education, 2016).

Currently, adult support and services are lacking, which places significant financial pressures on families, both directly and indirectly. Direct costs may include private adult diagnostic and support services (Rogge & Janssen, 2019). With few adult autism service providers available amid an increasing demand, stakeholders described high costs and limited capacity for such services. Families may then go without necessary preventative or management services, with potentially negative repercussions for the Autistic person and the family as a whole (Bonis, 2016; Nicholas et al., 2016; Tint & Weiss, 2016; Vogan et al., 2014). Indirectly, the stress of ongoing caregiving responsibilities may also result in higher medical costs (e.g., counselling, medication) for parents or other family members (de Leeuw et al., 2020; Rogge & Janssen, 2019). These costs may not be covered by workplace insurance benefits if one or both parents have decreased their work hours to provide day-to-day care.

Supporting the Labour Market Participation of Parents

Parents face multiple obstacles to employment, including misunderstandings with colleagues, lack of opportunities, and rigid human resource policies (Liao & Li, 2020). For parents of

Autistic children, part- or full-time paid employment was consistently associated with higher parental quality of life (Vasilopoulou & Nisbet, 2016). As such, strategies could focus on improving the lower labour market participation of parents of Autistic individuals. Parental supporters, while not typically viewed as an *equity-seeking group* by institutional Equity, Diversity, and Inclusion policies, may have particular needs and barriers that could be addressed, particularly if they themselves are autistic. Compassionate leave policies and flexible work arrangements may aid parents to remain in the workplace without compromising their Autistic family member's required care which may include frequent appointments or parent-mediated supports (Gnanasekaran et al., 2016). Some other examples of best practices include shifting employer and human resource professionals' attitudes towards these parents through acceptance and awareness campaigns and partnerships with employee assistance plans and services.

“The hardest was not being able to work - being told that I was a ‘liability to the corporation because I had an Autistic child’. How does one pay for any service if the parent doesn’t have a job due to the disability?”

- Family member of an Autistic person

An initiative developed by two Canadian unions shows potential merit in developing more supportive workplace practices for employees who are also parents of disabled children or adults, including parents of Autistic children or adults. In 1996, the Canadian Union of Postal Workers and the Union of Postal Communications Employees (Public Service Alliance of Canada) developed the [Special Needs Project](#) to offer support to their employees (Canadian Union of Postal Workers & the Union of Postal Communications Employees - Public Service Alliance of Canada, 2022). In 2005, this initiative was expanded through the Moving On Project to employers with disabled adult children, including those with Autistic adult children, who are dependents. Within two programs, employees are offered information, resources, and financial support through:

- Biannual contact with a special needs advisor,
 - Funding for services such as *life skills*, transportation, and uninsured health expenses,
 - A regular newsletter and website,
 - Ongoing support from the project office, and
 - An annual teleconference.
-

An evaluation of this program by the Canadian Centre of Disability Studies found that members who used these programs indicated increased knowledge and ability to identify supports

as well as an increase in the quality and quantity of the supports they currently accessed (Wicklund et al., 2017). Since joining the program, surveyed members also reported greater economic wellbeing. No data was available, however, on whether these programs influenced the work attendance of these parents.

Long-Term Financial Stability

In the current Canadian context, even relatively prosperous families of an Autistic person may struggle with financial stability, as few families can generate sufficient income to cover the high lifetime support costs for their Autistic child, especially if they have *complex support needs* (Dudley & Emery, 2014). Moreover, many families do not have power of attorney, a will, or an estate plan in place (Dudley & Nakane, 2017).

The Canadian system has few programs or services in place that promote financial literacy or planning for Autistic individuals or their families. While free tax clinics and individual assistance for tax filing are available through the Canada Revenue Agency, these services are typically limited to those with modest incomes and a simple tax scenario (Government of Canada, 2020b). Yet, as outlined in the background, the layers of intertwined tax deductions and credits, may create quite complex tax scenarios for many families of Autistic individuals. As such, developing, implementing, and evaluating financial and long-term planning supports and navigation (Cheak-Zamora et al., 2017) within person-centred, supported decision-making frameworks may help to ensure Autistic people and their families gain knowledge and proactively consider future life decisions (Hillman et al., 2012; Ratti et al., 2016; Volkmar et al., 2017).

Such financial services could raise awareness about the Registered Disability Savings Plan and other Canadian and provincial/territorial tax measures (Autism Ontario, 2009; Canadian Autism Spectrum Disorder Alliance, 2020b). Services could be offered online and in-person, perhaps as part of the role and responsibilities of system navigators/third party supporters (Dudley & Nakane, 2017; Government Accountability Office, 2013; 2016; Government of British Columbia, 2021; McLaughlin & Schneider, 2019; Department of Education and Early Childhood Development, 2009). Further, families may benefit from knowledge of, affordable access to, and linkages to microboards (see Chapter 3) and/or third-party supporters (Dudley & Nakane, 2017; Ontario Developmental Services Housing Task Force, 2018).

Inter-Ministerial Coordination

To meet the needs of such a heterogenous and intersectional population, economic policy options aimed at supporting Autistic people and their families require considerable flexibility, rather than a 'one size fits all' solution. Accordingly, to ensure that new and existing supports neither create gaps, nor duplications amongst sectors and systems, inter-ministerial and inter-sectoral bridging and coordination have been strongly suggested across multiple jurisdictions

(Eggleton & Keon, 2007; Scottish Government, 2011; Government Accountability Office, 2014; World Health Organization, 2013a; Autism Europe, 2019; Autism Europe, 2020; Canadian Autism Spectrum Disorder Alliance, 2020b; Autism Spectrum Disorder in the European Union, 2018, Autism Canada, 2011). Such governmental partnerships will likely require formal protocols and accountability mechanisms. They could begin by focusing on the longstanding issues facing Autistic Canadians and their families, such as the Disability Tax Credit and Registered Disability Savings Plan, housing waitlists, and adult services.

Key Findings - Financial Stability

Offsetting common out-of-pocket costs associated with autism such as home modifications, transportation, therapeutic products, and day supports can promote family and individual wellbeing and financial stability across the lifespan.

Labour market participation of parents of Autistic individuals can benefit the entire family and be supported through workplace policies and provisions, offered, for example, through unions, employee assistance plans, and supportive human resource departments.

Access to trusted, non-partisan financial planning and financial literacy supports and services can better equip Autistic people and their families to understand and make informed decisions that promote long-term financial stability and wellbeing.

A pathway for Autistic individuals to financial stability can be achieved by disability benefits that are flexible, needs-based, and accessible, taking into consideration the extra costs associated with the condition.

5.2 Post-Secondary Education and Lifelong Learning

5.2.1 Background

There are now more Autistic students on college and university campuses than ever before (Tipton & Blacher, 2014); yet, their post-secondary graduation rate remains lower than other disabled and non-disabled students (Berrigan et al., 2020; Sansosti et al., 2017). The lower enrollment of Autistic individuals in colleges and universities is troubling because many have the academic and cognitive capacity to participate in post-secondary education and obtain a degree, which is often necessary to secure employment in high demand occupations that pay a living wage (Sansosti et al., 2017). Despite the increased enrollment of Autistic people in post-secondary educational institutions as well as the quality of life (Mulder & Cashin, 2014; Schall et al., 2012) and the Equity, Diversity and *Inclusion* benefits of including Autistic individuals in post-secondary education (Clouder et al., 2020), Autistic individuals continue to face multiple barriers to accessing, engaging in, and benefitting vocationally from post-secondary pathways.

Research findings about Autistic students' participation in post-secondary education comes mainly from international studies. Moreover, Canadian post-secondary participation rates are challenging to estimate, with highly variable survey results. Based on the 2017 Canadian Survey on Disability, 45% of Autistic respondents had not completed any post-secondary education as compared to 33% of non-disabled people (Berrigan et al., 2020). A smaller survey by the National Education Association of Disabled Students found that only 3.4% of post-secondary students self-reported an autism diagnosis (National Educational Association of Disabled Students, 2018). The limitations of existing pan-Canadian surveys are discussed in more detail in Chapter 6.

While general disability service programs are available to Autistic students in colleges and universities, they often require more and/or different *accommodations*, programs, and services across multiple life domains (van Schalkwyk & Volkmar, 2017; Nuske, Rillota et al., 2019), which are not widely available on Canadian campuses. In addition, attitudes and knowledge of faculty, administrators, staff, students, and disability service providers can influence whether, and how, Autistic students are welcomed and supported to succeed on campus. Policy, legislation, eligibility, and funding structures also impact how Autistic students are supported to access, engage, and benefit from post-secondary education.

“I’m currently attending college and it’s been horrible and discriminatory so far. The department of accessible learning services baby talks to me, and the accommodations that I ask for are routinely argued about/denied by staff ... You’re essentially treated like you’re trying to scam/cheat the system every step of the way.”

- Autistic adult

5.2.2 Best and Promising Practices

The following section outlines potential implementation strategies across the key areas of:

- Enabling the proportional inclusion of Autistic individuals in post-secondary education,
- Providing autism-inclusive disability services and educational accommodations, including efforts to offer more flexible enrollment options,
- Addressing financial barriers to enrollment,
- Promoting *autism acceptance* and autism leadership on campus, and
- Facilitating flexible education-to-employment pathways.

Proportional Inclusion of Autistic Individuals in Post-Secondary Education

Autistic students' increased participation in post-secondary education parallels the overall increased prevalence of autism diagnoses over the last two decades (Housel, 2020; Kuder & Accardo, 2018; Widman & Lopez-Reyna, 2020). Furthermore, shifts in education and disability legislation to improve educational experiences have encouraged more Autistic students to complete secondary school and thus, meet college and university academic entrance requirements (Grogan, 2015). However, while more Autistic youth are enrolling in post-secondary education, they are still less likely than other disabled or non-autistic youth to enrol (Sansosti et al., 2017) and they are not graduating at the same rates (Mulder & Cashin, 2014).

Autistic students face greater retention challenges, as compared to other disability groups, and their experiences of discrimination (Pinder-Amaker, 2014) may warrant particular focus within Equity, Diversity, and Inclusion (EDI) and *intersectionality* frameworks. While acknowledged in many EDI frameworks, disability may not be given adequate and/or appropriate focus in all post-secondary institutions (Wolbring & Lillywhite, 2021). Even when incorporated, the particular challenges and needs of certain groups, such as Autistic people, may be overlooked and therefore, not sufficiently addressed. Clear campus processes and protocols are needed to address stigma and discrimination experienced by Autistic people. Further research to inform EDI efforts focused on disability more broadly and autism more specifically, along with professional development and ongoing education regarding autism and *neurodiversity* within EDI initiatives, could better address systemic barriers and biases experienced by Autistic students and staff in post-secondary institutions (Wolbring & Lillywhite, 2021).

To address the widening gap of post-secondary educational attainment between Autistic individuals and their non-autistic peers, post-secondary institutions should prioritize substantial admission of Autistic students across all forms of post-secondary education with integrated supports and accommodations aligned with individual needs (Beschen, 2018; Cashin, 2018; Luey, 2014; National Educational Association of Disabled Students, 2018). Universities and colleges, like elementary and secondary schools, are discovering that Autistic students have a

Summary Points

Autistic individuals are not proportionally included in Canadian post-secondary institutions in student admissions, and staff and faculty hiring, as they face stigma and discrimination.

Current supports and accommodations in post-secondary education are not aligned with the range of abilities and needs of Autistic students.

The costs of attending post-secondary education can be especially prohibitive for Autistic students who may need more time and more support to complete programs.

positive impact, not only on other students, but on the university community as a whole (Bruce, 2011; Mulder & Cashin, 2014).

Autism-Inclusive Programs, Services, and Accommodations

An important step to promote educational success is ensuring rapid, accessible, and seamless acceptance of Autistic students into student disability services (Anderson et al., 2019; Clouder et al., 2020; Kuder & Accardo, 2018; National Educational Association of Disabled Students, 2018; Department of Health, Social Services and Public Safety, 2015). However, many campus disability services may not offer the necessary services and accommodations to effectively support Autistic students (Duerksen et al., 2021; Nuske, Rillotta et al., 2019). In 2016, 45 US colleges and universities indicated that they offered specialized services for Autistic students; however, only 31 of the 45 actually provided services beyond what they offered to any other disabled student (Kuder & Accardo, 2018).

There is an emerging body of evidence highlighting autism-specific programs and practices to improve educational experiences and graduation rates. These programs and practices address documented challenges associated with:

- Transition to a new environment where Autistic students are typically expected to self-advocate for their needs (Kuder & Accardo, 2018; Mulder & Cashin, 2014; van Schalkwyk & Volkmar, 2017),
- The lack of autism-knowledgeable service providers and mentors in disability services (Clouder et al., 2020; Sarrett, 2018), and
- The limitations and inflexibility of generalist accommodations (Duerksen et al., 2021; Nuske, Rillotta et al., 2019).

In the United States, there are now more than 74 Autism-Specific or Specialist Programs on college and university campuses (Nachman et al., 2021). These programs are designed to support Autistic students' success by capitalizing on their strengths and providing them with support that meets their distinctive needs. While the mix of services offered by these programs vary dramatically, as do their administrative structures, program fees, and student enrollment, there are commonalities across the programs. All programs offer a combination of the following evidence-informed and/or best practices (Anderson et al., 2019; Nachman, 2016):

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- Testing accommodations,
 - Curriculum planning accommodations,
 - Tutoring services,
 - Specialized orientation or transition services,
 - Parent involvement,
 - Social skills training,
 - Life skills support,
 - Mental health support/therapy,
 - Accommodations for class activities, and
 - Peer mentors.
-

A very recent study scanned Canadian post-secondary institutions for similar autism-specific supports (Ames et al., 2022). The authors found that of the 258 publicly-funded post-secondary institutions in Canada, only 15 (6%) had at least one support. Of the 15 institutions identified, the most common autism-specific support included information on the institution's website (67%), followed by transition to university support (47%), social group(s) (33%), peer mentoring (27%), specialist tutoring and support with daily living (20%), transition to employment support (13%), and student-led societies and Autistic student advocates (7%). A much earlier study found that a few institutions, such as York University and Algonquin College in Ontario have run pilot programs (Luey, 2014). As per Ames and colleagues (2022), a disproportionate number of autism-specific supports are only available in central Canada. To promote and expand existing programs, it may be worthwhile to develop online repositories/resources for Canadian programs and services based on US examples (Beschen, 2018; Hewitt, 2011; Nachman et al., 2021; Zeedyk et al., 2016).

Studies have demonstrated the feasibility and social validity for particular autism-specific or specialist program components, such as:

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- **Peer mentoring** (Anderson et al., 2019; Beschen, 2018; Carter et al., 2014; Cashin, 2018; Cremin et al., 2021; Duerksen et al., 2021; Grogan, 2015; Kuder & Accardo, 2018; Luey, 2014; Nguyen et al., 2020; Paskins et al., 2018; Siew et al., 2017),
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- **On-campus transition programs** (Carter et al., 2014; Clouder et al., 2020; Grogan, 2015; Kuder & Accardo, 2018; Lei et al., 2020; White et al., 2017; White et al., 2021; Department of Health, Social Services and Public Safety, 2015),
 - **Residence life planning and supports** (Duerksen et al., 2021; Luey, 2014; Mulder & Cashin, 2014; Pinder-Amaker, 2014),
 - **Disability support groups** (Clouder et al., 2020; Pinder-Amaker, 2014),
 - **Life skills coaching** (Carter et al., 2014; Widman & Lopez-Reyna, 2020), and
 - **Inclusive extracurricular opportunities** (Aylward, 2016; Beschen, 2018; Widman & Lopez-Reyna, 2020).
-

However, there have been insufficient controlled trials to classify any practice as evidence-based (Anderson et al., 2019). Clear linkages between campus disability and mental health services were also identified as needed/desirable (Anderson et al., 2019; Luey, 2014; Mulder & Cashin, 2014; Nachman, 2016; Perryman et al., 2020; Pinder-Amaker, 2014). Conflict and miscommunication amongst services can lead to inconsistent supports (Clouder et al., 2020).

Offering accommodations relevant to the abilities and needs of Autistic students is also a major topic of interest. In addition to the general accommodations offered by disability services, such as tutors, scribes, and extra time and/or solitary environments for examinations, there are many examples of autism-specific accommodations that could be incorporated into standard practice. For example, offering preferred seating, allowing recording of lectures and presentations, modifying course loads, organizing for early/priority registration, and allowing course substitutions have been recommended (Anderson et al., 2019; Duerksen et al., 2021; Hewitt, 2011; Highlen, 2017; Kuder & Accardo, 2018; Luey, 2014; Mulder & Cashin, 2014; Sansosti et al., 2017; Toor et al., 2016; Widman & Lopez-Reyna, 2020). Other autism-specific accommodations included allowing for body movement (e.g., pacing or fidgeting) or using non-disruptive sensory items or sensory-limiting devices, such as wearing sunglasses or headphones, offering alternate formats for exams or assignments (e.g., video submissions), avoiding cold calling in class, and permitting to bringing objects, drink, or food, and taking breaks as needed.

It may be helpful to consider how accessibility legislation may apply to Autistic students in post-secondary environments (Beschen, 2018; Cox et al., 2020). This autism lens may include reviewing how institutions and professional programs implement degree or program certifications. Compulsory course requirements, timelines, and rigid assessment methods and criteria may act as barriers to enrollment and graduation. Such regulations can make it more challenging for many Autistic students to personalize their course load or to work towards degree requirements over a longer period of time.

Developing more individualized, less rigid approaches to fulfilling degree requirements, curriculum, and/or assessment methods may offer Autistic students more independent, non-

traditional, and/or online (Adams et al., 2019) study opportunities. Modularized course content can also allow for greater flexibility in meeting course and degree requirements at one's own pace. It recognizes that some Autistic students may have particular interests, which would allow them to excel in certain subjects, but experience challenges in other subjects due to factors related to their autism, such as potential difficulties with language courses. The notion of “diplomation fractionnée” takes this flexibility one step further, by suggesting that academic degree requirements, at either the secondary and post-secondary level, can be modified to account for Autistic peoples' strengths and areas of challenge.

In practice, a very limited number of post-secondary institutions have shifted towards offering flexible and creative pathways in and through educational programs for both Autistic and non-autistic students. For example, the national [Construire une Université Aspie-Friendly](#) project in France is looking to adapt the *Diplôme d'Accès aux Etudes Universitaires* [diploma to access university studies] to enable secondary school graduates, who do not have a bachelor's degree, to pursue a university degree that could lead to postgraduate studies (Aspie-Friendly, n.d.). At the Université de Montréal, the [Programme de Formation de Cliniciens - Chercheurs](#) offers three different pathways for students to complete their degree (Université de Montréal, Faculté de médecine, n.d.). Both of these programs exemplify how post-secondary policies and programs can be more inclusive of Autistic students. These examples demonstrate what may be possible rather than widely-implemented practices.

Added Financial Barriers to Post-Secondary Education

Reforms to the cost of tuition may make post-secondary education more accessible to Autistic students. Both the evidence and stakeholders suggest that the costs of completing a certificate or degree program is more expensive for Canadian Autistic students who often require more time to finish (National Educational Association of Disabled Students, 2018; Luey, 2014).

As a disability accommodation, institutions might consider revising university and student loan policies allowing part-time students to pay reduced fees, or subsidizing fees (Beschen, 2018; Cashin, 2018; National Educational Association of Disabled Students, 2018). Increased availability of scholarships, grants, and subsidized cooperative education programs targeted to Autistic students may also offset prohibitive costs (Beschen, 2018; Cashin, 2018; National Educational Association of Disabled Students, 2018). Pan-Canadian loan forgiveness for Autistic students who have completed their degrees (National Educational Association of Disabled Students, 2018) and entered the labour market could also reinforce transitions along the education-to-employment pathway. Providing a single residence room at a reduced cost is another useful form of accommodation (Luey, 2014). Currently there are several grant and tax deduction programs in place to offset the costs of education for disabled students who qualify for the Disability Tax Credit (Duclos et al., 2019), such as the:

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- **Disability Supports Deduction** (which allows deductions for expenses such as assistive devices, job coaching, note-taking, or tutoring services),
 - **Canada Student Grant for Services and Equipment for Students with Permanent Disabilities** (which was increased to \$20,000 in 2019), and
 - **Repayment Assistance Plan for Borrowers with a Permanent Disability** (which had restrictions removed in 2020 so that borrowers who have been out of study for five years can receive further grants and loans).
-

However, a system barrier to student enrollment and persistence is the extensive verbal and written communication required to apply for and access college, disability services, and student loans and grants. Parental or family involvement during the transition to a post-secondary environment is often essential for student success and requires ongoing communication between university disability service providers and family members (Bryan et al., 2015; Carter et al., 2014; Clouder et al., 2020; Luey, 2014; Nuske, McGhee et al., 2019; Toor et al., 2016). However, collaboration between family members and post-secondary education staff can be difficult due to barriers imposed by relevant privacy legislation and institutional policies (Nuske, Rillotta et al., 2019). As a starting point, providing transparent and accessible information and hands-on support for Autistic students and their families would help ensure they can clearly understand, apply for, and manage student loans, admissions, and disability service application processes (Duerksen et al., 2021; Luey, 2014; National Educational Association of Disabled Students, 2018; Bryan et al., 2015; Nuske, Rillotta et al., 2019).

Autism Acceptance and Leadership on Canadian Campuses

Autistic students and their parents have repeatedly asked for greater acceptance and awareness as well as knowledge of autism in post-secondary educational institutions (Anderson et al., 2019; Nuske, McGhee et al., 2019; Sarrett, 2018), through campus-wide autism education campaigns and training for staff and faculty members (Duerksen et al., 2021; Nachman, 2016; Sansosti et al., 2017; Sarrett, 2018; Tipton & Blacher, 2014). Developing inclusive extracurricular programs and activities that bring together diverse students has been shown to foster positive student experiences and campus inclusion (Aylward, 2016; Beschen, 2018).

Many disability service providers are not trained to understand and support the specific needs of Autistic students (Luey, 2014; Mulder & Cashin, 2014), and a lack of funding and professionals specialized in neurodiversity can hamper service effectiveness resulting in under-enrollment and students withdrawing from programs due to a lack of follow-up, support, and resources (Clouder et al., 2020). Advanced professional development for these providers may improve autism acceptance and awareness. To counter the limited resources and geographic disparities in service access, further investment in supportive, knowledgeable admission, mental health, and disability service providers including psychologists, speech-language pathologists, and

occupational therapists may be required (Anderson et al., 2019; Carter & McCabe, 2021; Cashin, 2018; Grogan, 2015; Highlen, 2017; Perryman et al., 2020).

Campus inclusivity and accessibility can be further improved by applying a sensory lens to campus and residence building design and infrastructure (Anderson et al., 2019; Luey, 2014). The social and physical environment, as well as the available space and infrastructure, can create barriers by forming busy, loud, large, and crowded classes, campuses, and residences that do not naturally accommodate the neurodiverse needs of Autistic students (Toor et al., 2016). In a survey study, sensory-friendly spaces and practices were the second most desired accommodation, preceded by increased *autism awareness* on campus (Sarrett, 2018). Suggested modifications to the classroom and campus environment included access to private, quiet, and low sensory environments located close to tutoring or counselling centres (Anderson et al., 2019; Luey, 2014).

Faculty and instructors also have a role to play in autism acceptance and could benefit from advanced professional development specific to autism. Instructors have reported difficulty in fostering group interaction among socially anxious and Autistic students (National Educational Association of Disabled Students, 2018). Knowledge dissemination and implementing Universal Design for Learning in the classroom may also support increased educational practices that are designed for multiple learning preferences (Adams, 2017; Clouder et al., 2020; Grogan, 2015; Housel, 2020; Jansen et al., 2018; Luey, 2014; National Educational Association of Disabled Students, 2018; Sarrett, 2018).

Autistic students would benefit from campus support focused on building *self-advocacy* skills (Clouder et al., 2020). The principle of autism acceptance is closely linked to autism leadership and self-advocacy. Campus autism-specific programs, practices, and research should be designed and implemented in consultation with Autistic persons. Additionally, proportional representation of Autistic persons on campus should be accompanied by commensurate representation on student and post-secondary disability-related boards or committees.

Education-to-Employment Pathways

There are multiple economic and social benefits to completing post-secondary education, including improved career prospects, higher lifetime earnings, access to greater social capital, and increased learning opportunities (Carter et al., 2014). However, college-educated Autistic people still experience high rates of unemployment or non-employment without real-time, real-life paid work experience (Schall et al., 2012). The current ‘education’ logic inherent in Canada’s post-secondary training system has diminished the employment experiences and training all youth and young adults (Arnold et al., 2018; Wheelahan & Moodie, 2017). Autistic students, therefore, may benefit from enhanced and intentional access to internships, cooperative education, and campus employment services (Lei et al., 2020; Luey, 2014; Nachman, 2016;

National Educational Association of Disabled Students, 2018; Pinder-Amaker, 2014; Stainton et al., 2018). Accordingly, a preliminary step could involve ensuring proportional representation of Autistic students within existing pan-Canadian programs such as the Student Work Placement Program and the Employment Opportunity for Students with Disabilities (a component of the Federal Student Work Experience Program). More supportive processes within academic institutions may also encourage Autistic students to attend graduate school, such as supporting social skill development in how to obtain reference letters from professors or to inquire about participating as a lab or research team member (Zeedyk et al., 2016).

We could not find evidence pertaining to the inclusion of Autistic individuals in trades and technical institutes. Currently there are few formal pathways to experiential work for Autistic individuals, who are not enrolled in university or college. Further research is needed to fill this gap, as well as to evaluate the impact of current education-to-employment pathways (Highlen, 2017; Housel, 2020; Widman & Lopez-Reyna, 2020). The extent to which flexible and seamless access to accommodations and supports provided by knowledgeable providers are available, irrespective of the education-to-employment pathway, is unknown (Stainton et al., 2018). Under the mandate of Employment and Social Development Canada, two programs, the Skilled Trades Awareness and Readiness Program and Supporting Apprenticeship Training and Access to Skilled Trades are aimed at encouraging careers in the trades. There may be opportunities within these programs' mandates to consider ways to include Autistic individuals who might be interested in and/or benefit from such a hands-on education-to-employment pathway.

Key Findings - Post-Secondary Education and Lifelong Learning

Incorporating neurodiversity within post-secondary Equity, Diversity, and Inclusion frameworks can bring stronger acceptance and support of Autistic individuals, and mitigate stigma and discrimination. It can also promote autistic leadership and participation in decision-making on campuses.

Wider-spread implementation of autism-specific supports and programs, as well as more general disability accommodations and financial supports, can promote positive student experiences and academic success of Autistic students.

Diversifying current education-to-employment pathways to include trades and technical programs and on-the-job training with commensurate supports and accommodations, can further support the economic inclusion of Autistic individuals.

5.3 Employment Pathways

5.3.1 Background

Employment has been linked to many positive experiences and outcomes (Bunt et al., 2020; Schall et al., 2020). For Autistic people, employment can promote personal dignity, improve quality of life and self-esteem, enhance cognitive performance and self-sufficiency, and reduce experiences of stigma and social isolation (Dunn et al., 2018; Hedley et al., 2017; Jacob et al., 2016; Khalifa et al., 2020).

“... He sets up tables ... for the lunch program. He’s almost ... like a caretaker, basically, like wiping down stuff ... once you tell him and he does it over and over, then it comes to a point where you don’t have to tell him because he knows exactly what to do so ... and he’s got a really sharp memory ... ” Autistic adult with family member

Yet, around the world, Autistic individuals are more likely than non-autistic and other disabled adults to be unemployed, underemployed, and overqualified or overeducated relative to job level (Lindsay et al., 2021; Munandar et al., 2020; Nicholas & Klag, 2020; Sansosti et al., 2017). For instance, national data from the United Kingdom indicates that only 21.7% of Autistic adults were employed in 2020, representing the lowest employment rate among all disabled groups surveyed (Putz et al., 2021). Even when employed, their work roles are often precarious (e.g., low pay, short-term contracts with no benefits) (Hedley et al., 2017; Scott et al., 2019). Job advancement opportunities may be impacted by uneven job histories, leading repeatedly to entry-level jobs regardless of educational level (Dudley & Zwicker, 2016b). The cascading effects of unemployment or underemployment for Autistic people include financial insecurity, poor self-esteem, reduced ability to live independently, and lower community participation (Dunn et al., 2018).

Summary Points

Autistic secondary school and post-secondary students do not have equitable and intentional access to employment readiness and work experience opportunities, which means they are disadvantaged in the pursuit of long-term employment.

Employment services do not fully consider the strengths, abilities, or needs of Autistic job seekers. Furthermore, many employment service providers and human resource professionals have limited skills and knowledge specific to the needs of Autistic persons.



Many Autistic individuals want to and are able to work, representing a motivated, but largely untapped workforce. A survey by the National Autistic Society in the United Kingdom showed that 77% of unemployed participants wanted to work. Ideally, work would be meaningful, aligned with their strengths and interests, and take place in integrated settings for equitable wages (Bunt et al., 2020; Canadian Association of Community Living, 2011; DePape & Lindsay, 2016; Dudley & Zwicker, 2016b; Nicholas et al., 2015).

Employment offsets the growing economic costs associated with autism (Hedley et al., 2017; Rogge & Janssen, 2019). More Autistic individuals transitioning from the disability income system to competitive employment equates to increased tax earnings and contributions to the Canadian Gross Domestic Product (Dunn et al., 2018). It also translates into less reliance on government funds and publicly-funded community programs (Bunt et al., 2020; Jacob et al., 2016; Khalifa et al., 2020; Scott et al., 2019). Lost employment for Autistic adults accounted for 36% of the £25 billion (approximately CAN\$45 billion) aggregate national cost associated with autism in the UK (Buescher et al., 2014).

However, in order to see these potential cost savings, governments may need to consider shifting public funding to support evidence-informed employment programs and services for Autistic people. Recent cost analyses suggest that over the long-term, providing supported employment services for Autistic adults would not only cut costs when compared to standard practices (e.g., disability supports/welfare, day programming), but also result in better overall outcomes for Autistic people and their families (Jacob et al., 2016).

Enhancing opportunities for Autistic adults to join the workforce is not only inclusive, but also economically beneficial (Jacob et al., 2016). Implementing inclusive business practices (e.g., diversity) is financially beneficial to businesses/organizations through improved financial targets and better business outcomes, being innovative and agile, and encouraging high performing teams (Bourke, 2021). While individual strengths and challenges vary significantly among Autistic people, many have multiple skills and abilities that can be assets in work environments, such as honesty, integrity, efficiency, reliability, precision, consistency, low absenteeism, attention to detail, lack of interest in office politics, accurate visual perception, systematic information processing, technical abilities, concentration, long-term memory, strong work ethic, prompt task commencement, and a high tolerance for repetitive activities (Jacob et al., 2016; Khalifa et al., 2020; Lindsay et al., 2021; Scott et al., 2019).

Overall, Autistic adults are disproportionately excluded from Canadian employment, with an employment rate of 14.3% for individuals over 15 years of age (Zwicker et al., 2017). Canadian Autistic youth and young adults face several barriers along pathways to meaningful employment, such as lack of vocational education opportunities (Nicholas et al., 2015), limited autism awareness and ableist attitudes of employers and human resource professionals (Bunt et al., 2020; Lindsay et



There are benefits of inclusive workplaces and contributions of Autistic workers. Without supports for Autistic people and for employers, this largely untapped workforce may continue to experience systemic exclusion from entering into and advancing within the labour market.

al., 2021; DePape & Lindsay, 2016), few accessible employment programs with appropriately trained service providers (Hedley et al., 2017; National Autistic Society, 2016; Nicholas, Zwaigenbaum et al., 2018), and disincentives to work built into the health and social service systems (Khayat-zadeh-Mahani et al., 2020; Emery, 2019). The majority of Autistic adults in Canada are neither employed, nor unemployed, rather they are not engaged in the labour market or intending to work. Their absence from the labour market is largely due to an unreceptive and unsupportive employment context (Dunn et al., 2018; Nicholas & Klag, 2020; Romualdez et al., 2020).

A fragmented and siloed service environment contributes to inequitable transitional and employment service access and adequacy among Autistic people (Nicholas, Zwaigenbaum et al., 2018). Limited employer engagement with families and an overall lack of community and employer capacity were also identified as pressing gaps. Further, a lack of accessible transportation and mental health services, housing, inadequate training, discrimination, jobs not adapted to needs, concerns about being isolated on the job, as well as losing income security and disability benefits all contribute to suppressed job search activity (Crawford, 2011; Nicholas, Zwaigenbaum, et al., 2018). Canadian evidence suggests that loss of disability benefits is a major barrier with more than 25% of persons with *developmental disabilities* (including Autistic people) being concerned they would lose some or all of their income and benefits (Crawford, 2011). Another Canadian report suggested that these clawbacks were the largest factor limiting an individual's hours of work in an Employment First program for persons with developmental disabilities and Autistic people (Emery, 2019). As described in Figure 7, Employment First approaches support a policy of employment in the general workforce as the first and preferred option for disabled individuals receiving assistance from publicly-funded systems.

5.3.2 Best and Promising Practices

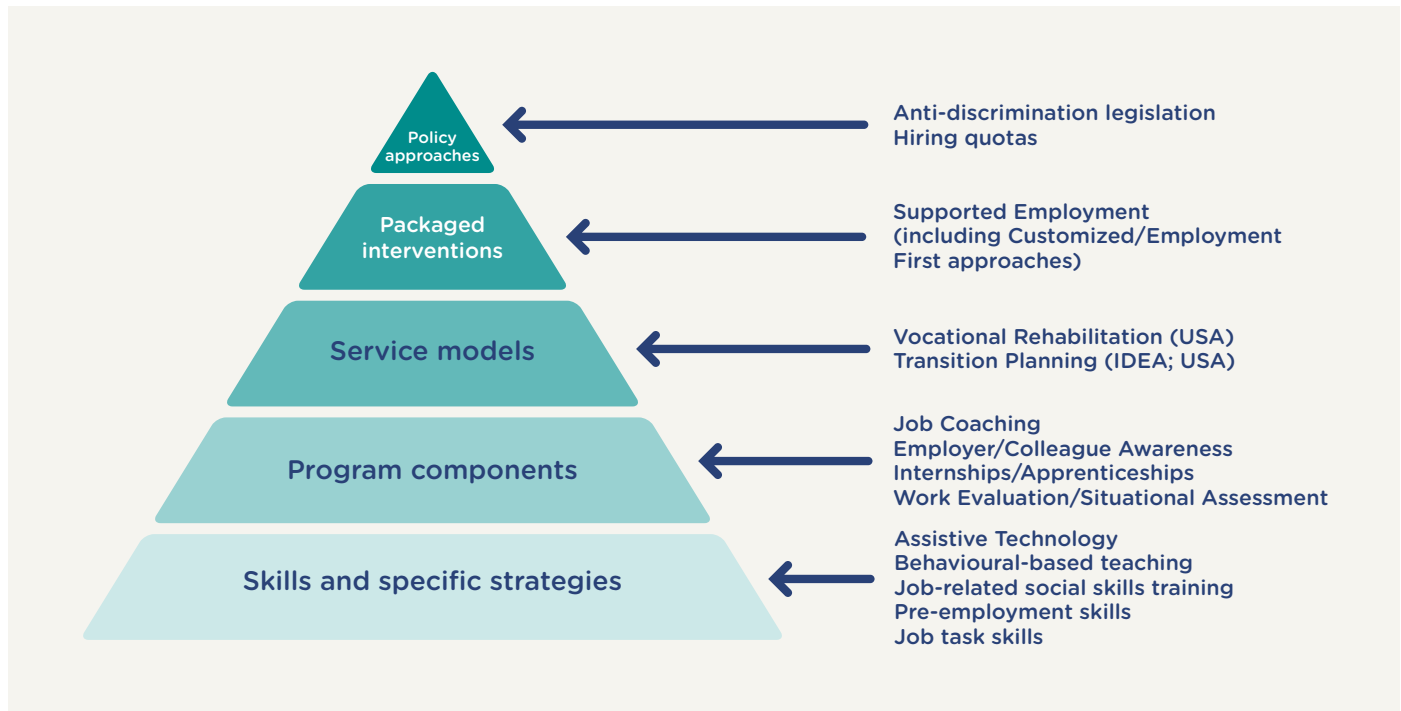
There are several directions to improve the employment outcomes of Autistic Canadians, including:

- Providing autism-inclusive job supports and accommodations,
- Ensuring equitable access to employment readiness and work experience opportunities,
- Addressing social assistance disincentives,
- Increasing availability and accessibility of general employment services, and
- Promoting and incentivizing strengths-based autism acceptance in employment settings.

Evidence-Informed, Autism-Inclusive Job Supports and Accommodations

There were multiple approaches to improving employment outcomes for Autistic people found in the research literature, such as policy approaches, packaged interventions, services models, and specific skills and strategies (see Figure 7). A recurring intervention approach in the literature was that of supported employment.

Figure 7. Categories of Employment Supports found in the research evidence.



As outlined by a recent systematic review (Lindsay et al., 2021), there are many specific forms of accommodations that an Autistic worker may desire or require, such as:

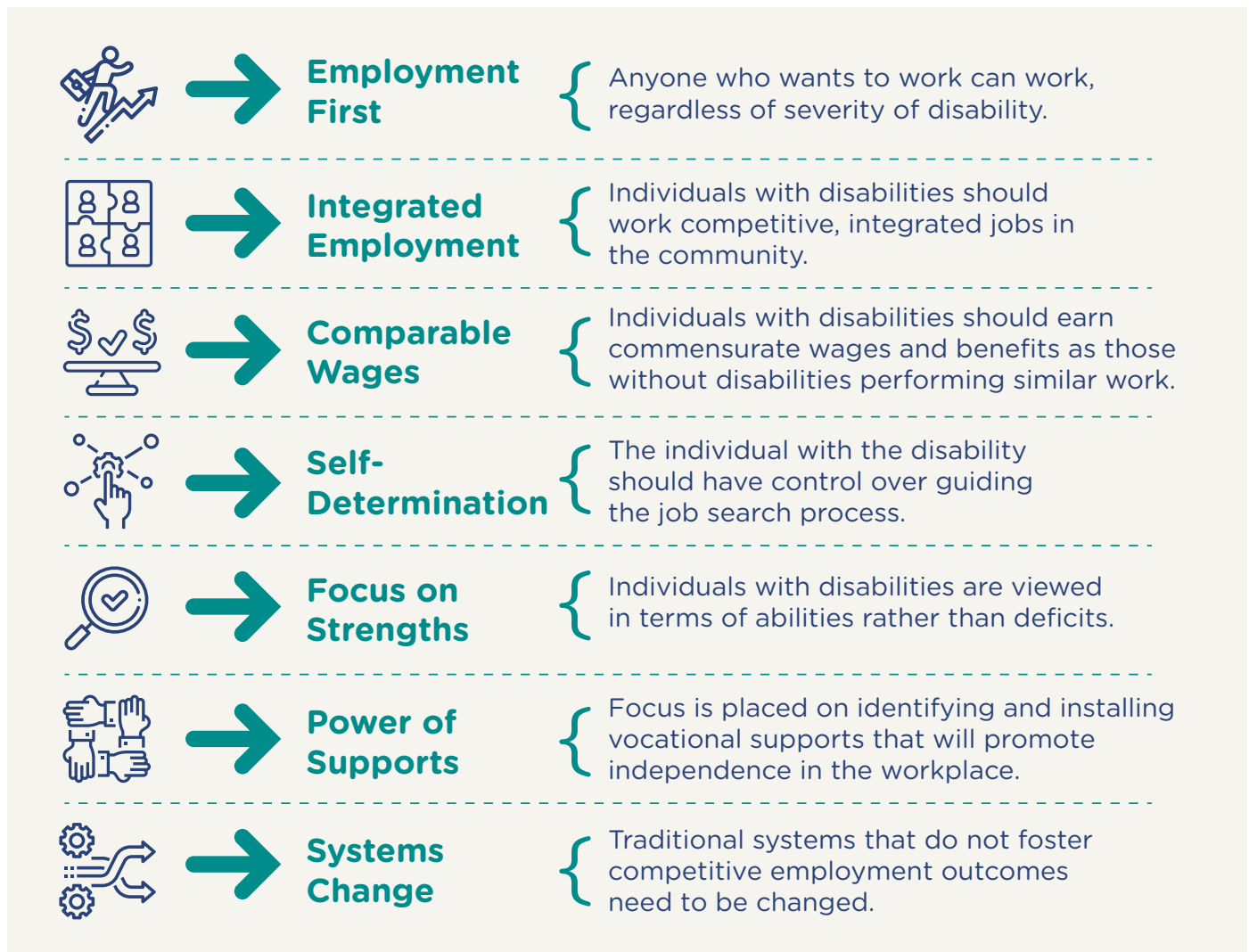
- Online or written format alternatives for job interviews,
- Maintaining a consistent schedule and responsibilities,
- Using organizers to structure the job,
- Reducing unstructured time,
- Using direct communication and providing reminders and assurances,
- Sensory/environmental modifications,
- Single occupancy rooms when travelling for work,
- Recording meetings,
- Working from home or in quiet space,
- Greater disability awareness and sensitivity from colleagues,
- Flexible hours,

- Special lighting,
 - Exemption from customer facing tasks,
 - Tailored supervision such as written instructions,
 - Use of video modelling/work simulation, and
 - Assistive dogs in integrated employment settings.
-

Supported employment approaches may be one of most impactful practice that results in sustained job retention for Autistic youth and adults (Dudley & Zwicker, 2016b; Sansosti et al., 2017; Schall et al., 2020; Vogeley et al., 2013). Services related to supported employment can include advice and education regarding preparing resumes, completion of job applications, and developing interview skills. Job training could also be offered using simulation training, visual imagery, and the use of compensatory strategies (e.g., technologies, checklists, and others) (Khalifa et al., 2020). Approaches such as interview and job training, job coaching, support to find jobs and liaise with employers, as well as internships and other applied opportunities, have effectively increased employment for Autistic people with and without co-occurring intellectual disability (Lorenc et al., 2018; Schall et al., 2020). According to Schall et al., (2020), 73 - 90% of Autistic individuals with and without co-occurring intellectual disability who participated in a supported employment program that incorporated highly-trained autism employment specialists, provided internship opportunities, and fostered collaborations across multiple agencies, obtained competitive integrated employment, compared to only 6 - 17% of those who did not participate in the program. The principles of supported employment are outlined in Figure 8.

Canadian statistics suggest that more than 40% of workers with developmental disabilities require workplace accommodations, including modified work hours (28.9%) and duties (26.1%), as well as human supports (17.9%) (Zwicker et al., 2017). Autistic workers may also need other forms of accommodations that differ from the physical modifications required by physically disabled persons (Lindsay et al., 2021). For instance, the initial interviewing process to obtain employment is an area that many Autistic people find challenging (Scott et al., 2019; Lorenz et al., 2016). Adaptations such as more explicit and structured interview questions (e.g., requesting for specific details and examples), asking one question at a time, and providing interviewees with a print-out of the questions can contribute to better quality responses by Autistic interviewees (Maras et al., 2021).

Figure 8. Principles of Supported Employment. Principles as described by Schall et al., 2020 in the context of Project SEARCH.



Currently there are a concerning lack of supported employment programs particular to the unique needs of Autistic people across Canada. In some jurisdictions (e.g. Newfoundland and Labrador), autism-specific supported employment programs are being developed, such as [Avalon Employment's Transitions for Individuals with Autism](#) pilot program which is now expanding to other parts of that province. However, not all autism-specific employment programs may adhere to service delivery components, such as job coaching, aligned to supported employment principles.

Canada would benefit from the development of pan-Canadian autism employment guidelines with pathways that include autism-specific, secondary school-based supports through to job retention (e.g., inclusive of career exploration, job matching, advocacy during job

seeking, interviewing, on-the-job supports, self-advocacy skills for disclosure, requesting accommodations, and conflict management) (DePape & Lindsay, 2016; Dudley & Zwicker, 2016b; Khalifa et al., 2020; Sansosti et al., 2017; Schall et al., 2020; Vogeley et al., 2013; Wehman et al., 2020).

Such guidelines would be best informed by research aimed at examining the utility, feasibility, and scalability of evidence-based programs, such as supported employment (Schall et al., 2020) across Canadian employment contexts. In the US, every state has a [Vocational Rehabilitation Agency](#) that is designed to support disabled people in obtaining and maintaining employment (Employer Assistance and Resource Network on Disability Inclusion, n.d.). A study found that Autistic participants who received these vocational rehabilitation services (such as assistance in preparing or searching for employment, job placement services, on-the-job support, and *assistive technology*) were much more likely to obtain competitive employment compared to those who did not receive these supports (Kaya et al., 2016).

Employment service providers, as well as newly hired staff, will likely require professional development to support Autistic job seekers and employees to find work and to implement autism-specific workplace accommodations (Buckley et al., 2021; Shattuck et al., 2012; National Autistic Society, 2016; Walsh & Hall, 2012). In Wales, the [Employment Certificated Autism Scheme](#) is an e-learning resource to increase knowledge and awareness about the support needs of Autistic people for those who provide Autistic people with employment support (Autism Wales, 2020b). Such professional development opportunities should include direct exposure to the perspectives of Autistic workers (Hedley et al., 2017; Sansosti et al., 2017; Schall et al., 2020; Scott et al., 2019). It may also be beneficial to hire and retain employment service providers with specialized skills to work with Autistic people (Hedley et al., 2017; Lindsay et al., 2021; Nicholas et al., 2017). Autistic people have also voiced their desire for more workplace supports, such as job mentors (i.e., colleagues or other Autistic workers) (Buckley et al., 2021; Nicholas et al., 2017; Scott et al., 2019; Wehman et al., 2020).

Equitable Employment Readiness and Work Experience Opportunities

Among the primary obstacles to obtaining integrated employment for Autistic young adults or young adults with developmental disabilities is the absence of strong employment skill instruction in secondary school (Gilson et al., 2017). Broader community-level findings indicate continued minimal collaboration between schools, vocational service agencies, and other health and social services in Canada (Nicholas, Zwaigenbaum, et al., 2018; Scott et al., 2019), despite evidence suggesting that such collaboration could improve work outcomes (Gilson et al., 2017). Given these challenges, it may be wise to offer integrated and more protracted, highly-supported pathways from secondary to vocational and other post-secondary educational settings through to long-term employment (Crawford, 2011; Gilson et al., 2017;

Nicholas, Mitchell, et al., 2018; Scott et al., 2019). Employment outcomes can be improved with foundational vocational skills and opportunities gained in secondary school (Crawford, 2011; Dudley & Zwicker, 2016b; Dunn et al., 2018; Gilson et al., 2017; Nicholas & Klag, 2020; Park et al., 2016; Sansosti et al., 2017; Schall, 2010; Seaman & Cannella-Malone, 2016; van Schalkwyk & Volkmar, 2017), including:

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- Career development activities and outcomes (e.g., incorporated into IEPs; resume/record of experience) such as varied apprenticeships, work experiences, volunteering opportunities, and internships (Dudley et Zwicker, 2016b; Remington & Pellicano, 2019; Schall et al., 2020; Wehman et al., 2020; Wehman, 2011), and
 - Standardized vocational and career assessments as well as planning by transition teams or professionals embedded within the education system (Murray et al., 2016; Schall et al., 2020; Weaver, 2015; Wehman et al., 2020).
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In England, the [Autism Exchange Programme](#) has been offering three-week paid internship experiences as well as tailored career advice and support for young Autistic adults aged 16 - 25 years since 2015 (Ambitious about Autism, 2022; Bloomer, 2021). The program works in partnership with the Ambitious About Autism, a national charity, to help match applicants to appropriate roles across the civil service based on the individual's skills and interests (Bloomer, 2021; The Royal Borough of Kensington and Chelsea, 2019).

For Autistic youth who have left secondary school or are in post-secondary settings, other strategies may include offering incentives and external supports (e.g., job coaches) to inclusive employers and socially-oriented businesses (e.g., social enterprise and entrepreneurships) to hire and/or offer internships and co-ops (Dudley & Zwicker, 2016b; Dunn et al., 2018; Khalifa et al., 2020; Nicholas et al., 2017). Targeted funds (e.g., Opportunities Fund for Persons with Disabilities) specific to the needs of Autistic youth could be used to develop partnerships and fund local demonstration initiatives related to enhancing work readiness and pre-employment skills (Crawford, 2011; Jacob et al., 2016; Nicholas & Klag, 2020; Seaman & Cannella-Malone, 2016).

For example, from 2014 - 2017, the Government of Canada funded two pilot initiatives, Ready, Willing, and Able and Worktopia, aimed to improve the work outcomes of Autistic people through the Opportunities Fund for Persons with Disabilities (Duclos et al., 2019). Unlike most other funded Opportunities projects, these two initiatives did not make use of targeted wage subsidies (Employment and Social Development Canada, 2018).

[Worktopia](#) (including EmploymentWorks and CommunityWorks Canada®) offers work readiness/pre-employment programs for Autistic youth and adults through a peer-supported model. In one government evaluation, Worktopia served 264 participants through this project, and among these participants, 34 (13%) found employment, and 63 (24%) returned

to school (Employment and Social Development Canada, 2018). Other Autistic participants of the CommunityWorks Canada® program have also been shown to increase self-reported employment readiness and these findings are corroborated through other stakeholder data (Nicholas et al., 2019). For example, employers reported numerous positive experiences and benefits from working with Autistic individuals, including workplace productivity, greater recognition of the contributions Autistic individuals' make, and improved quality of work which in turn was viewed to improve employer amenability for inclusive hiring.

[Ready, Willing, and Able](#) is another Canadian employment program which is designed to improve employer awareness of hiring persons with developmental disabilities, including Autistic people, as well as frontline provision of job coaching, transportation, and other hands-on support, such as job site assessments, worksite accessibility accommodations and alterations, and adaptive technology (Employment and Social Development Canada, 2018). In Ready, Willing and Able, there were 543 Autistic people who participated over three years, 218 of whom were in ongoing jobs of at least 15 hours per week at some point during the program (Stainton et al., 2018). The findings of the evaluation offered some key learnings including:

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- Actions and policies to dissuade territoriality amongst employment agencies due to limited supply of inclusive work environments and future funding tied to wage subsidies,
 - The need for more training of frontline service workers (e.g., job coaches) to support Autistic workers,
 - A perceived need for more intensive care management and wraparound mental health supports for project participants, and
 - Development and inclusion of social enterprise models.
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Additionally, under the Youth Employment Skills Strategy, Employment and Social Development Canada invested in a 6-month mentorship and training program in data processing, which includes a two-month paid work experience (Employment and Social Development Canada, 2021b; see [Autism CanTech!](#), n.d.). The outcomes of such pilot programs should be disseminated and scaled up for more general accessible and inclusive workplace practices. Finally, more incentives and training supports could also be offered to Autistic people who desire self-employment (Dudley & Zwicker, 2016b; Dunn et al., 2018).

Addressing Social Assistance Barriers to Employment for New or Precarious Workers

Recipients of disability income may not be interested in working additional hours, as they are at risk of receiving less after-tax earnings and government transfer payments (Khayatzadeh-Mahani et al., 2020). More than 25% of surveyed Canadians with developmental disabilities were concerned about losing some or all of their income and benefits (Crawford, 2011). Another Canadian report suggested that these clawbacks were the largest factor limiting individuals'

hours of work in an Employment First program for persons with developmental disabilities (Emery, 2019). Economists and disability advocates have suggested offering continued access to disability supports during precarious/short-term employment to address these concerns (Canadian Association of Community Living, 2011; Emery, 2019; Khayatzadeh-Mahani et al., 2020; Zaresani, 2018; 2020). Given the high rate of medication use by Autistic people (Feroe et al., 2021), maintaining medical and dental benefits attached to disability income supports until long-term employment offers equitable benefits is vital (Crawford, 2011; Dunn et al., 2018; Nicholas, Mitchell, et al., 2018). These latter two recommendations may also benefit other disabled Canadians.

Autism Inclusivity in General Employment Supports and Services

Many employment service providers are not trained to meet the unique and varying needs of Autistic people, nor do they understand the strengths of this population to support their employment success (Shattuck et al., 2012; National Autistic Society, 2016; Walsh & Hall, 2012). This situation is compounded by the emphasis on general employment services which may limit the development of appropriate specialist services (Walsh & Hall, 2012). Accordingly, employment services often overlook the social support needs and on-the-job training required by Autistic employees and tend to treat their needs homogeneously (Scott et al., 2019). When Nicholas, Zwaigenbaum and colleagues (2018) surveyed Canadian employment agencies regarding their knowledge and inclusion of Autistic job seekers, they found that only 41% of these agencies felt they had sufficient resources to address the vocational needs of Autistic job seekers, 28% had a vocational service strategy for Autistic persons, and less than 36% felt they had sufficient staffing levels overall.

Accordingly, expanding and adapting existing employment programs for disabled people may be required to better meet the needs of Autistic people (Canadian Association of Community Living, 2011; Dudley & Zwicker, 2016b; National Autistic Society, 2016; Vogeley et al., 2013). Furthermore, professional development for employment service providers and human resource professionals regarding evidence-informed approaches to communication, accommodation, and accessibility when serving Autistic job seekers may be warranted (Dunn et al., 2018; Gnanasekaran et al., 2016; Grinker, 2020; Lindsay et al., 2021; Munandar et al., 2020; Nicholas & Klag, 2020; National Autistic Society, 2016; Vogeley et al., 2013; Zwicker et al., 2017). To ensure geographic equity and program fidelity, it also may be useful to develop Canadian standards or guidelines for employment services/program offerings and professional development opportunities across jurisdictions (Nicholas et al., 2017; Sansosti et al., 2017; Scott et al., 2019). Such guidelines would highlight the importance of accommodating the diverse needs and abilities of Autistic people in employment supports and accessibility legislation (Buckley et al., 2021; Crawford, 2011; Nicholas et al., 2017).

While the long-term payoffs of providing employment support to Autistic people have been documented (Jacob et al., 2016; Rogge & Janssen, 2019), the costs of such supports are typically higher at the outset for Autistic job seekers in comparison to other disabled job seekers (Bennett & Dukes, 2013). These initial costs may be a deterrent for employment agencies and governments to provide adequate employment services and supports (Rogge & Janssen, 2019; Scott et al., 2019). As such, financial incentives for employment agencies to support Autistic people with complex employment-related needs to find and retain employment may be warranted (Crawford, 2011; Jacob et al., 2016; Nicholas, Mitchell, Zulla, & Dudley, 2019; Stainton et al., 2018).

Workplace Acceptance: Employer Incentives and Career Development

Autistic people have high rates of unemployment and negative employment experiences due to workplace discrimination and stigma (Bunt et al., 2020; Crawford, 2011; Grinker, 2020; Hayward et al., 2018; Khayatzadeh-Mahani et al., 2020; Lindsay et al., 2021; Sansosti et al., 2017; Zwicker et al., 2017). Discrimination and stigmatization by employers and co-workers are major barriers to labour market participation (Bunt et al., 2020). Attitudinal barriers also include employers' underestimation of the Autistic individual's skills, discrimination in hiring, a lack of accommodation and promotion of Autistic workers, and workplace harassment and bullying (Sansosti et al., 2017).

“I feel like my employer and my team have little knowledge or understanding about autism. I otherwise look and sound “normal” ... they think I just need to try harder ... there are jobs and promotions I have not pursued because I’m afraid I’d have to work too hard for accommodations ... many will think I’m not capable of the positions because I’m autistic, even though I know I am capable as long as my sensory differences are taken into consideration and respected.”

- Autistic adult

To address these concerns, several strategies, some of which are already underway (e.g., [Ready, Willing and Able](#) [2015], [Worktopia](#) [2022], [CIRCA](#) [2021]), have been recommended. Canadian guidelines could consider these strategies:

- **Employer and human resource education**, acceptance and awareness, and professional development related to autism (Dunn et al., 2018; Nicholas, Mitchell, Zulla, & Dudley, 2019; National Autistic Society, 2016; Zwicker et al., 2017) built on the involvement, perspectives, and priorities of Autistic workers (Krzeminska et al., 2019; National Autistic Society, 2016),
- **Wage subsidies and tax credits for employers**, particularly for longer-term inclusive hiring practices (Bunt et al., 2020; Crawford, 2011; Dudley & Zwicker, 2016b; Dunn et al., 2018; Lindsay et al., 2021),

- **Certification/awards**, such as the Autism Friendly Employer Award/Autism Employment Ambassador (e.g., as in the United Kingdom/Wales) to promote and recognize workplace inclusivity (National Autistic Society, 2016),
- **Vocational job bank** that connects Autistic employees to inclusive employers and socially-oriented businesses (e.g., social enterprise/entrepreneurships; Nicholas et al., 2017), and
- **A pan-Canadian Community of Practice in autism-inclusive employment** that brings together the knowledge, expertise, and practices of Autistic workers, autism advocacy organizations, service providers, community employment agencies, inclusive employers, and researchers.

In addition to these new directions, funding and evaluating new and ongoing initiatives specific to Autistic workers should continue to be addressed within each pan-Canadian-provincial/territorial Multilateral Framework for Labour Market Agreements for Persons with Disabilities (Bunt et al., 2020; Canadian Association of Community Living, 2011). Finally, the public sector can lead the way by implementing inclusive and neurodiverse hiring practices and policies and evaluating outcomes across the Canadian, provincial/territorial, and municipal government departments, as well as federally-regulated occupations and sectors (Lindsay et al., 2021; National Autistic Society, 2016). These sectors can then serve as models for non-government organizations and businesses.


Key Findings - Employment Pathways

Providing Autistic students with intentional access to employment readiness and work experience opportunities offers them more equitable opportunities in the pursuit of long-term employment.

By building on an Autistic person's strengths, abilities, and aspirations, autism-specific and inclusive employment and self-employment supports and accommodations promote labour market participation.

Autism-inclusive workplaces can also be promoted through a combination of:

- Dissemination of evidence-based guidelines and resources for employers and human resource professionals,
- Inclusive employer awards and/or certification processes,
- Socially-oriented job banks,
- Communities of practices, and
- Incentives for longer-term inclusive hiring practices.



Maintaining access to disability income and benefits during early work experiences, when self-employed, and when in short-term employment positions can support financial stability and labour market participation of Autistic people.

5.4 Autism-Inclusive Housing Options

5.4.1 Background

The term housing will be used to refer to any form of shelter where an Autistic person might reside, spanning the range of residential options from fully self-reliant and financially independent living and family homes (e.g., head/co-head of household, residing with parents or siblings), through supported and supervised residential settings, to institutions, such as hospitals, long-term care, prisons, and homeless shelters. Framed by the values of the Convention on the Rights of Persons with Disabilities (United Nations, 2006), the goals of community living for Autistic people go beyond food and shelter. It also considers wellbeing and community inclusion.

Summary Points

Waitlists for subsidized and supportive housing have reached critical levels in Canada. The system is currently unprepared for the significant number of Autistic persons who over the next decades may lose their major source of housing supports – their family members.

Autistic people without co-occurring intellectual disability or physical impairments are often not considered as a disability priority group for affordable housing.

While some publicly-funded housing may meet current universal design or accessibility standards, it often does not consider other modifications required to be suitable for Autistic people.

Autism-inclusive housing represents residential spaces and models that consider the unique needs of Autistic people within the design, layout, activities, geographic location, and where necessary, staffing complement and access to other community supports (such as mental health) that can be flexibly individualized.

5.4.2 What is Autism-Friendly Housing?

Autism-specific, inclusive, or friendly housing (autism-inclusive moving forward) represents residential spaces and models that consider the unique needs of Autistic people within the design, layout, activities, geographic location, and where necessary, staffing complement and access to other community supports (such as mental health). Autism-inclusive housing is designed with multiple options that can be flexibly individualized (Hutchinson et al., 2018). While universal design and physical accessibility can provide some guidance to design and layout, typically autism-inclusive spaces require further specificity regarding sensory, perceptual, communication, and space calculations and considerations as well as the durability aspects of design (Brand, 2010; Chan, 2018; Lowe et al., 2014; Mostafa, 2010). Broadly, autism-inclusive housing solutions must not only consider design and geographic placement, but also the formal and informal supports available to the Autistic person to maximize their potential, minimize barriers, and optimize person-environment fit.

The wide range of abilities and needs of Autistic people means that a wide range of housing options and concomitant support models are required to meet the diverse and increasing demand. Some Autistic people may benefit from more affordable rent and accepting neighbours, but require minimal staffing supports. Many others may need ongoing support within an intentionally designed community residence in order to be maximally included in society. Others may continue to live with their parents or other family members by choice, but the family may need supports to manage ongoing and changing care needs as the Autistic person ages.

A residential setting that promotes the inclusion or wellbeing of an Autistic individual who is relatively independent and/or working, and/or has a partner and children might look quite different from an inclusive residential setting for an Autistic individual who is non-verbal and may be extremely sensitive to environmental changes and stimuli. Housing is extremely complex and one size does *not* fit all (Lansdowne Consulting/CT Labs, 2021).

“It would be really helpful if there were housekeeping services (cooking, cleaning) for Autistic people. I was in situations that were emotionally unsafe with a former roommate and a former boyfriend because they took care of my cooking and cleaning when I wasn’t able to myself.”

- Autistic adult

5.4.3 Where do Autistic People live?

Evidence from Canada (Berrigan et al., 2020; Stainton et al., 2011), the United States (Anderson et al., 2014; Farley et al., 2018; A. S. Hewitt et al., 2017; Perkins & Berkman, 2012), and the United Kingdom (Brand, 2010; Rogge & Janssen, 2019; Walsh & Hall, 2012) suggest that Autistic

people are far less likely to live independently (i.e., self-sufficiently in terms of finances and home management) than non-autistic individuals. Research has shown that only 3–25% of Autistic individuals live independently in the community (Farley et al., 2018; Levy & Perry, 2011; Steinhausen et al., 2016).

There is very little Canadian data regarding the residential status of Autistic people. A secondary analysis of the Canadian Survey on Disability (2017) found that less than 30% of Autistic people owned or paid rent, even partly, on their own residence (Berrigan et al., 2020). Provincial data suggests that many families and Autistic people desire to live outside of home settings, but appropriate options are limited (Hutchinson et al., 2018; Ontario Developmental Services Housing Task Force, 2018). In Ontario, nearly 16,000 people with developmental disabilities (including Autistic people) were waitlisted for residential placements and that waitlist continues to grow (Ontario Developmental Services Housing Task Force, 2018). In fact, the waitlist is greater than the total number of persons who currently receive residential services across that province.

Residential care, housing with staff supports, is the single largest cost over the lifetime of Autistic individuals (Buescher et al., 2014; Mandell, 2017). In the era of community living (e.g., post-deinstitutionalization), parents have borne the brunt of residential and associated support costs for Autistic people who are not financially independent (Dudley & Emery, 2014; Dudley & Nakane, 2017; Perkins & Berkman, 2012). The costs to provide staff support to an Autistic individual who needs 24-hour, seven days a week support in the family home context is at least \$158,359 per year of after-tax income (Dudley & Emery, 2014). However, much of this labour and time goes unpaid. Perhaps unsurprisingly then, the odds that an Autistic young adult had ever lived independently since leaving high school were higher for those in families with higher household incomes (Anderson et al., 2014). Transportation may be another barrier to moving away from the family home (Kersten et al., 2020; Lindsay, 2017). Many Autistic people do not have their driver's license and may rely on family members/supporters or public transportation (Lindsay, 2017).

Over the last four decades, the deinstitutionalization discourse has promoted the positive benefits of community-based options (“community living”). However, these gains are not inevitable and there are major limitations to espoused positive community living outcomes (McCarron et al., 2019), particularly if supports are not stably available. One of the few Canadian studies comparing community residential settings for persons with developmental disabilities (including Autistic people) found that on all measures other than choice and control, group homes and family model homes (or host families) showed better outcomes (e.g., in satisfaction, access to and delivery of formal supports, linkages to community activities) than either independent settings or family homes (Stainton et al., 2011). These findings suggest

that the move to more *independent living* settings has not been accompanied by appropriate supports.

“We need more supportive housing. Parents don’t live forever and our children need somewhere to go. I worry about what will happen to my daughter when I am gone.”

- Family member of an Autistic person

The available data presented above exposes complicated and multi-factorial challenges that contribute to the current housing crisis faced by Autistic Canadians and their families. With rising autism rates (Public Health Agency of Canada, 2018) and longer lifespans (Felce, 2017), the number of Autistic youth and families that desire and/or require residential supports will continue to grow. The dual needs of the young and aged adults is described as the “double cliff” of housing vulnerability where suitable options may not be readily available and other options may not be successful (Lansdowne Consulting/CT Labs, 2021)

5.4.4 Best and Promising Practices

This section discusses strategies for promoting autism-friendly housing. Key considerations include:

- Building on person-centred planning and *self-determination*, including skill development,
 - Ensuring sufficient availability of suitable autism-inclusive housing options in Canada,
 - Addressing long residential waitlists and dwindling support from family members/supporters,
 - Building and strengthening the capacity of formal and informal supporters,
 - Promoting family relationships and residential stability,
 - Fostering community inclusion through housing design and geographic placement, and
 - Addressing pressing needs such as aging, eligibility criteria, and support needs.
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Person-Centred Planning and Self-Determination

Successful housing strategies are built on the principles of person-centred and directed planning and self-determination, and that should frame policy and practice regarding residential transitions and decision-making.

A person-directed planning approach assists someone to plan their life and supports, aiding them to discover what is most important, and specifying the opportunities, accommodations, and assistance they require to meet their life goals (Ministry of Community and Social Services, 2013; O’Brien, 2014). An autism-specific, person-centred planning approach, includes individualized, strengths-based approaches that promote choice and flexibility as well as skill development and guidance using real-life experiences (Hatfield et al., 2018).

Promoting self-determination skills such as choice and decision-making, goal setting, problem-solving, self-monitoring, self-regulation, self-advocacy, and self-awareness can support Autistic people to be actively and meaningfully involved in residential planning regarding where and with whom they live (Cheak-Zamora et al., 2020; Field & Hoffman, 2015). In alignment with the goals of the United Nations' Convention on the Rights of Persons with Disabilities (article 19), best practices for residential service planning include providing:

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- **Individualized supports** irrespective of living arrangements as preferred by Autistic people and their families (Hutchinson et al., 2018; Wehmeyer & Bolding, 1999),
 - **Formalized mechanisms to make self-determined housing choices and options** within evidence-informed, person-centred planning and supported decision-making (Innes et al., 2012; May et al., 2019; Shattuck et al., 2012a; O'Brien, 2014), and
 - **Skill development** of Autistic people, as needed, that promotes maximal self-determination and self-sufficiency in housing choices, planning, access, maintenance, and management (Chan, 2018; Enner et al., 2020; Hallett & Armstrong, 2013; Marcotte et al., 2020; Mostafa, 2010).
-

The multiple systems barriers to promoting these principles and implementing housing strategies within many Canadian jurisdictions include:

-
- **A very limited supply of adequate, evidence-informed, autism-inclusive housing options** (Office of the Auditor General of Ontario, 2016; Mandell, 2017; McCarron et al., 2019). Waitlists for quality housing for those with developmental disabilities, including Autistic people, have reached crisis levels (Dubé, 2016; Dudley & Nakane, 2017; Ontario Developmental Services Housing Task Force, 2018).
 - **Increasing demand for residential supports as Autistic people and those that support them age** (Owen & McCann, 2018; Perkins & Berkman, 2012). A historic reliance on informal care from unpaid family and friends may not be sustainable as age and mobility burdens increase among the family members/supporters (May et al., 2019).
 - **Staff shortages, skill levels, and ability to implement evidence-informed approaches to home-based support** (May et al., 2019; Schepens et al., 2019). Often, care is not evidence-based and community mental health or developmental service staff positions have been deprofessionalized (Mandell, 2017). Staff shortages and high turnover rates are stressful not only for agencies, but also for families hiring service providers through direct funding models (Dubé, 2016; Ontario Developmental Services Housing Task Force, 2018).
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Potential solutions to address the above-mentioned systemic barriers will be described below.

Autism-Inclusive Housing Options in Canada

Affordable/publicly-funded housing stock is critically lacking in Canada amid steadily

increasing demand by Autistic people and their families for residential services that often must include specialized environments and/or staffing supports (Dubé, 2016; Ontario Developmental Services Housing Task Force, 2018).

“The whole process is challenging and can be based in discrimination ... some landlords or companies will not rent to you if you are receiving social assistance. It would not matter if you are making more off of unemployment than you are making from your job ... [social assistance] is another issue that needs to be addressed, as the money that is left after paying rent is not a lot to live off besides getting groceries, while barely being able to afford that.”

- Autistic adult

Investing in the infrastructure of evidence-informed, autism-inclusive housing stock will be required. This housing stock should best reflect the increased prevalence and changing needs of Autistic people over the life course (Innes et al., 2012; Perkins & Berkman, 2012; Schepens et al., 2019). Community-based approaches, such as subsidized housing in the social assistance sector, supportive housing in the mental health sector, and supported independent living in the developmental sector, can potentially be adapted, expanded, and diversified to meet the needs and abilities of Autistic people (Brand, 2010; Chan, 2018; Felce, 2017; Kinnaer et al., 2016; Mostafa, 2010; Nagib & Williams, 2017; Owen & McCann, 2018).

The development, redesign, and expansion of residential models to increase the range of autism-inclusive housing can incorporate and build upon transdisciplinary evidence from architecture, geography, occupational therapy, sociology, and community living research (Brand, 2010; Chan, 2018; Dalton, 2016; Gaines et al., 2016b; Kinnaer et al., 2016; Lowe et al., 2014; Mostafa, 2010; Nagib & Williams, 2017; Owen & McCann, 2018). Furthermore, several jurisdictions have developed innovative housing solutions that may serve as models. These include: the [Lights](#) model in Toronto, [Reena’s Community Residence](#) and autism-specific pod living, as well as some of the projects described by Brand (2010) and Gaines and colleagues (2016b).

Residential Waitlists and Dwindling Supports from Family Members

“At this point many consider ourselves lucky if we don’t end up on the street.”

- Autistic adult

In line with these critical systems pressures, housing solutions aligned with individual needs and abilities are urgently required (Lansdowne Consulting/CT Labs, 2021, Brand, 2010; Dubé,

2016; Dudley & Nakane, 2017; Hewitt et al., 2013; Ontario Developmental Services Housing Task Force, 2018). As a first step, enhancing inter-ministerial or partnerships among all levels of government (Dubé, 2016; Ontario Developmental Services Housing Task Force, 2018) could support the development of pan-Canadian solutions. A renewed Canadian-provincial/territorial partnership (e.g., between the Canadian Mortgage and Housing Corporation and provincial Ministries of Housing) could prioritize housing solutions for Autistic people and their families and promote more effective cooperation amongst Ministries and municipalities (Ontario Developmental Services Housing Task Force, 2018). New infrastructure projects should focus on funding autism-friendly residential settings that promote inclusion through flexibility of supports, community linkages, geographic integration in desirable neighbourhoods, proactive inclusive design principles, and promote residential stability (DuBois et al., 2021). The projects should demonstrate scalability and be evaluated based on these indicators of inclusion rather than just physical accessibility.

Staff Shortages and Skill Development

Overall, community-based services and staffing should correspond with assessed individual needs (Brand, 2010; Dubé, 2016; Dudley & Nakane, 2017; Innes et al., 2012; Ontario Developmental Services Housing Task Force, 2018). To address staffing shortages and skill levels, evidence-informed and needs-based supports should be provided by skilled housing workers and service providers (Dubé, 2016; Flynn et al., 2018; Hewitt et al., 2017; Kersten et al., 2020; Lindsay, 2017; Mandell, 2017; McCarron et al., 2019; Schepens et al., 2019; Walsh & Hall, 2012). Solutions may include formal (e.g., service providers, case managers) and informal (e.g., family, friends, peer coaches) providers having enhanced access to a variety of methods to develop their skills (Brand, 2010; Felce, 2017; Flynn, 2019; Hewitt et al., 2017; Hoppestad, 2013; Innes et al., 2012).

“I am mostly capable of independent living, don’t qualify for any services, but could still benefit from some minor specific supports ... I need help with cooking, chores, bills, grocery shopping, etc ... I currently live with my brother who is able to help with some of these needs ... but it is not enough support, makes me feel like a burden on his life, and he does not want to live with me forever and I am not sure how I will manage when he moves out.”

- Autistic adult

In addition to patient-centred planning, other residential support approaches include active support (Flynn et al., 2018), teaching independent living skills (Marcotte et al., 2020), home modifications (Nagib & Williams, 2017), and least restrictive, positive environmental supports (Lavigna & Willis, 2012). Such approaches require investment in service provider (and family) training to ensure safe and effective application. Step-wise, experiential programs and

support services should be offered by qualified professionals to promote learning and skills development for maximal self-sufficient living beginning in early adolescence (Enner et al., 2020). Furthermore, while there is a paucity of housing and residential care research that includes the first-person perspectives of Autistic people, advanced professional development for service providers should aim to actively involve and be *co-designed* by Autistic people.

Promoting Family Relationships and Residential Stability

Residential care is the single largest cost over the lifetime of Autistic individuals (Buescher et al., 2014; Mandell, 2017). However, much of this care is provided by uncompensated family members. Further, home modifications are often paid out-of-pocket by parents. In a survey of Canadian and US parents of Autistic children, more than 50% reported out-of-pocket costs for home modifications, including 22% that had spent more than US\$5,000 (approximately CAN\$6,638) (Nagib & Williams, 2017). Only 2% of respondents had received any government support for these modifications.

Even for those families with resources to contribute, options outside of market rentals are extremely limited (Brand, 2010; Ontario Developmental Services Housing Task Force, 2018). As such, it is relevant to consider how family wellbeing and aging-in-place may promote the ongoing care relationships and living arrangements among Autistic people and their families/supporters (Innes et al., 2012; Perkins & Berkman, 2012; Schepens et al., 2019). Building on the key findings from the first section on financial stability, family-centric strategies could include offering subsidies for autism-specific home modifications and equipment (e.g., safety needs, sensory differences, communication; Nagib & Williams, 2017; Owen & McCann, 2018). Examples of these modifications were provided in Chapter 3 in the sections on safety and accessibility.

It may be timely to update accessibility criteria/eligibility and rationales in housing funds/policies pertaining to necessary and reasonable repairs and modifications. In Canada, this may occur through the National Housing Co-Investment Fund, which sets accessibility requirements for new and renewed projects and targets the construction, repair, and revitalization of affordable housing for people with developmental disabilities (Canada Mortgage and Housing Corporation, 2020). Furthermore, by applying an autism lens, jurisdictions, including the Canadian government, should ensure that accessibility policies within residential services and affordable housing address the range of individual needs of Autistic residents (e.g., varying cognition, support needs, durability, space calculations; Chan, 2018; Canada Mortgage and Housing Corporation, 2020; Mostafa, 2010). Finally, many affordable housing policies and municipal by-laws may act as barriers to necessary home modifications or additions (Nagib & Williams, 2017). Such policies and by-laws should be reviewed and updated using an accessibility lens. For example, subsidized buildings should offer the flexibility to remove or modify internal partitions (e.g., between the living room and kitchen) to allow for extended

monitoring or a larger living space. Additionally, building codes should enforce quality sound insulation between neighbouring units.

Currently, families who want to direct and develop innovative housing solutions may face challenges with finding appropriate market rentals or purchases and implementing wraparound supports. Current legislation, ineffective policies, and lack of resource sharing agreements severely limit families who wish to plan, act, and contribute resources (Ontario Developmental Services Housing Task Force, 2018). Developing new financial partnerships and resource sharing between Autistic people/families and housing providers could expand opportunities for autism-friendly housing cooperatives, condominiums, or intentional communities (Ontario Developmental Services Housing Task Force, 2018). Developed in consultation with individuals, families, and other stakeholders, cost-sharing options may stimulate innovation, transparency, economies of scale, and proactive person-centred decision-making, while decreasing the length of provincial/territorial residential waitlists. Such arrangements could also incorporate grass roots, shared service arrangements, such as the Developmental Services Workers Cooperative demonstration project (Ontario Developmental Services Housing Task Force, 2018) or parent-led, step-wise residential transition models, such as Lights in Toronto.

Fostering Community Inclusion through Housing

A person's home cannot be separated from the community context. Without strong community linkages, a community-based residential setting can be isolating and exclusionary – an 'asylum without walls' (Hall, 2004). Indeed, autism-inclusive housing options support residents to build and maintain strong community connections (Brand, 2010; Chan, 2018; Kinnaer et al., 2016; Nagib & Williams, 2017), by considering the geographic location and walkability of the residence to amenities, social networks/family, work, recreation, and day supports (Brand, 2010; Chan, 2018; Dubois et al., 2021; Schepens et al., 2019). The public's attitude can be shifted to understand that inclusion of Autistic people benefits neighbourhoods and society as a whole (Chan, 2018; Mandell, 2017). Through autism acceptance campaigns from all levels of government, homeowners, landlords, housing developers, and the general public may become more knowledgeable about autism, which may mitigate the existing systemic stigma and prejudice as evidenced by 'Not in My Back Yard-ism' (NIMBYism), ghettoizing, and evictions (Dubé, 2016; DuBois et al., 2021). Solutions for inclusive housing options include promoting and incorporating inclusive municipal zoning, which integrates affordable and accessible units into all new housing developments (Ontario Developmental Services Housing Task Force, 2018). Landlords and condominium associations can also be incentivized to offer long-term, autism-friendly housing units (Mandell, 2017).

Addressing Pressing Needs: Aging, Eligibility Criteria, and Complex Support Needs

While housing issues are faced by Autistic Canadians across the spectrum, there are several

sub-populations (e.g., young adults with complex support needs, aging Autistic adults, Autistic adults that do not meet criteria for developmental services) who are at particular risk of not having their housing needs met. Eventually, parents will no longer be available to provide housing supports or to advocate for these individuals (Autism Canada, 2018; Dudley & Nakane, 2017; Perkins & Berkman, 2012). Further, many Autistic Canadians will not be able to live well and harmoniously within current models of supported independent living/affordable housing, due to complex support needs (sensory, cognitive, safety, and social), without significant and proactive design, policy, and planning considerations.

Jurisdictions should begin planning for the expanding aging autistic cohort (e.g., through aging-in-place, updated housing stock/modifications, adequate transition assessments, mental healthcare, dementia care and end-of-life care, and life story work) (Schepens et al., 2019). Residential agencies need support to develop strong aging-in-place missions to keep persons in their current residential settings (Perkins & Berkman, 2012). Promoting awareness and solutions for the aging cohort is an increasingly urgent priority to be addressed within a pan-Canadian disability or autism strategy.

For Autistic individuals who do not meet eligibility criteria for residential services in the developmental sector, changes to affordable housing programs that include Autistic people may increase their access to subsidized rentals. For example, increasing provincial/territorial shelter allowances to an average market rent would benefit Autistic people receiving disability supports. In Ontario, the Ontario Disability Support Program maximum shelter allowance for a single person is \$489 per month, which is insufficient relative to the Canada Mortgage and Housing Corporation's average market rent of \$1,202 in Toronto, \$845 in Hamilton, \$807 in Sarnia, or \$778 in Thunder Bay (Ontario Developmental Services Housing Task Force, 2018). Moreover, Autistic people could be included as a specific population within affordable housing program quotas (Ontario Developmental Services Housing Task Force, 2018). Autistic people are often not included in municipally-run affordable housing programs, because they do not fit into typical disability categories, such as mental health, addictions, or physical disabilities. The National Housing Strategy exemplifies this, as autism is seldom, if ever, mentioned. Thus, many municipalities may not consider allocating funds specifically to support Autistic people's housing needs.

Despite traditional exclusion of autism as a priority group in their own right, recently more pan-Canadian attention has been paid to the particular needs of Autistic adults. For example, the Canadian Mortgage and Housing Corporation and National Housing Strategy are currently funding two research projects related to autism and housing. The first project, Housing through an Autism Lens, is currently underway. They have collected information regarding existing housing models (such as supported independent living, intentional communities, and co-living)

and promising practices across Canada. They suggest that in order for any housing model to work, three elements are required: (1) capital, (2) sustainability, and (3) funding (Lansdowne Consulting/CT Labs, 2021). A second project underway is combining smart technologies with adapted housing models in the hopes of improving independence for Autistic adults (Canada Mortgage and Housing Corporation, 2021).

Finally, Autistic persons with complex support needs and their families face additional housing challenges related to a lack of available specialized housing, reticence of some community agencies to serve those with more complex support needs, and increased risk of neglect or abuse. In Ontario, there are no regulations or policies in place to ensure that Autistic persons on residential waitlists with the highest or most pressing needs are served first (Office of the Auditor General of Ontario, 2016). There are few incentives offered or mandates requiring agencies to accept, house, and support persons with complex support needs, such as those with *behaviours that challenge*. This contrasts with the United Kingdom and Denmark that have regulated processes and provide interdisciplinary, community teams of health professionals to ensure adequate community care (Dudley & Nakane, 2017; Walsh & Hall, 2012).

Increased regulatory and accountability structures of community-based agencies would encourage increased equity, transparency, and sufficient access to supports (Dubé, 2016; Dudley & Nakane, 2017; Mandell, 2017). For example, service agencies could be required to provide detailed explanations for rejecting applicants for residential vacancies who are in crisis situations and/or have complex needs (Dubé, 2016). Developing and maintaining provincial/territorial-wide inventories of residential placements for Autistic persons with complex support needs may also improve housing access (Dubé, 2016).

Key Findings - Autism-Inclusive Housing Options

Many Autistic people and their families require ongoing supports to choose, plan for, access, maintain, and manage housing which occurs through person-centred planning, navigation, and skill-building approaches.

Suitable housing for Autistic persons with complex support needs incorporates distinct environmental design, long-term supports, and ongoing opportunities for community participation.

Developing adequate housing options that promote belonging for Autistic people involves stable community linkages, promotion of neighbourhood and landlord acceptance, accessibility of and eligibility for affordable housing, and proactive community planning.

5.5 Chapter Summary

Economic inclusion entails removing barriers to financial stability, employment, post-secondary education and lifelong learning, as well as suitable housing for Autistic people and their families. Currently, Autistic adults and their families face financial barriers that may preclude their full participation in society.

Economic inclusion can be promoted through offsetting common out-of-pocket costs associated with autism, offering flexible and needs-based benefits, improving access to pan-Canadian tax credit programs, providing incentives for labour market participation, and strengthening financial literacy and planning services for Autistic people and their families.

Post-secondary education can be made more inclusive through wider implementation of transitional and autism-specific supports and accommodations.

Some ways to improve employment outcomes include:

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- Providing autism-specific employment supports and accommodations,
 - Ensuring equitable access to work experience opportunities,
 - Addressing disincentives, and
 - Promoting autism acceptance within workplaces.
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Finally, following best practices for community planning and developing autism-inclusive housing models can promote a larger supply of suitable housing options for Autistic people and their families.



Chapter 6:

Positioning for Impact: Ongoing Evaluation

6.0 Introduction

The previous three chapters have focused primarily on policy-oriented best and promising practices and key findings that directly impact the quality of life of Autistic people and their families. Our systematic search and analysis of policy documents and plans (described in Chapter 1) revealed that the following enabling strategic directions were frequently mentioned:

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- Enhanced and ongoing meaningful involvement of stakeholders in the development, implementation, and evaluation of a national autism strategy,
 - Transparent and accessible information about *autism* and autism-related supports and services,
 - Development and implementation of *capacity building*, professional development, and education about autism that is *co-designed* with Autistic people,
 - Increased research evidence and data collection and sharing pertaining to Autistic individuals across the lifespan, and
 - Formal cross-governmental and ministerial bridging and coordination in the implementation and evaluation of a national strategy.
-

Several of the countries have made government-level efforts to enable these strategic directions through legislation. Some examples of how legislation has aligned to these strategic directions are presented in Table 3.

Chapter 1 highlighted the importance of stakeholder engagement, while Chapters 3 to 5 presented some of the best and promising practices regarding autism education, acceptance and awareness, and training, as well as workforce capacity building. This chapter focuses on three cross-cutting enablers: data, research, and collaboration, with a particular focus on supporting pan-Canadian collaboration, knowledge dissemination, and the exchange of evidence-based knowledge between governments and organizations.

Table 3. Frequently identified enabling strategic directions with examples of legislation. This table outlines enabling strategic directions that are frequently mentioned within autism policy, along with how they have been highlighted within autism-specific legislations enacted in select countries.

Strategic directions highlighted in most autism policy documents	Examples of legislation
Enhanced and ongoing meaningful involvement of stakeholders in the development, implementation, and evaluation of a national autism strategy	United States: The Autism Collaboration, Accountability, Research, Education and Support Act of 2019 changed the statutory membership of the Interagency Autism Coordinating Committee, which is responsible for coordinating and monitoring autism-related activities within the Department of Health and Human Services, to allow for additional non-federal members, specifically more individuals with <i>lived experience</i> and autism expertise (Autism Society, 2019).
Increased research evidence and data collection and sharing relevant to Autistic individuals across the lifespan	United States: The Autism Collaboration, Accountability, Research, Education and Support Act of 2019 ensures support, including financial support, for research and prevalence tracking (Interagency Autism Coordinating Committee, 2020).
Development and implementation of capacity building, professional development, and education about autism that is co-designed with Autistic people	England: The Autism Act 2009 required the Department of Health to publish an autism strategy that included a focus on increasing awareness and understanding of autism among frontline professionals (Foster et al., 2022). As part of this requirement, the Department of Health published statutory guidance for local authorities and National Health Service organizations regarding training for those who provide services to Autistic people (see Chapter 3 for further details).
Formal cross-governmental and ministerial bridging and coordination in the implementation and evaluation of a national strategy	Northern Ireland: The Autism Act (Northern Ireland) 2011 required the Department of Health, Social Services and Public Safety to lead the development and implementation of a cross-departmental autism strategy and provide annual updates with input and cooperation from other departments (Department of Health, Social services and Public Safety, 2015).
Transparent and accessible information about autism and autism-related supports and services	England: The Autism Act (2009) requires that the National Autism Strategy developed by the government focus on developing a clear and consistent pathway for diagnosis. As part of this action area, the National Health Service collects data on diagnosis wait times and identifies areas where wait times exceed the National Institute for Health and Care Excellence recommended 13 weeks between referral and assessment (Department of Health and Social Care, & Department for Education, 2021a). Wales: Under the Social Services and Well-being (Wales) Act 2014 and the National Health Services (Wales) Act 2006, the Welsh Government developed a statutory Code of Practice on the Delivery of Autism Services , which requires that autism services are compliant with the national waiting time standard of 26 weeks from referral to the first diagnosis appointment (Welsh Government, 2019; Welsh Government, 2021b).

6.1 Data Collection and Sharing

In the United Kingdom's most recent national autism strategy (2021 - 2026), one of three key enablers featured improved data collection and reporting to monitor implementation of their strategy and drive system improvements. Their strategic direction involves, but also goes beyond, surveillance. Surveillance refers to tracking incidence and prevalence of target populations as well as identifying characteristics that can influence or contribute to their health (Fox et al., 2015). According to the United Nations' Convention on the Rights of Persons with Disabilities (2006), the collection of disaggregated statistical and research data used by national governments for the purpose of developing and implementing policies and practices to meet the needs of Autistic people of all ages and their families, is an express priority. An additional consideration in Canada is how to manage data sovereignty outlined by the United Nations' Declaration on the Rights of Indigenous Peoples (United Nations, 2007).

Summary Points

Surveillance is best suited to tracking incidence, prevalence, and factors associated with diagnosis rates over time. When linked to other databases that include information on service utilization and health or social indices, more meaningful data on equitable access and overall needs can be generated.

Some Autistic people are uncomfortable with the term “surveillance” interpreting the intention with alternative meanings of social control, forced observation, and a lack of freedom.

A ‘functional’ disability approach, whereby issues with specific body functions have replaced screening for diagnostic labels such as autism, have been adopted in many pan-Canadian surveys in Canada. This approach limits the availability of information about the experiences of Autistic Canadians as a group.

6.1.1 Canadian Context

As described in Chapter 1, there have been previous efforts to collect Canada-wide autism surveillance data. However, currently there is no Canadian-level data collection system to measure and track trends of Autistic people and their families across the lifespan. Data linkages through surveillance efforts make it possible to report on autism incidence and risk ratios

(Balogh et al., 2019; Dallman et al., 2021). Surveillance is best suited to tracking incidence (for example, of new diagnoses), prevalence, and factors associated with variation in diagnosis rates over time. When linked to other provincial/territorial and/or pan-Canadian databases or sets that, for example, include information on service utilization and health or social indices, more meaningful data on equitable access and overall needs can be generated (Balogh et al., 2019). Consequently, without pan-Canadian mechanisms in place to coordinate data collection and sharing, it will be challenging to track indices related to equitable access to services, rates of co-occurring conditions, and other social or economic factors which may be relevant to service planning and contribute to overall quality of life.

To date, Canadian data about Autistic individuals have been collected through:

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- The National Autism Spectrum Disorder Surveillance System (Public Health Agency of Canada, 2018),
 - The Canadian Health Survey on Children and Youth (Public Health Agency of Canada, 2022),
 - Secondary analysis of the Canadian Survey on Disability or other Statistics Canada surveys, or from
 - Integrated hospital or jurisdictional datasets developed through research partnerships between Canadian universities or research institutes.
-

National Autism Spectrum Disorder Surveillance System

Currently, the National Autism Spectrum Disorder Surveillance System is limited to individuals aged 5 - 17 years, and has primarily focused on prevalence and incidence rates, as well as the age of diagnosis. While the National Autism Spectrum Disorder Surveillance System (NASS) has provided useful data, it has limitations. For example, information about individual and family sociodemographic characteristics, such as gender, race/ethnicity, household income, parental educational level, living arrangements, and co-occurring conditions were not reported. Furthermore, the reports to date do not reflect information from across Canada, but rather a subset of seven provinces and territories.

Statistics Canada and Other Federally-Funded Surveys

The Canadian Health Survey on Children and Youth (CHS-CY; ages 1 to 17 years) provides current, detailed, and ongoing health-related information on issues impacting the physical and mental health of children and youth at the pan-Canadian, provincial, and territorial levels (Statistics Canada, 2020b). As described in Chapter 1, The Public Health Agency of Canada used the 2019 outcomes of the CHS-CY to release updated autism prevalence estimates. The data is limited in certain ways³¹, including being based entirely on parent report. There is also no representation from children in care/congregate settings, or from Indigenous settlements or

³¹ The findings and limitations of this survey are provided in more detail in Chapter 1.

reserves. The 2023 survey is expected to include a larger sample of Autistic children and youth (Georgiades et al., 2021).

Most Canadian data about Autistic adults (aged 18+) provided in this assessment was derived from secondary analysis of the Canadian Survey on Disability. This Statistics Canada survey includes Canadians aged 15+, whose everyday activities are limited because of a long-term condition or health-related problem categorized across 10 disability types: hearing, vision, mobility, flexibility, dexterity, pain, learning, mental health, memory, and **developmental disabilities** (Cloutier et al., 2018). In this and other Statistics Canada surveys, autism is categorized as a developmental disability. As such, secondary analysis of the developmental disability category is required to obtain and interpret autism-specific population data. This categorization limits the number of Autistic respondents and the generalizability of findings. Furthermore, respondents must voluntarily provide this diagnostic information. A ‘functional’ disability approach which has been adopted in many pan-Canadian surveys in Canada impacts the availability of information about the experiences of Autistic Canadians as a group.

As summarized by Berrigan and colleagues (2020), the Canadian Survey on Disability also does not capture data for the homeless and disabled people who are living on First Nations reserves or in collective dwellings such as senior and assisted living facilities, prisons, hospitals, or military bases. This is a notable limitation since a sizable portion of Autistic Canadians may live in collective dwellings, such as group homes. Furthermore, the survey methodology only captures the perspectives of respondents who can complete the survey verbally or in a written format, thus excluding Autistic people who communicate in other ways.

Other federally-funded surveys are similarly limited. For example, the Canada Election Study does not allow for statistical analysis of voting patterns of specific groups of disabled people and for the 2019 election, the disability screening questions were removed. Furthermore, in line with a ‘functional approach’, the disability type (e.g., diagnostic labels such as autism) are not collected and/or provided (Statistics Canada, 2012). The Labour Force Survey might be another means to collect information about Autistic workers’ participation in the Canadian labour market at any one time; however, disability or illness as a reason for not working is only captured for persons actively seeking or participating in employment, thus leaving out a majority group who are non-employed (see Chapter 5).

Integrated Hospital, Health Systems, or Jurisdictional Datasets

Much of the reports and statistics available about the experiences of Autistic Canadians have been prepared by university researchers, either through:

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- Secondary analysis of Statistics Canada datasets (e.g., Berrigan et al., 2020, Zwicker et al., 2017),

- Access to independent, non-profit, provincial/territorial population-based health and social data from research organizations (for example, [ICES](#) in Ontario or the [Manitoba Population Research Data Repository](#)) sometimes limited in scope to children and youth, and
 - Original multi-site research studies (e.g., cross-sectional or longitudinal), such as the ASD Pathways Study (e.g., Szatmari et al., 2015, Georgiades et al., 2022).
-

While these publications and datasets have expanded the Canadian-specific autism knowledge base, they are limited by individual efforts and knowledge of researchers in a short-term funding environment and typically rely on localized partnerships. As such, these efforts may be easily de-stabilized through intermittent funding and relationships, making longitudinal research programs and long-term pan-Canadian outcomes difficult to establish and maintain. Furthermore, they may also over-represent the context of particular jurisdictions and thus, not truly reflect the extent of Canada's geographic, economic, or cultural diversity. Stable funding for autism projects which are pan-Canadian in scope may alleviate some of the evidence gaps in Canada.

Stakeholder Perspectives

There was support from stakeholders for collecting cross-country data, particularly if related to aspects of identity, diversity, exclusion, or violation of rights. But, some Autistic people in our stakeholder engagement process were uncomfortable with the term 'surveillance,' given the linguistic associations of the term with social control, forced observation, and a lack of freedom (Little, 2014). This may be particularly concerning for Autistic people whose behaviours have historically been and continue to be observed, criticized, and controlled. As such, the use of the term 'surveillance' may contribute to or exacerbate existing feelings of distrust.

This language sensitivity exemplifies how actively involving Autistic people in research and policy may improve overall outcomes and processes. Consultation with stakeholders regarding the naming and scope of a pan-Canadian surveillance, research, and/or data sharing might promote better uptake and participation in much-needed large-scale, long-term Canadian research efforts. Further, these concerns also speak to deeper issues around what is involved in data collection, who has control over the data, and how data is used. As such, meaningful collaboration with Autistic people and their families in the collection and use of data is critical to building trust and ensuring that the data is being used to truly address the needs and improve the lives of Autistic people.

6.1.2 Best and Promising Practices

Increased research evidence and shared data sources with and about Autistic people of all ages is a strategic direction that was frequently suggested in international autism policy (Interagency Autism Coordinating Committee, 2012; 2017; World Health Organization, 2013a; 2013b; Government Accountability Office, 2013; Caputo et al., 2015; Guldberg et al., 2019).

Effective data infrastructure and information technology required to enable data collection and research include (Institute of Medicine, 2007; Lessard et al., 2017; Menear et al., 2019):

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- Processes of designing and managing a data infrastructure,
 - Promoting good data governance,
 - Monitoring and ensuring data quality and security,
 - Facilitating data integration and interoperability, and
 - Establishing clear strategies for data access, storage, and sharing.
-

Other jurisdictions can offer pertinent models. The United Kingdom has already made strides in data sharing and collaboration, particularly in relation to some of the ethical challenges put forth by cross-ministerial data sharing. In the United States, the [Autism and Developmental Disabilities Monitoring Network](#), a collaborative network funded by the Centers for Disease Control and Prevention, relies on community partnerships to collect data on Autistic children (Centers for Disease Control and Prevention, 2021). As of 2018, this network had started to follow-up on a cohort of 16-year-olds in certain states to better inform transition planning. In Denmark, there are national registries that collect clinical autism data in a systematic way (e.g., Denmark Twin Registry; Denmark National Patient Registry), allowing retrospective studies, which, in turn, improves clinical investigations and evaluates service use and impacts (Nordenbæk et al., 2014; Rødgaard et al., 2021).

To lessen the shortage in evidence regarding adult experiences of autism there may be existing pan-Canadian surveys that can be updated or redesigned to better capture information in relation to Autistic Canadians. For example, as previously mentioned, by including an autism screening question, the Canada Election Study, the Labour Force Survey, and the National Graduate Survey could all capture information about Autistic adults' outcomes, opportunities, and contributions.

Furthermore, developing and standardizing relevant adult-based indicators, such as outcomes in employment, higher education, income/poverty, safety, living arrangements, and indices of family wellbeing could improve data pooling across sectors and communities. In 2021, the Office for National Statistics in the UK published the [Outcomes for Disabled People in the UK: 2020](#) covering multiple life domains such as education, employment, social participation, housing, wellbeing, loneliness, and crime (Putz et al., 2021). The report was developed largely based on data collected through the Annual Population Survey, which, as of January 2020, has included autism as a response option.

Much of the supports and services for Autistic people in Canada, particularly Autistic adults, are provided by community-based organizations across various settings (e.g., health, education, etc). Supporting community organizations to track and share information can improve

population-level data and aid in determining trends across these settings (Balogh et al., 2019; Dallman et al., 2021). Such data sharing and tracking are important elements of systems change as will be described in the final section of this chapter.

Key Finding - Data Collection and Sharing

Expanding infrastructure for Canadian data collection and sharing would offer consistent and sufficient information to guide policy development and service delivery for Autistic people.

Not only collecting information, but also regularly publishing surveillance findings is a best practice that can promote collaboration between different stakeholders, and lead to more effective partnerships (Lee et al., 2016; Rice et al., 2007). As per the United Nations' Convention on the Rights of Persons with Disabilities (2016), it is also an expectation within human rights and ethical principles. These findings can be used to identify service gaps at the provincial/territorial level to determine autism policy and program design needs from jurisdiction to jurisdiction (Coo et al., 2017). Accessibility principles and legislation support the dissemination of findings in multiple formats, including plain language and easy read versions. For instance, previous progress reports on England's Think Autism (2014) strategy included colour contrast and easy read versions (Social Care, Local Government and Care Partnership Directorate, Department of Health, 2016b).

6.2 Research

Expanding and improving autism research was also frequently cited as a strategic direction in the autism policy documents we reviewed. For example, the UK's [2021 to 2026 National Strategy](#) described continued evidence gaps pertaining to autism policies, practices, and service delivery that they recognized could be, in part, addressed through research and innovation (Department of Health and Social Care, & Department for Education, 2021a).

Summary Points

Research, from prioritization of focus areas to knowledge mobilization, is best completed in collaboration with a diversity of Autistic people and other key stakeholders to ensure it is impactful for the community.

Future autism research would benefit from robust and sustained research investment across four research themes of: biomedical, clinical, health services, and social, cultural, environmental and population health research.

6.2.1 Canadian Context

To date, much of the research about autism (in Canada and internationally) has been conducted through a biomedical lens, focusing on the causes, prevention, and characterization of this condition, typically in childhood. This research base offers important insights into the neurological differences and genetic conditions associated with autism and offers the potential of further informing personalized healthcare and support strategies (Baribeau & Anagnostou, 2022). However, other research strategies are needed to address the day-to-day needs of Autistic people across the lifespan and therefore, further prioritizing areas of investigation and research funding aligned to the themes of this assessment (i.e., Social Inclusion, Diagnosis, Supports, and Services, and Economic Inclusion) is also essential. For example, it has been suggested that research investment in the UK has focused on the basic science underlying biological mechanisms of autism, rather than yielding evidence-based strategies on the best ways to meet Autistic people's needs (Autistica, 2019). Similarly, in 2016, the United States invested over US\$364 million (approximately CAN\$480 million) into autism research, most (~60%) of which was focused on the biological underpinnings and potential causes of autism (Interagency Autism Coordinating Committee, 2020). In contrast, community-based services and supports for Autistic adults remain severely under-researched (Lorenc et al., 2018), with less than 2% of US-funded autism research focused on adults (Cashin, 2018). While it is important to continue to invest in biological research, research investments aligned to other thematic areas addressed in this assessment are also needed. Our extensive literature review identified many gaps in research, where research advancements could have an important impact on the lives of Autistic people and their families (see examples in Table 5).

In the absence of a comprehensive Canadian research base on the effectiveness of autism supports and services, policy decisions have been made based on limited clinical and/or community trials or expert opinion. Furthermore, the implementation, fidelity, and outcomes of such supports and services are not typically evaluated or publicly-reported within the Canadian health, social, or educational systems.

Randomized controlled trials remain the gold standard in evaluating the effectiveness of programs and services. As per Sandbank and colleagues (2020), they are also viewed as feasible and yielding clearer results than other designs. However, randomized control trials can be challenging to implement for complex or multi-component supports and services. To improve feasibility, studies may take place under highly controlled settings which may lack ecological validity, so results may not readily generalize to real-world, community settings. As such issues essential to successful implementation (e.g., mobilizing and training **service providers**, maintenance of fidelity, integration of new programs into existing service structures) are not fully considered. Accordingly, it is important that studies take place in real-world, community settings, and incorporate advanced designs (e.g., Sequential Multiple Assignment Randomized Trial) to better adapt to individual needs. Quality improvement methodology is

complementary to these rigorous research approaches and ensures ongoing adaptation of evidence-based programs within a dynamic service delivery environment (Shelton, 2014).

Research Gaps

While not the central aim of this assessment, our evidence review uncovered many research gaps across all themes, both specific to the Canadian context and more broadly. While these evidence gaps shed some light on potential research directions, a long-term, systematic prioritization and alignment of autism research priorities and processes is needed in Canada, developed in collaboration with stakeholders, especially Autistic people and their families (see Table 4).

Table 4. Identified Research Gaps from across Working Groups. This table provides examples of research directions that were suggested by the Working Groups based on gaps in research identified during the process of this assessment.

Social Inclusion	Diagnosis, Supports, and Services	Economic Inclusion
<ul style="list-style-type: none"> Studies that examine the impact of stigma and social exclusion in diverse communities, including that experienced by Autistic women, Autistic members of the 2SLGBTQIA+ community, and Autistic parents. Mitigating strategies should also be developed and evaluated in real-life settings. The impact of systemic racism and autism in racialized communities within the service delivery system and in other aspects of their everyday lives. Autism research inclusive of participants reflecting the diversity of Canadian society, with consideration of language, socioeconomic status, residence (urban/rural), race/ethnicity, and sex and gender. The diversity of Autistic people must also be reflected among research participants. Development and evaluation of strategies aimed at shaping attitudes and changing behaviour among frontline service providers as well as first responders. 	<ul style="list-style-type: none"> Diagnosis and assessment for autism and for co-occurring physical and mental health conditions in girls, adults, and individuals from diverse cultures. For example, diagnostic tools need to be assessed and adapted for cultural validity and across the gender continuum. Developing or adapting diagnostic measures to be more meaningful, respectful, and valid, considering strengths and needs, particularly for adults. Exploring disparities in rates of autism and what drives that in particular populations (e.g., Indigenous populations) The development and evaluation of strategies for preventing and managing mental health concerns and other co-occurring conditions in Autistic children, youth, and adults. Evaluation of care models, particularly programmatic approaches implemented within complex systems. Strategies for scaling up services and supports to increase capacity, access, and equity. 	<ul style="list-style-type: none"> Research aimed at understanding the complex interactions and patterns of relationships during transitions to aid health policymakers and practitioners in determining key areas of support, the impact of these supports on the system, and the potential intended and unintended consequences of change (Ally et al., 2018). Evaluation of supported employment initiatives to allow for evidence-informed decision-making in the Canadian context, including measures of fidelity: Which employment supports and programs best suit which Autistic people (e.g., along severity and cognitive spectrums). Evaluation of autism acceptance and awareness training programs and effects on employment over time. Longitudinal research of higher education approaches and outcomes (e.g., long-term; quality of outcomes) for Autistic people and their family members.

<ul style="list-style-type: none"> • Data on prevalence rates of Autistic people in the Canadian prison systems and on factors that lead to pathways towards and away from incarceration. • Further research on the development and application of technology aimed to support autonomy and social inclusion. • Equity, Diversity, and Inclusion initiatives in academic institutions and by research funders that include <i>neurodiversity</i> within priorities and metrics. 	<ul style="list-style-type: none"> • Clinical trials of integrative health therapies to clarify potential benefits and risks. • Clinical trials of standard-of-care protocols for addressing common co-occurring conditions • Cost-effective models of autism care delivery and integrated supports and services across various domains of health. • Evaluation of school-based delivery of autism supports and services. • Evaluation of novel models of virtual care and how to effectively integrate/blend with in-person services. • Further evaluation of novel models of care prioritized by Autistic adults (e.g., Autistic peers involved in service delivery, in mentorship, navigation, or other roles). • Development and evaluation of outcome measures within clinical trials and other research studies aligned with priorities of stakeholders with lived experience (e.g., quality of life, wellbeing, mental health, autonomy). • Studies characterizing lived experience and the emotional, cognitive, and physical health needs of older Autistic adults. This includes health service needs, development, and evaluation of age-appropriate supports and services as well as consideration of social and financial wellbeing. 	<ul style="list-style-type: none"> • Evaluation of the effects of different housing arrangements and design on outcomes for Autistic adults (Mandell, 2017). • What factors influence needs and successful implementation of residential support arrangements, so that relationships between environmental characteristics, costs, and outcomes can be identified with greater confidence (e.g., setting features and location, resource input [cost, service provider to resident ratios], orientation, attitudes and working methods). • Further exploration and research focused on the identification of technology-based initiatives and advancements that could be utilized to address housing and residential support needs for Autistic people (e.g., web-based cueing, smart homes, video modelling, and smart phones and watches with GPS and prompting). • Research initiatives addressing ‘complex’ situations and unsupported individuals.
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6.2.2 Best and Promising Practices

Research may have the strongest knowledge mobilization if it begins from applied objectives focused on policy and practice. For example, a Canadian framework for research could consider:

- Principles of participatory and inclusive research (e.g., active involvement of Autistic people and their supports), which are promoted across Canadian funders and research institutions,
- Systematically addressing current research gaps, particularly pertaining to data collection from the Canadian context and across the lifespan,
- Supporting and sustaining longitudinal studies offering lifespan outcomes and trajectories through high quality research infrastructure,
- Promoting interdisciplinary collaborations to offer multiple perspectives and mixed methodological approaches to better understand the breadth of autism-related issues within and across the Canadian context,
- Reflecting the needs and experiences of Autistic people and their families in research priorities (research questions/domains being addressed, funding, infrastructure, translational activities), and
- Offering research training and leadership opportunities to clinical and research-stream undergraduate and graduate students, inclusive of Autistic students and Autistic researchers.

More Inclusive Research Approaches

Traditionally, decisions about what is important to research, what policies are needed, and what services require funding have been made by researchers, policymakers, and funders, rather than by Autistic people themselves or those who support them (Benevides, Shore, Palmer et al., 2020). There is a growing recognition of the importance for clinicians, service providers, researchers, funders, and policymakers to collaborate with Autistic people and their families, including in strategic priority-setting (Interagency Autism Coordinating Committee, 2020).

In academic research, terms, such as community-based participatory, participatory action, and inclusive research are often used interchangeably, even though the meanings and underlying methods can be different (Frankena et al., 2015). However, broadly all inclusive research methodologies are driven by the needs, experiences, and desires of Autistic people themselves as team members or co-researchers, improving understanding and ensuring relevance (Richardson & MacRae, 2011). These research and action priorities are warranted to move research rapidly and inclusively to best practice.

Stakeholders and others with lived experience want to be actively involved in research. As described in Chapter 1, active involvement is about research being carried out ‘with’ or ‘by’ Autistic people rather than ‘to’, ‘about’, or ‘for’ them (INVOLVE, 2021). Walmsley, the originator

of inclusive research and “nothing about us without us”, contends that it is steeped in social justice, attempts to redress past and present discrimination and inequities, and importantly values the contributions by disabled people (Walmsley & Johnson, 2003).

Participatory and action-oriented research is an approach that is increasingly embraced by those with lived experience as well as academic communities, as it promotes respect, access, and ensures the relevance of research (Maye et al., 2021). Such approaches involve community members and researchers collaborating as equal partners and in shared decision-making to co-design and conduct actionable research that improves the health and wellbeing of the participating community members (Israel et al., 2003; Wallerstein & Duran, 2003; Maye et al., 2021). Participatory research refers to research methods that go beyond traditional approaches to recruitment and data collection, and/or analysis to actively engage participants. These intentional efforts, such as using plain language recruitment materials (Kidney & McDonald, 2014) or incorporating visual, hands-on, or arts-based methods, may promote greater engagement from a wider range of participants who may not communicate in typical ways (Cluley, 2016; Povee et al., 2014; Renwick et al., 2019; Stanley et al., 2019; Weiss et al., 2017). Emerging best practices for enabling the meaningful involvement of diverse Autistic people, including those with co-occurring *intellectual disability*, in research involve accommodating diverse ways of communicating, using inclusive decision-making processes, and fostering safe spaces that are sensory and cognitively accessible (Nicolaidis & Raymaker 2015; Luke et al., 2012; Satkoske et al., 2020; Maye et al., 2021). These are described in greater detail in Chapter 1. In general participatory approaches aim to promote (Kidney & McDonald, 2014):

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- Respectful engagement,
 - Direct and intentional *inclusion*,
 - Accessibility and *accommodations*,
 - Individualized approaches,
 - Flexible options, and
 - Being attentive and responsive.
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These approaches are particularly pertinent when considering *intersectionality* for equity-seeking, and often hard to reach populations, who have typically been left out of traditional research. For example, unique to the Canadian context, an Indigenous-led program of empirical research, that adheres to data sovereignty, could provide much-needed baseline information about Indigenous Peoples and autism. A similar strategic direction has been suggested in New Zealand (New Zealand Ministries of Health and Education, 2016).

Capacity Building in Research

Building training, research, and leadership capacity are key to the long-term sustainability of autism research. Accordingly, promoting longevity in Canadian autism research requires

inspiring and enabling the next generation of autism researchers towards learning and career opportunities. A key component of capacity building would be to offer high quality autism research and clinical training programs at universities at the undergraduate, graduate, and professional levels (Alcorn MacKay, 2010; Nova Scotia Department of Education, 2010; Organisation for Economic Co-operation and Development, 2011; Interagency Autism Coordinating Committee, 2012; Autistics for Autistics, 2019; Social Care, Local Government and Care Partnership Directorate, 2016a; Department of Health, Social Services and Public Safety, 2015), and focused Tri-Council funding for autism research priorities.

Training not only prepares future autism researchers and service providers, it also spawns crossover knowledge amongst different disciplines with simultaneous opportunities to build project management, research, leadership, and teamwork skills. This can also promote coordinated efforts to scale up and expand effective supports and services, which enables research to inform clinical and community practice. Opportunities to connect with researchers and other key stakeholders across the country can also promote knowledge development, for example through conferences (Welsh Government, 2019) and inclusive communities of practices that promote respect and authenticity, challenge assumptions, develop infrastructure, and offer empathy (Fletcher-Watson et al., 2019).

The input and leadership of Autistic researchers could further promote collaboration and strengthen and expand the autism research base. There are Canadian examples of teams that are inclusive of Autistic researchers (Mottron, 2011). As mentioned in Chapter 1, there is an emerging body of research by Autistic researchers (see Botha, 2021; Grant & Kara, 2021); however there are still very few Autistic researchers who are researching autism in Canada. In addition to having the knowledge and skills required of all autism researchers, Autistic researchers bring lived experience that is beneficial to build trust and move beyond stigmatization and negative social narratives, as described in Chapter 3. They are uniquely positioned to combine experiential and academic knowledge, provide insights into areas of research that are currently overlooked, ensure appropriate and accurate representations of Autistic people, develop more accessible research methodologies, and more readily connect with Autistic people who are meant to benefit from autism research (Dywer et al., 2021).

The [Participatory Autism Research Collective](#) in the UK is an example of a research community network that brings together Autistic researchers and activists with non-autistic researchers and practitioners who work with Autistic people to advance autism research through the sharing of knowledge and expertise. There is also a growing international community of Autistic scientists as exemplified by the International Society for Autism Research (INSAR) appointment of its inaugural Autistic Researchers Committee in 2020. This committee's mandate includes fostering scientific career development for Autistic researchers. A primary approach to build this capacity is to ensure proportional representation of Autistic students and researchers

within Canada's post-secondary institutions from an Equity, Diversity, and Inclusion orientation. This approach is described in Chapter 5.

It is also important to acknowledge that multiple research approaches are needed to inform a comprehensive approach to the thematic areas addressed in this assessment. Ultimately, to facilitate a person-centred approach we may need to understand brain and body differences and the underlying biology, as well as needs identified through the lived experience of individuals and families. We must also take account of personal and cultural preferences, and the social determinants of health and wellbeing, and of an inclusive society. Research across all these domains is critical to advance pathways towards quality of life outcomes, defined by what Autistic people prioritize in their lives.

Key Findings - Research

There are best practices and principles of inclusive and participatory research approaches that can be applied.

Future autism research would benefit from:

- **Better alignment to the priorities of Autistic people and their families**
- **Recruiting Autistic collaborators and research participants that reflect the diversity and intersectionality of autism,**
- **Longitudinal designs that take account changes over the lifespan,**
- **Cross-sector research by transdisciplinary teams,**
- **Advancing service delivery and workforce capacity across the lifespan, and**
- **Translational efforts that accelerate the pathways from discovery to impact.**


Sustained investment in training and career development opportunities can support the cultivation of the next generation of Canadian researchers prepared to address these critical research priorities. This includes funding and supporting the training and mentorship advancement of Autistic researchers.

6.3 Collaboration: From Data and Research to Practice

The Rapid Learning Health Systems framework may be a useful, evidence-based approach for informing systems change (Institute of Medicine, 2011; Lavis et al., 2018). Learning health systems embed knowledge generation for continual improvement in programs and services (Institute of Medicine, 2007). They are innovative and pragmatic approaches to ensuring a bi-directional flow of research-to-practice and practice-to-research, while promoting collaboration and data sharing amongst institutions and sectors (Guise et al., 2018; Safaeinili et al., 2020).

A learning health system approach draws upon best available evidence, emphasizes prevention and health promotion, delivers the most value, and adds learning through delivery with an ultimate goal of improving the health and wellbeing, in this case, of Autistic people and their families (Institute of Medicine, 2007; Canadian Institute of Health Research, 2021). In turn, through service delivery, new research knowledge is systematically and proactively collected in order to further improve (and scale up) supports and services (Canadian Institute of Health Research, 2021).

Summary Points



Framed by Rapid Learning Health Systems, collaboration can ensure a bi-directional flow of research-to-practice and practice-to-research, while promoting data sharing amongst institutions and sectors. At a government-level, this can allow for incremental and manageable policy changes that enhance both the efficiency and quality of services and optimize outcomes based on tightly-focused evaluations.

6.3.1 Canadian Context

The Canadian Institute of Health Research's Institute of Health Services and Policy Research Strategic Plan 2021-2026, seeks to “build on the tremendous strengths and accomplishments of Canadian healthcare and health services and policy research, while not shying away from the fundamental challenges that our healthcare systems face” (Canadian Institute of Health Research, 2021, p. 5).

A Learning Health Systems approach is currently being applied in different forms and for different issues across provincial health systems in British Columbia, Alberta, Ontario, and

New Brunswick (Moat et al., 2020; Lavis et al., 2018). It has also been recently proposed for neurodevelopmental conditions, including autism (Moat et al., 2020).

Given the complexity and far-reaching implications of autism, multiple ministries, including health, education, social/community, childcare, employment/labour, and corrections/justice are involved at the pan-Canadian, provincial and territorial levels (as described in Chapter 1). At a government-level, rapid learning systems can allow for incremental and manageable policy changes that balance quality outcomes with cost-effectiveness based on tightly focused evaluations (Lavis et al., 2018). As such, embedding data collection to support ongoing quality improvement can ensure more effective tailoring of strategies to diverse community contexts across Canada for maximal benefits. Similar quality improvement frameworks involving collaboration across systems can be applied in and across other sectors as well (see LeMahieu & Cooper, 2020 for a review of methods used in the education system).

6.3.2 Best and Promising Practices

Review of European and American autism policy suggests that planning and preparing a pan-Canadian autism framework requires long-term commitment with coordination mechanisms and ongoing monitoring of outcomes (Government Accountability Office, 2013; 2014; Autism Europe, 2020).

Coordination Mechanisms

To this end, strengthening governance, leadership, and accountability was one of the key enablers for systems change laid out in the United Kingdom's (2021) most recent updates to their National Autism Strategy. These system enablers parallel the organizational approach to governance and organizational structure outlined in learning health systems (Menear et al., 2019). Methods used to formalize governance vary according to need, with decision-making processes identified and linked to the organizational structure (Lessard et al., 2017). When adopting collaborative and person-centric approaches (Menear et al., 2019) as well as the principles of citizen participation and *self-advocacy*, governance includes representation of Autistic people from diverse backgrounds, such as those who have been historically excluded from decision-making processes due to systemic barriers and marginalization.

The United Kingdom and the United States have approached governance through legislated or mandated inter-ministerial or departmental agreements and coordination. For instance, in the US, the Office of Autism Research Coordination coordinates and manages the Interagency Autism Coordinating Committee and serves as a liaison between the Interagency Autism Coordinating Committee and federal agencies, Congress, and the public (Interagency Autism Coordinating Committee, 2020). The Interagency Autism Coordinating Committee, initially established under the Children's Health Act of 2000, is the federal advisory committee tasked with coordinating federal autism-related activities and providing advice to the Secretary of

Health and Human Services. The Committee consists of federal agencies as well as Autistic self-advocates, family members and other *supporters*, and researchers. Additionally, the National Autism Coordinator role was created under the Autism Collaboration, Accountability, Research, Education and Support Act of 2014 to provide further support with coordinating federal autism-related activities.

Ongoing Evaluation and Monitoring

Based on previous international policy efforts in this area, effective implementation of a national autism strategy involves ongoing evaluation which begins by developing indicators or performance measures (Alcorn MacKay, 2010; Nova Scotia Department of Education, 2010; World Health Organization, 2013b; Houlden, 2015; Autism Education Trust, 2016; Guldberg et al., 2019; Autism Spectrum Disorder in the European Union, 2017, 2018; State of Victoria, Department of Health and Human Services, 2019; Spoelstra & Bountrogianni, 2019; Autism Europe, 2019, 2020; Welsh Government, 2019; Ministère de la Santé et des Services sociaux, 2017; New Zealand Ministries of Health and Education, 2016). For example, the [Victoria Autism Plan](#) in Australia (State of Victoria, Department of Health and Human Services, 2019), has adopted a comprehensive set of indicators and measures. These indicators were initially introduced in Victoria's state disability plan [Absolutely Everyone](#) (State of Victoria, Department of Health and Human Services, 2018) and aim to achieve a range of outcomes among disabled people across multiple domains such as inclusion, health, safety, education, and employment.

Strategies supporting transformative change within complex systems (Lessard et al., 2017; Menear et al., 2019) include:

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- Measures to track the achievement of goals,
 - Monitoring change and evaluating its impacts,
 - Mobilizing new partners and resources,
 - Rewarding new practices, and
 - Fostering environments conducive to continuous learning and improvement.
-

As per countries who have aimed to implement autism strategies, effective monitoring processes are transparent, accessible, and occur regularly (Government Accountability Office, 2013, 2014; State of Victoria, Department of Health and Human Services, 2019; Autism Europe, 2020; Welsh Government, 2016, 2018; Department of Health, Social Services and Public Safety, 2015).

England's most recent National Autism Strategy 2021 - 2026 included a strong commitment to data collection and reporting to monitor implementation of the strategy and drive system improvements (Institute of Medicine, 2007; Lessard et al., 2017; Menear et al., 2019). For example, prior to the development of this update, the government undertook a review of the

previous, Think Autism strategy, involving surveys and focus groups with Autistic children and adults, families, carers, professionals, and organizations. This feedback process was then used to inform the development of the 2021 - 2026 strategy (Department of Health and Social Care, & Department for Education, 2021b). Additionally, the Department of Health developed the [Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy](#) (Social Care, Local Government and Care Partnerships, Mental Health and Disability and Dementia, 2015), which is accompanied by an annual self-assessment exercise that is made publicly-available to Autistic people, families, and carers. This process also enables England's Department of Health to compare progress across different regions.

In Wales, annual reports are published as part of the implementation of the autism action plan to highlight accomplishments from the past year and goals for the following year (Welsh Government, 2021a). Further, stakeholder engagement opportunities are held to obtain feedback from Autistic people, families, carers, and local authorities to inform objectives for the following year. Priming and promoting communities of interest to adopt long-lasting monitoring processes can ensure that value is demonstrated and maintained after taking actions assumed to be beneficial (Meneer et al., 2019).

Fostering Open and Ongoing Dialogue

In Chapter 1, we introduced how concepts related to autism have and will likely continue to evolve. This evolution has created a diversity of perspectives on autism and autism supports and services. It is only through fostering open and ongoing dialogue amongst multiple stakeholders, who may hold differing views, that a clearer consensus and deeper understanding can be reached. The national autism strategy may provide both a process and framework through which a policy environment “conducive to open dialogue and to the frank and respectful exchange of opinion and ideas” (Jose et al., 2020, p. 9) can be developed amongst Autistic individuals, family members, service providers, researchers, and policy-makers. Building on the best practices of collaboration and meaningful engagement, making space for such discussions will sometimes involve being open to and learning from differing perspectives. It also involves ensuring two-way understanding about what research and policy can offer. This may include building trust amongst stakeholder groups, such as Autistic people and researchers, where mistrust may exist due to past or present social injustices (McDavitt et al., 2016).

As described in several sections of this report, historically autistic perspectives have been marginalized. Even today, Autistic people are often not considered as primary stakeholders in autism policy. It is thus integral that all individuals wanting to take part in such dialogue be aware of, and continually reflect on, existing power dynamics between Autistic and non-autistic individuals, which, either consciously or unconsciously, often benefit non-autistic (majority)

perspectives. In order to move forward in collaborative dialogue, attentive and respectful listening and centring of autistic perspectives is needed.

In considering how to support and make space for such dialogue, some of the principles of Open Dialogue, a human-rights aligned therapeutic approach, may be relevant to consider here, such as (Von Peter et al., 2019):

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- Eliciting multiple viewpoints,
 - Emphasizing the present moment,
 - Being attentive to and sensitive to meanings/language,
 - Emphasizing different perspectives and stories, not symptoms,
 - Being transparent, and
 - Tolerating uncertainty.
-

Ultimately, such open and inclusive dialogue could serve to catalyze meaningful change that advances clinical practice, improves service delivery systems, and removes barriers to meaningful inclusion, participation, and contribution of Autistic people at all levels of Canadian society.

Key Findings - Collaboration

Coordination amongst different levels of government, ministries, industry, and philanthropic and non-profit organizations creates opportunities for synergies, innovation, and sufficient capacity to address strategic priorities.

Rigorous and ongoing evaluation of practices and publicly-funded programs, framed by learning health system approach and other quality improvement approaches, ensures that supports and services for Autistic people:

- **Reflect current evidence,**
- **Offer needs-based services,**
- **Avoid adverse events, and**
- **Have a positive impact on overall quality of life.**

Models of and research on autism-friendly solutions, for example in housing and building design, can be promoted, and shared across Canada through interdisciplinary communities of practice and targeted knowledge sharing.

6.4 Chapter Summary

Data collection and sharing, research, and collaboration are three key enablers for the successful implementation of strategic autism policies.

Data collection includes surveillance, which enables the tracking of incidence and factors associated with autism diagnosis rates over time. When linked strategically to other databases that provide more in-depth information about health and wellbeing, such data can also provide information on overall needs. Improving data collection and sharing requires strengthening infrastructure, processes, and information technology.

To date, much of the research about autism has been conducted through a biomedical lens, focusing on the causes, prevention, and characterization of this condition, typically in childhood. This research base offers important insights, but is not necessarily aligned to answering critical questions about the day-to-day needs of Autistic individuals across the lifespan. Strategies to improve the applicability of research to the daily lives of Autistic people and their families include:

-
- Using inclusive and participatory approaches,
 - Evaluating and scaling up community-based services and supports, particularly in adulthood,
 - Implementing longitudinal and evaluative methodologies, and
 - Building long-term capacity of current and future autism researchers, including Autistic researchers.
-

Implementation science and quality improvement frameworks, such as rapid learning health systems, may be expedient tools to move research into practice and vice versa. Embedding data collection to support ongoing quality improvement can ensure more effective tailoring of strategies to diverse community contexts across Canada for maximal benefits to Autistic individuals and their families.

Report Conclusion

As a conclusion to this report, we have offered evidence and examples regarding autism research and data collection. These are two of many key enablers that have been outlined within this report across the themes of Social Inclusion, Economic Inclusion, and Diagnosis, Supports, and Services. In undertaking this assessment, the breadth and complexity of the needs of Autistic people were highlighted. System change to better address these needs is possible through sustained and equitable collaboration amongst all levels of government, Autistic people and their families, and other stakeholders, including researchers, clinicians, and educators. A shared vision of a more inclusive society for Autistic Canadians and their families will continue to inspire these efforts. The diverse insights and perspectives that come from lived experience will continue to illuminate the way forward.

Glossary

Throughout the Assessment on Autism, we paid attention to the words Autistic people use to describe autism. We also paid attention to the words researchers and service providers use. You can read about the importance of language in Chapter 1.

Here are some definitions of important words that appear in the report. The definitions are organized into two groups: Autism Words and Other Words.

Terms that appear in *teal italics* have their own entry so you can look up what they mean.

Autism Words

Autism	<p>Autistic people’s brains work differently. Autistic people communicate and connect with other people differently. Autistic people may be overwhelmed by sensations such as loud noises and bright lights, but may really like other sensations. Autistic people may also benefit from certain routines or predictability and may focus intensely on certain interests.</p> <p>Autistic people often have other physical, intellectual, learning, or mental health challenges or conditions.</p>
Autism acceptance	<p>Embracing autism in a <i>neuro-affirming</i> way—as a difference, not a disorder. Autism acceptance involves:</p> <ul style="list-style-type: none">• Developing an understanding of Autistic people’s ways of being, thinking and doing, and recognizing those ways as valid, and• Accepting and embracing Autistic people’s differences in all aspects of society. <p>Autism acceptance works to change public attitudes and behaviours towards Autistic people.</p>
Autism awareness	<p>Educating the public about autism. In the past, very few people knew what autism was. Autism awareness and education is a starting point for autism acceptance.</p>
Autistic-led	<p>Spaces and initiatives that are led by Autistic people, where Autistic people are the main decision-makers. For example:</p> <ul style="list-style-type: none">• Autistic-led spaces include organizations, programs, and groups that meet online or in-person.• Autistic-led initiatives include advocacy and research.

Other Words

<p>2SLGBTQIA+</p>	<p>A short form for some of the many ways people describe their sexual identity and gender. It means: two-spirit, lesbian, gay, bisexual, transgender, queer, intersex, and asexual. The “+” stands for other forms that are not straight male/female or heterosexual. It is a reminder that our language and understanding about sexuality and gender keeps growing.</p>
<p>Accommodations</p>	<p>Supports or services that help a person to function effectively in an environment or situation. For example, classroom accommodations for an Autistic student might include: a quiet place to work, visual cues, such as photographs to illustrate instructions, and routines that are clear and consistent.</p>
<p>Assistive technologies</p>	<p>Tools and other things that help people with tasks they would not be able to do without help. There are assistive technologies that can help with learning, work, daily activities, and play. For example, many Autistic people use augmentative and alternative communication (AAC) systems to help them communicate more comfortably.</p>
<p>Augmentative and alternative communication (AAC)</p>	<p>Ways to help people communicate, particularly people who may not be able to use their own natural speaking voice or who prefer not to use it.</p> <p>Some solutions may be simple while others involve high technology. For example:</p> <ul style="list-style-type: none"> • Low-tech tools include pen-and-paper and picture boards. • High-tech tools include apps for smartphones and tablets, tools for generating speech, and tools for tracking where a person is looking.
<p>Behaviours that challenge</p>	<p>Behaviours that present a challenge to the individual and others (such as service providers and family members). The individual may have a purpose for these behaviours (such as trying to communicate a need).</p>
<p>Built environment</p>	<p>Human-made physical structures that make up the spaces where we live, learn, work, and play. These include, for example: homes, schools, workplaces, businesses, transportation, green spaces, and streets. The built environment can impact the health and wellbeing of individuals and whole communities.</p>
<p>Capacity building</p>	<p>Getting better at doing something and at adapting to change. Individuals can build their capacity and so can groups.</p> <ul style="list-style-type: none"> • Individuals build capacity by advancing their knowledge and skills. • Organizations and whole sectors build capacity by improving their systems—for example, by designing effective policies, providing and using resources well, and developing strong community partnerships.

Co-create/co-design/ co-produce	A commitment to work together when people have a common interest but come from different backgrounds and have different expertise. The process requires equitable decision-making, compromise, communication, and reflection with Autistic people and their supporters.
Complex support needs	<p>Needs that are varied, ongoing, or extensive. Autistic people with complex support needs require specialized support across multiple areas of daily life. For many, the need for supports and services remains consistently high across the lifespan. Autistic people with complex support needs typically have co-occurring conditions such as intellectual disabilities, significant mental illnesses or serious physical or medical conditions.</p> <p>We do not use terms such as “high/low functioning,” or “high/low severity of autism,” or “special needs.” These terms can be hurtful and do not describe the combined strengths, challenges, and support needs of Autistic people.</p>
Developmental disability	<p>A significant limitation in a person’s ability to develop skills for daily living, socializing, and learning. Developmental disabilities start before the age of 18 and continue throughout a person’s life. They affect thinking and doing.</p> <ul style="list-style-type: none"> • <i>Thinking</i> includes reasoning, organizing, planning, making judgements, and anticipating consequences. • <i>Doing</i> includes learning and applying various daily living skills. <p>In Canada, developmental disability is an administrative term applied to individuals who are eligible for provincial or territorial developmental services, such as respite and residential services. To meet eligibility, a combination of impairment in intellectual quotient and adaptive functioning is required.</p> <p>The United Kingdom uses the term <i>learning disability</i> in place of developmental disability. We have used the term intellectual disability rather than ‘developmental disability’ in this report.</p> <p>An intellectual disability is different from a learning disability or difference. Learning disabilities may include dyslexia or dycalculia. Many, but not all Autistic people have an intellectual disability or a learning disability.</p>
Double stigma	The notion of “double stigma” describes the stigma experienced by individuals or groups of individuals who have two or more stigmatized conditions or identities. The stigmas do not just add up; they interact with one another in complex ways that multiply the disadvantages.

<p>Equity-seeking groups</p>	<p>Communities that experience barriers to full participation in society. The barriers are systemic, meaning that they are built in and widespread. Attitudes, social norms, the built environment, and other factors can all create barriers for groups of people.</p> <p>Seeking equity is different from seeking equality. Equality means everybody gets the same thing; equity means everybody is treated fairly, based on their needs and abilities. Because different groups face different barriers, achieving equity will require different supports and resources.</p>
<p>Executive function</p>	<p>Mental processes that are required to carry out everyday activities. These processes include inhibition (self-control), working memory, cognitive flexibility, reasoning, planning, and problem solving.</p>
<p>Family member</p>	<p>A parent/guardian, grandparent, sibling, spouse, or other non-paid supporter of an Autistic person. We use this broad understanding of family because defining “who is family” is deeply personal and cultural.</p> <p>We use the term parent when we are referring specifically to that relationship.</p> <p>Unless otherwise specified, a family member may be an Autistic person or a non-autistic person. For example, we sometimes differentiate between an Autistic parent and a non-autistic parent. An Autistic parent is a parent who is autistic.</p>
<p>Identity-first language</p>	<p>Language that recognizes a condition (such as autism) or a disability as an inherent part of a person’s identity. It is in contrast to person-first language, which views the condition or disability as an attribute of the person and not a core part of who they are.</p> <p>As part of the Assessment on Autism, we conducted a language survey to hear from Autistic people and parents of Autistic people about the terminology they prefer. The people who responded generally preferred identity-first language—for example, Autistic person, rather than person with autism.</p>
<p>Inclusion</p>	<p>A commitment to recognize and consider the needs and interests of Autistic people so that they are actively engaged in their communities. Inclusion goes beyond integration. With integration, the commitment is simply to have Autistic people present in the same space as non-autistic people.</p>
<p>Independent living</p>	<p>Having an active role in one’s own environment rather than being a passive recipient of the environment. Independent living:</p> <ul style="list-style-type: none"> • Involves choice and autonomy, • Implies living in the community rather than an institution, and • Requires the development of life skills.

Intellectual disability	Refers to significant impairments in both intellectual and adaptive functioning. In this report, we have primarily used the term <i>intellectual disability</i> rather than developmental disability . Some Autistic people have a co-occurring <i>intellectual disability</i> .
Intersectionality	<p>The idea that:</p> <ul style="list-style-type: none"> • An individual has many identities, and • These identities interact in complex ways to affect one’s experience of advantage or disadvantage in the world. <p>The concept of intersectionality provides a deeper understanding of the barriers that Autistic people face. Race*, culture, socio-economic status, gender, sexual orientation, age, ability, and other identities can compound the advantages and barriers that Autistic people experience.</p> <p>*See also racialized people.</p>
Life skills	<p>Abilities that people need to manage and adapt to daily demands and challenges. These abilities include:</p> <ul style="list-style-type: none"> • Cognitive skills (such as decision-making, problem-solving, creative thinking, and critical thinking) • Emotional skills (such as self-awareness and self-management), and • Communication and interpersonal skills (such as relationship skills, communication, and social awareness).
Lived experience	Direct, first-hand experience with the impact of one or many social issues. In this assessment, those with lived experience include Autistic people and their family members .
Neuro-affirming	<p>An approach to interacting with Autistic and other neurodiverse individuals that:</p> <ul style="list-style-type: none"> • Accepts, understands, values, and celebrates neurodiversity, and • Does not try to fix different ways of thinking and being, or consider those differences to be illnesses.
Neurodiversity	An understanding that brain differences among people are a natural and valuable part of human diversity.
Racialized people, communities, groups, youth, or families	People who face systemic disadvantages because they are not white. We use the term racialized rather than “visible minority” or “person of colour” to acknowledge that characterizing and discriminating against people in this way comes from the society; the problem is not rooted in the people themselves.

Self-advocacy	<p>Work by Autistic people to improve their situation. This includes:</p> <ul style="list-style-type: none"> • Autistic individuals expressing their own personal interests, needs, and rights, and • Autistic-led initiatives that improve situations for Autistic people.
Self-determination	<p>Acting on one’s own free will, preferences, choices, and interests; not forced to do things by other people or by circumstances.</p>
Service provider	<p>An individual or group that is paid to provide a service that supports Autistic people. For example, the service provider might provide health, education, social services, or employment support.</p>
Supporters	<p>People who play important roles in an Autistic person’s life and provide support in various ways. Supporters can include family members, friends, other Autistic people, allies, and neighbours, as well as people who are paid, such as service providers and support workers.</p> <p>Many people prefer the term “supporters” rather than “caregivers.” In our report, we tried to be specific whenever possible—for example, specifying “Autistic people’s families”, “service provider,” or “friends.”</p>
Trauma-informed	<p>An understanding of how distressing life experiences or events affect people and how to provide support that:</p> <ul style="list-style-type: none"> • Is appropriate and accessible, and • Does not cause more trauma. <p>A trauma-informed approach begins with the assumption that a person may have experienced serious trauma that continues to affect their lives, including how they interact with service providers.</p>
Universal design	<p>The goal of making all products, buildings, exterior spaces, and related services usable to everyone who wants to use them. Advocates for universal design often refer to these seven principles:</p> <ul style="list-style-type: none"> • Equitable use, • Flexible use, • Simple and intuitive use, • Perceptible information (it is clear how to use the thing), • Tolerance for error, • Low physical effort (ease of use), and • Size and space for approach and use.



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Index

- Summary** 15
- Autism in Canada..... 15
- The Assessment on Autism 15
- Themes 15
- Intersectionality and Diversity 15
- Social Inclusion 16
- Diagnosis, Supports, and Services17
- Economic Inclusion 18
- Positioning for Impact.....20
- Conclusion 20
- Chapter 1: Overall Approach**21
- 1.0 Introduction22
- 1.1 What is Autism? 23
 - 1.1.1 Evolving Understandings of Autism..... 23
 - 1.1.2 Characterizing Autism 26
- 1.2 Canadian Context27
 - 1.2.1 Prevalence of Autism in Canada27
 - 1.2.2 Meeting the Needs of Autistic People in Canada..... 28
- 1.3 International Context..... 29
 - 1.3.1 United Kingdom 30
 - 1.3.2 United States 30

1.3.3	Australia.....	31
1.4	Why a National Autism Strategy?.....	34
1.4.1	Planning for Now and for the Future.....	34
1.4.2	Addressing the Breadth of Needs and Complexities	34
1.4.3	Facilitating Collaboration	35
1.5	Meaningful Engagement of Autistic People.....	35
1.5.1	Citizen Engagement	35
1.5.2	Co-Creation of Policies, Programs, and Services	37
1.6	The Charge and Methodology.....	39
1.6.1	Setting the Stage.....	39
1.6.3	Overall Approach	42
1.6.3	Reviewing the Evidence.....	42
1.6.4	Summary of the Engagement Process.....	44
1.7	The Report.....	48
1.7.1	Structure of the Report.....	48
1.7.2	Scope and Limitations of the Assessment Report	48
1.8	Chapter Summary	51
	Chapter 2: Priority Considerations that are Cross-Cutting.....	52
2.0	Autism, Diversity, and Intersectionality	53
2.1	Autism and Indigenous Peoples	56
2.1.1	Acceptance of Diversity.....	58
2.1.2	Prevalence of Autism in Indigenous Communities.....	58
2.1.3	Barriers to Accessing Healthcare and Autism Diagnosis	58

2.1.4	Culturally-Responsive, Evidence-Informed Supports and Services	60
2.1.5	Funding for Supports and Services Across Canada.....	61
2.1.6	Safety Concerns associated with being Indigenous and Autistic	62
2.1.7	Engagement with Indigenous Peoples of Canada.....	62
2.2	Autism and Diversity related to Race and Ethnicity	63
2.3	Autism and New Canadians and Language Minorities.....	65
2.4	Autism, Gender, Gender Identity, and Sexual Orientation	67
2.5	Autism and Diversity of Family Structures.....	70
2.5.1	Experiences of Parenting: Autistic Parent Perspectives.....	70
2.5.2	Families that include Autistic People.....	71
2.6	Complexity of Support Needs	72
2.7	Autism and Rural and Remote Communities.....	73
2.8	Autism and Socioeconomic Status.....	74
2.9	Addressing the Needs of Equity-Seeking Groups	75
2.10	Chapter Summary	76
	Chapter 3: Social Inclusion	77
3.0	Elements of Inclusive Communities.....	78
3.1	Addressing Stigma and Ensuring Human Rights	79
3.1.1	Background.....	79
3.1.2	Best and Promising Practices	83
	Key Findings - Addressing Stigma and Ensuring Human Rights.....	97

3.2	Promoting Physical and Emotional Safety	98
3.2.1	Background.....	98
3.2.2	Best and Promising Practices	104
	Key Findings - Promoting Physical and Emotional Safety	111
3.3	Enhancing Community Participation and Accessibility	112
3.3.1	Background.....	112
3.3.2	Best and Promising Practices	117
	Key Findings - Enhancing Community Participation and Accessibility	124
3.4	Social Inclusion through Technology	125
3.4.1	Background.....	125
3.4.2	Best and Promising Practices	126
	Key Findings - Social Inclusion through Technology.....	129
3.5	Chapter Summary	130
	Chapter 4: Diagnosis, Supports, and Services	131
4.0	Introduction	132
4.1	Equitable Access to Diagnosis, Supports, and Services.....	133
4.1.1	Background	133
4.1.2	Best and Promising Practices	137
	Key Findings - Equitable Access to Diagnosis, Supports, and Services	146
4.2	Recognition and Diagnosis across the Lifespan.....	147
4.2.1	Background.....	147
4.2.2	Best and Promising Practices	150
4.3	A Lifespan, Family-Centred Approach.....	153

Key Findings - Recognition and Diagnosis Across the Lifespan	154
4.3.1 Background	154
4.3.2 Lifespan and Chapter Approach	157
4.3.3 Family Wellbeing and Family-Centric Pathways	157
Key Findings - A Lifespan, Family-Centred Approach	161
4.4 Preschool and Early Childhood (0 - 5) Supports and Services	161
4.4.1 Background.....	161
4.4.2 Best and Promising Practices	166
4.5 Supports and Services for School-Aged Children and Adolescents	171
Key Findings - Preschool and Early Childhood	172
4.5.1 Background.....	173
4.5.2 Best and Promising Practices	180
Key Findings - Supports and Services for School-Aged Children and Adolescents	191
4.6 Adulthood	192
4.6.1 Background.....	192
4.6.2 Best and Promising Practices	197
Key Findings - Adulthood	205
4.7 Advances related to Neurobiology	206
4.8 Chapter Summary	206
Chapter 5: Economic Inclusion	208
5.0 Introduction	209
5.1 Financial Stability	209
5.1.1 Background.....	209

5.1.2	Best and Promising Practices	211
	Key Findings - Financial Stability	218
5.2	Post-Secondary Education and Lifelong Learning	219
5.2.1	Background.....	219
5.2.2	Best and Promising Practices	220
	Key Findings - Post-Secondary Education and Lifelong Learning	227
5.3	Employment Pathways	228
5.3.1	Background.....	228
5.3.2	Best and Promising Practices	230
	Key Findings - Employment Pathways	239
5.4	Autism-Inclusive Housing Options.....	240
5.4.1	Background.....	240
5.4.2	What is Autism-Friendly Housing?	241
5.4.3	Where do Autistic People live?	241
5.4.4	Best and Promising Practices	243
	Key Findings - Autism-Inclusive Housing Options	250
5.5	Chapter Summary	251
	Chapter 6: Positioning for Impact: Ongoing Evaluation	252
6.0	Introduction	253
6.1	Data Collection and Sharing.....	255
6.1.1	Canadian Context	255
6.1.2	Best and Promising Practices	258
6.2	Research.....	260

6.2.1	Canadian Context	261
6.2.2	Best and Promising Practices	264
	Key Findings - Research	267
6.3	Collaboration: From Data and Research to Practice	268
6.3.1	Canadian Context	268
6.3.2	Best and Promising Practices	269
	Key Findings - Collaboration	272
6.4	Chapter Summary	273
	Report Conclusion	274
	Glossary	275
	Autism Words	275
	Other Words	276
	Reference List - Alphabetized	281