FRAMEWORK

for Autism in Canada

INCLUDE. ENGAGE. COLLABORATE.

Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canada

To promote and protect the health of canadians through leadership, partnership, innovation and action in public health.

—Public Health Agency of Canada

Également disponible en français sous le titre :
Cadre pour l'autisme au canada

To obtain additional information, please contact:

Public Health Agency of Canada
Address Locator 0900C2
Ottawa, ON K1A 0K9
Tel.: 613-957-2991
Toll free: 1-866-225-0709
Fax: 613-941-5366
TTY: 1-800-465-7735

E-mail: publications-publications@hc-sc.gc.ca

Publication date: September 2024

Cat.: HP15-69/1-2024E-PDF
ISBN: 978-0-660-73561-0
Pub.: 240521

TABLE OF CONTENTS

ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
AIDE	Autism and Intellectual Disabilities Knowledge Exchange Network
CAHS	Canadian Academy of Health Sciences
CHSCY	Canadian Health Survey on Children and Youth
CIHR	Canadian Institutes of Health Research
CRA	Canada Revenue Agency
CRPD	Convention on the Rights of Persons with Disabilities
CSD	Canadian Survey on Disability
DIAP	Disability Inclusion Action Plan
EAF	Enabling Accessibility Fund
ESDC	Employment and Social Development Canada
FPT	Federal-Provincial-Territorial
OF	Opportunities Fund
OLMC	Official Language Minority Communities
PHAC	Public Health Agency of Canada
UN	United Nations
WHA	World Health Assembly
WHO	World Health Organization
2SLGBTQIA+	Two-spirit, lesbian, gay, bisexual, transgender, queer, intersex, asexual, and additional sexual orientations and gender identities

MINISTER'S MESSAGE

I am honoured to share the *Framework for Autism in Canada* (Framework). In the Spring of 2023, the *Federal Framework on Autism Spectrum Disorder Act* received Royal Assent, outlining the need for coordinated services and supports benefiting people on the autism spectrum, their families, supporters, and caregivers in Canada.

Developed in collaboration with the Federal-Provincial-Territorial Working Group on Autism and Indigenous partners, the Framework sets out guiding principles related to autism policies and programs in Canada and specific federal measures to be implemented in response to the Act. It provides overarching direction and inspiration for action, while respecting provincial and territorial areas of primary jurisdiction such as the administration and delivery of healthcare, education and most disability programming. The Framework was informed by a broad engagement and scientific review process, including the Canadian Academy of Health Science's Assessment on Autism and the Public Health Agency of Canada's 2022 and 2024 National Autism Conferences.

We heard from stakeholders that there is still work to be done to address the broad range of support needs among Autistic people, their families, and caregivers across Canada. The unique needs and contributions of Autistic people across the entire lifespan need to be considered—from childhood, to adolescence, to adulthood and onwards—along with the evolving needs of family members and caregivers who play an important role in providing care and support through the life journey. We also heard about the need for research, education, understanding, acceptance and inclusion, services, equal access to medical and financial supports, assistance with barriers to employment, housing and support for integration into the workforce.

Important efforts have been underway by the Government of Canada, provincial and territorial governments, stakeholders, and partners to address these complex and diverse needs. Together, we will strengthen coordination and collaboration to learn from best practices and expand upon programs that have proven to have positive impacts.

The Government of Canada recognizes the need for concrete and coordinated action to address autism priorities from a social determinants of health perspective. As such, *Canada's Autism Strategy* was also developed to support the implementation of the Framework. The Strategy is a multi-year strategic plan outlining additional federal initiatives to address five key priority areas and will be adjusted over time to reflect evolving needs and priorities of neurodiverse Canadians. The Strategy will leverage existing federal initiatives such as the Disability Inclusion Action Plan, to help address autism priorities. The Framework and Strategy align and build upon the Government of Canada's broader efforts to support persons with disabilities.

Together, we can ensure that every Autistic person in Canada is fully accepted and supported to live, work and play to their fullest.

The Honourable Mark Holland, P.C., M.P.
Minister of Health

EXECUTIVE SUMMARY

Autism (also known as autism spectrum disorder or ASD) is a lifelong neurodevelopmental condition. Autistic people may communicate and connect with other people differently, have sensory processing differences, or focus intensely on certain interests or activities. Autistic people may also have other physical, intellectual, learning, or mental health conditions which can introduce complexities and challenges. Since everyone has different experiences and characteristics, the type and extent of supports needed can vary considerably and should be adapted to individual needs.[1]

The *Federal Framework on Autism Spectrum Disorder Act* (the Act) was passed in March 2023. The Act outlines a commitment for the Minister of Health to bring forth a Framework to guide efforts to provide much needed support to people on the autism spectrum, their families, and caregivers in Canada.

The Public Health Agency of Canada has consulted with stakeholders through a variety of forums to inform the development of a Framework, including:

- The Government of Canada's first National Autism Conference in November 2022, which brought stakeholders together from across Canada, including Autistic people, their families and caregivers, and representatives from medical and research communities.
- The Government of Canada's second National Autism Conference held in August 2024, to discuss the Framework's five priority areas and the actions needed to advance them, bringing together Autistic people, families, caregivers, academics, service providers, and government representatives, along with the general public.
- A federal interdepartmental committee focused on autism with representation from nine other federal departments including: Department of Finance Canada, Canada Revenue Agency, Employment and Social Development Canada, Canadian Institutes of Health Research, Health Canada, Canada Mortgage and Housing Corporation, Public Safety Canada, Indigenous Services Canada and Treasury Board of Canada Secretariat (observer).
- An intergovernmental autism working group, with representation from provinces and territories*, as well as the Government of Canada.
- A broad and inclusive engagement and scientific review process, undertaken by the Canadian Academy of Health Sciences (CAHS). Representatives from medical and research communities were also consulted during the stakeholder engagement process and their input served to inform the development of the 2022 CAHS report entitled *Autism in Canada: Considerations for Future Public Policy Development*.

- Indigenous-led engagement through National Indigenous Organizations, including organizations that focus on autism in Indigenous communities, as required in the Act, which will lead to the identification of Indigenous-specific autism priorities.

AS OUTLINED IN THE ACT, the Minister of Health must engage with "organizations that focus on autism spectrum disorder in Indigenous communities". For the purposes of the Framework, this has been interpreted to include all Indigenous organizations that provide policy and program support to persons with disabilities, including autism (e.g., National Indigenous Organizations).

Framework for Autism in Canada

In addition to setting out federal-specific Framework measures to be implemented in response to the Act, the *Framework for Autism in Canada* (Framework) also sets out guiding principles to help inform policies and programs and ensure communities, public and private institutions are inclusive of all people on the autism spectrum.

The purpose of the Framework is to promote the health and well-being of people of all ages on the autism spectrum, their advocates (such as those who assist with communication on behalf of children or those who can't speak for themselves), families, and caregivers across the life-course. The Framework will also provide a common direction for autism in Canada that lays the foundation for collaborative and complementary action to be taken by all sectors.

This Framework draws heavily from the findings of the 2022 CAHS Assessment on Autism Report. It also draws from what was heard at the Government of Canada's 2022 and 2024 National Autism Conferences. The report, conferences, and engagement with various stakeholders, including provinces and territories through an intergovernmental working group, helped to provide a comprehensive picture of the needs and realities of Autistic people in Canada.

Guiding principles

The following principles guide the Framework:

- Evidence-informed approach
- Human rights-based approach
- "Nothing Without Us"
- Intersectionality and diversity
- Distinctions-based approaches
- Life-course approach
- Collaboration

Priority areas

The Framework outlines five priority areas:

- Screening, diagnosis and services
- Economic inclusion
- Data collection, public health surveillance and research
- Public awareness, understanding and acceptance
- Tools and resources

Each Framework priority area outlines:

- **VISION** | For each priority area, a vision statement sets out a desired future to support Autistic people in Canada, their families and caregivers. Each vision statement reflects the direction for change needed to address the barriers faced by this community.
- **OPPORTUNITIES AND BEST PRACTICES** | For each priority area, information regarding possible multi-jurisdictional and aspirational policy directions to address existing needs and barriers is provided. These high-level opportunities and best practices were identified by stakeholders and various partners including Autistic people in Canada, their advocates, families and caregivers, through a synthesis of consultations, including the 2022 and 2024 National Autism Conferences and the Canadian Academy of Health Sciences' report. For a detailed list of opportunities and best practices, identified in consultations with stakeholders, see Appendix A. These opportunities and best practices are intended to guide future action across sectors, federal departments, and various levels of government.
- **FRAMEWORK MEASURES** | For each priority area, one or more federal-specific Framework measures have been identified. Additional measures are outlined in the section "Moving Forward: Reporting to Parliament", which provide mechanisms to ensure that federal funds for Autistic people and their families are used responsibly and transparently. These measures fall within the Minister of Health's mandate and have been identified in response to the requirements of the Act. The measures are intended to provide support for Autistic people, their families, and caregivers in Canada.

Though the Framework is meant to be a broad common policy direction, it also recognizes that Indigenous communities and individuals have distinct understandings and lived experiences of autism. While moving toward implementation of the Framework, the Government of Canada will continue to take an Indigenous-led approach to engaging with First Nations, Inuit, Métis, and Urban-Indigenous Peoples. This ongoing engagement will inform the way forward while exploring distinctions-based and Indigenous-led approaches to addressing autism-related priorities.

The Framework outlines federal-specific measures to be implemented and provides overarching principles to support Canada's collective efforts on autism. Implementation of the Framework will require coordinated efforts across governments in Canada, as well as many partners, organizations, and individuals whose work touches on autism-related initiatives. Provinces and Territories have primary jurisdiction over the administration and delivery of most health, education, and social supports and services. The Government of Canada will continue to work with provinces and territories to advance the needs of Autistic people in Canada. Every person in Canada can contribute to making communities inclusive of everyone on the autism spectrum, including children, youth, adults and older adults, as well as their advocates, families, and caregivers.

INTRODUCTION

Language statement

The Government of Canada acknowledges the diverse views of people on the autism spectrum, “their caregivers, and the community as a whole. Careful thought was put into the language used in this document. Both ‘person-first’ and ‘identity-first’ language is used. A person-first approach acknowledges the person before the disability and is seen in wording such as ‘people with autism.’ With identity-first language, phrases such as ‘Autistic people in Canada’ are used. The language used to describe an individual is personal. It is the stated goal of the Government of Canada to create an environment of acceptance, inclusion, and respect.

Federal Framework on Autism Spectrum Disorder Act

The *Framework for Autism in Canada* (Framework) has been developed in accordance with the *Federal Framework on Autism Spectrum Disorder Act* (the Act). The Act (Appendix B) received unanimous support in both houses of Parliament and received Royal Assent on March 30, 2023. The Act requires the Minister of Health to develop a Framework on autism spectrum disorder. The Framework will guide efforts to provide much needed support to people on the autism spectrum, their families, and caregivers in Canada.

The Act outlines measures to be identified in the Framework, related to screening and diagnosis, financial support, support for caregivers, research and data collection, improving public knowledge, understanding and acceptance, resources, and mechanisms to ensure accountability in the use of federal funds for Autistic people and their families. The Act further identifies requirements for consultation with federal departments, representatives that are responsible for health from provinces and territories, and relevant stakeholders, as well as for a national conference to inform the development of the Framework. It also sets out specific requirements for reporting to Parliament.

Framework for Autism in Canada

The Framework sets broad, high-level guiding principles related to autism policy and programs, which are multi-jurisdictional in scope and aligned with other disability-related activities, such as Canada’s Disability Inclusion Action Plan (DIAP).

The Framework also sets out federal-specific Framework measures, to be implemented following the tabling of the Framework. These measures will support further coordinated action to be taken across federal departments, and in collaboration with other levels of government. Framework implementation will be supported through a corresponding multi-year autism strategy, developed in collaboration with key federal partners, as well as through the engagement of a new National Autism Network (the Network), which will include Autistic people, their advocates, families and caregivers. The Framework also supports the broader mandate of the Public Health Agency of Canada (PHAC).

One of the federal government's key roles is its convenor role, and its ability to bring partners together across jurisdictions and sectors to share knowledge and best practices, and to advance progress in key priority areas. To ensure that the views of Autistic people, family members, researchers, stakeholders and other partners help guide the implementation of the Framework, a new National Autism Network will be created that will provide a mechanism to engage this community on an ongoing basis.

Five key priority areas have been identified to allow for an overarching umbrella of ongoing and evolving action:

- Screening, diagnosis, and services
- Economic inclusion
- Data collection, public health surveillance, and research
- Public awareness, understanding and acceptance
- Tools and Resources

THE ACT CALLS FOR the Minister of Health to develop a federal framework on autism spectrum disorder, which must identify measures to provide "support for caregivers of Autistic persons". This document integrates this support throughout each of the priority areas, where applicable. This approach reflects the reality that the needs of caregivers are multifaceted and complex and touch each priority area. The terms "supporters" and "caregivers" are both used throughout the Framework (see definitions in Appendix G).

It is known that autism is a lifelong neurodevelopmental condition. Supporting those with autism and their families requires flexibility and a variety of services from childhood to older adulthood. The Framework takes a life-course approach to ensuring programs, tools, resources, and research exist for Autistic people of all ages.

Indigenous populations across Canada are diverse and have distinct experiences and needs. The Government of Canada will take an Indigenous-led and distinctions-based approach to supporting Autistic people across these communities.

Additionally, this Framework applies a social determinants of health perspective, which acknowledges the personal, social, economic, and environmental factors that influence an individual's health and intersect with autism.

This Framework draws heavily from the findings of the 2022 CAHS Assessment on Autism Report. It also draws from the Government of Canada's 2022 and 2024 National Autism Conferences. The report and conferences helped to provide a comprehensive picture of the needs and realities of Autistic people in Canada. See Appendix C for a detailed description of how the consultations and findings from these initiatives informed the priority areas laid out in this Framework. For more details and specific examples of the challenges and paths forward surrounding autism in Canada, please consult the CAHS report.

CURRENT CONTEXT

Autism in Canada

Autism (also known as autism spectrum disorder or ASD) is a lifelong neurodevelopmental condition. Autistic people may communicate and connect with other people differently, have sensory processing differences, or focus intensely on certain interests or activities.

They may also have other disabilities or conditions that affect learning, cognitive functioning, and physical or mental health, which can introduce complexities and challenges. Since everyone has different experiences and characteristics, the type and extent of supports needed can vary considerably and should be adapted to individual needs.[1]

The most recent national prevalence estimates of autism in Canada are based on the 2019 Canadian Health Survey on Children and Youth (CHSCY) which covers individuals aged 1 to 17 living in Canada.[2] According to the 2019 CHSCY, 1 in 50 (or 2%) children and youth living in Canada aged 1 to 17 years were diagnosed with autism spectrum disorder.[2] The Government of Canada continues to explore options to measure and report on autism in adults living in Canada in an effort to build the evidence base required to inform public health actions aimed at improving the health and well-being of Autistic people across the life-course.

Autism is often referred to as a spectrum condition because there is a wide range in the type and intensity of autism characteristics.[3] Experiences of Autistic people may vary further as autism is frequently accompanied by co-occurring conditions. In Canadian youth the most common co-occurring conditions are attention deficit disorder/attention hyperactivity disorder (ADHD), learning disability/disorder, and anxiety disorder;[2] however the range is vast, including speech and language problems, motor difficulty, eating disorders, gastrointestinal symptoms, learning delays, and intellectual disability, among others. Social, environmental, and economic factors such as; gender, age and race, experiences of discrimination, presence of appropriate local services, and income, can further complicate the lives of those with autism and their families, impacting quality of life.[3]

Support needs vary from person to person, with some Autistic people living completely independently, and others requiring substantial levels of care. Needs often change across the lifespan and may include (but are not limited to) assistance with daily living activities, housing, support accessing and participating in community activities, school support, and meaningful participation in post-secondary education or employment pathways.[3] Advocates, caregivers and families play critical roles in providing an extensive range of support and care for Autistic children, youth, adults and older adults, especially for Autistic children and adults with complex support needs.

> "If you've met one person with autism, you've met one person with autism."
> — *Dr. Stephen Shore*

In Canada, the availability and accessibility of autism services and supports differs significantly across provinces and territories, and even across the life-span.[3] There are efforts underway to better understand the ongoing needs of people across the life-course on the autism spectrum in Canada.

The challenges faced by many Autistic people and their families are long-standing, and persistent. In 2007, the Standing Senate Committee on Social Affairs, Science and Technology released a historic report entitled, *Pay Now or Pay Later: Autism Families in Crisis* after its enquiry on funding for autism in Canada. The Report recommended that the federal government establish a comprehensive autism strategy for Canada with the participation of the provinces and the territories as there is no national program to ensure equal and uniform access to supports for autism. Recognizing this as a priority, the Minister of Health's 2019 and 2021 mandate letters included a commitment to work collaboratively with provinces, territories, families, and stakeholders toward the creation of an autism strategy for Canada.

Over 1000 individuals in the autism community participated in the 2022 National Autism Conference, hosted by the Government of Canada (see Appendix C). Participants included self-advocates, people with lived experience, caregivers, and representatives of the provincial and federal governments, service providers, representatives from the medical and research communities and from organizations in Indigenous communities. Participants expressed that raising young children who are Autistic can be both rewarding and challenging. The conference heard that making expected life transitions such as the one from youth to adulthood can be especially hard for many Autistic people in Canada. Conference participants also indicated that, compared to other age groups, older Autistic adults as well as aging parents and caregivers are often groups with the least amount of support. The research community during the conference discussed the need to coordinate goals to better support evidence-based outcomes, and that people across Canada would benefit from being better informed about autism and autism acceptance.

The Government of Canada hosted the 2024 National Autism Conference to build on the previous engagement that took place during the development of the Framework. Over 650 participants, including; Autistic people, families, caregivers, academics, service providers, and government representatives, discussed the Framework's five priority areas and the actions needed to advance them. The conference demonstrated how the feedback obtained through extensive engagement will be reflected in the Framework, reviewed how the federal government plans to address the Framework priorities and finally, explored considerations for implementing the Framework. Input received from conference panelists and participants was used to inform the final version of the Framework.

Evolving perspectives on autism

Understandings of autism are complex, debated and continue to evolve with new autism research in a range of biological, medical and social science fields; as well as changing social paradigms. For decades, a medical model of disability has guided the shared understanding of autism, through the diagnosis of behaviours framed in terms of deficits and impairments. Institutions have historically relied on this shared definition to frame research, create appropriate supports and services and determine who can access them. More recently, both a global neurodiversity movement and a growing application of the social model of disability are reframing the public understanding of autism.[3]

Today, many view autism as more than a diagnosis; it is also a social identity.[4] The self-advocacy community includes many who are proud of their unique characteristics and wish to be seen for their strengths, rather than pathologized for their differences.[5][6] For them, their neurodivergence presents a quality inseparable from who they are as a person and that (often) they would not wish to change, despite the challenges they may experience. Not all share this view, however; some Autistic people (and some parents and caregivers) feel their quality of life is profoundly affected by their experience of autism and co-occurring conditions.[5][7][8] The diverse perspectives and lived experiences of autism mean that for different people and purposes (medical/legal/self-identification), autism can be a diagnosis, identity, disability, developmental disorder, or difference.

The understanding of autism and appropriate supports will continue to evolve over time with new research (including more participatory approaches), knowledge, understanding, and acceptance initiatives, ongoing dialogue and testing of best practices.

Roles and responsibilities to support autism in Canada

All governments in Canada, across many stakeholders and sectors, have a role to play in providing supports for people on the autism spectrum in Canada. The promotion and protection of health is an area of shared jurisdiction in Canada.

Although the federal, provincial, and territorial governments share roles and responsibilities, provinces and territories are responsible for the planning and delivery of most health, education, and social supports and services (see Appendix D). Autism-specific legislation or plans exist in some provinces; however, they are primarily focused on supports and services for Autistic children.[3]

In Canada, the federal government contributes funding to the provinces and territories, who are then responsible for delivering health, including mental health, education, and social services in their jurisdiction, with most provincial and territorial governments subsidizing autism services in childhood.[3] In addition, the federal government, provides funding for First Nations' elementary and secondary education on reserve, including funding for special education. As a result of these responsibilities falling on various governments, the delivery of services and supports may be significantly different depending on the location. In some cases, people on the autism spectrum who require care have had to seek out services that are only offered via the private sector.[3] Due to this jurisdictional variability in service delivery and funding models, Canada has regions that suffer from service shortfalls. However, this variability in service delivery has also resulted in many examples of innovative best practices across the country.[3]

Addressing these complex issues requires collaboration and a coordinated effort across multiple federal departments and all governments in Canada. Establishing positive working relationships and mechanisms for ongoing engagement is critical. The implementation of the Framework will thus leverage the federal government's role as a convenor across jurisdictions in Canada, not-for-profit and private sectors, and advance best practices to support Autistic people in Canada of all ages and their families. To this end, existing governance structures, including the FPT (Federal-Provincial-Territorial) Working Group on Autism, provide a forum to support progress and efforts to address priority areas for action on autism across the country.

Indigenous Peoples

The *Framework for Autism in Canada* (Framework) is informed and guided by the *United Nations (UN) Convention on the Rights of Persons with Disabilities*, and the *UN Declaration on the Rights of Indigenous Peoples*.

Autistic First Nations, Inuit and Métis Peoples and their families face unique challenges associated with colonization and inter-generational traumas, particularly when attempting to seek diagnoses in remote communities, or accessing culturally responsive supports and services.[3]

Additionally, there is a lack of data on the prevalence of autism and other important measures in First Nations, Inuit and Métis populations in Canada; yet, the available research indicates that autism is likely underdiagnosed among these populations.[3]

The CHSCY 2019 provided 2019 prevalence data for autism in children and youth (aged 1-17 years) in Canada, but the survey excluded children and youth living on First Nations reserves and other Aboriginal settlements in the provinces, those living in foster homes, and institutions.[2] Even though Indigenous children represent only 7.7% of children under the age of 14 in Canada, they represent 53.8% of children in foster care and would have been excluded from the survey.[9]

Indigenous Peoples, communities and organizations were provided the opportunity to participate in the broad engagement process designed to support this Framework. The 2022 CAHS report was informed by an Indigenous Advisory Committee that was responsible for overseeing the entire process and for providing guidance to the Oversight Panel on how best to reflect the unique issues of First Nations, Inuit and Métis Peoples within the context of a Pan-Canadian assessment. Subsequently, since 2022, PHAC has collaborated with Employment and Social Development Canada (ESDC) to undertake a joint engagement process with First Nations, Inuit and Métis Peoples regarding the DIAP, an autism strategy for Canada and this Framework. Engagement was Indigenous-led and distinctions-based, undertaken by National Indigenous Organizations who had existing Engagement Protocol Agreements with ESDC.

> "**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, Métis, and Inuit peoples."[3]

However, this engagement was preliminary in nature. To address the unique needs and diverse circumstances of First Nations, Inuit, Métis, and Urban-Indigenous Peoples, and to allow sufficient time for meaningful and ongoing engagement, an Indigenous-led engagement process is continuing through Indigenous Organizations. Ongoing and more extensive engagement approaches will aim to capture the unique interests, circumstances and perspectives of First Nations, Inuit, Métis, and Urban-Indigenous Peoples. This engagement will continue as progress is made towards distinctions-based and Indigenous-led approaches to addressing autism-related priorities.

International

The World Health Organization (WHO) and its partners have identified strengthening the capacity of countries to improve the health and well-being of people with autism as a priority. In fact, in 2014, the World Health Assembly (WHA) adopted a resolution entitled *Comprehensive and coordinated efforts for the management of autism spectrum disorders*, which describes how WHO and Member States must work together to enhance infrastructure for autism support and develop strategies to improve early detection and develop community-based interventions.

In 2021, WHO released the Comprehensive mental health action plan 2013–2030, which along with the WHA Resolution WHA73.10 for "global actions on epilepsy and other neurological disorders" states that countries must "address the current significant gaps in early detection, care, treatment and rehabilitation for mental and neurodevelopmental conditions" and "address the social, economic, educational and inclusion needs of people living with mental and neurological disorders, and their families, and to improve surveillance and relevant research".[10]

The *Framework for Autism* in Canada touches on each of these points, while respecting the principles laid out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which is an instrument outlining how those with disabilities must be able to enjoy the full spectrum of human rights and fundamental freedoms.[11] Additionally, the Framework is informed by the best practices outlined in the CAHS report which draws from recent advancements on autism initiatives internationally.

FRAMEWORK

Vision

A Canada where Autistic people and their families are safe, included, accepted and supported in a way that leads to an improved quality of life.

Purpose

The purpose of the *Framework for Autism in Canada* (Framework) is to promote the health and well-being of children, youth, adults and older adults on the autism spectrum, their advocates, families, and caregivers; and to provide a common direction for autism in Canada that lays the foundation for collaborative and complementary action to be taken by all sectors. The Framework was created in response to the *Federal Framework on Autism Spectrum Disorder Act*.

Scope

The Framework is a multi-jurisdictional common policy direction for autism initiatives in Canada, developed with the involvement of Autistic Canadians, their families, advocates and caregivers. It is intended to be a foundational document highlighting key findings from stakeholder consultations and high-level, aspirational opportunities and best practices. It also sets out federal Framework measures to be implemented as required under the Act.

GUIDING PRINCIPLES

The following principles are intended to guide the Framework, as well as other autism-specific initiatives in Canada.

Evidence-informed approach

Involves collecting, critically analyzing, and sharing the highest quality evidence available to inform public health recommendations and decision making.[12]

Human rights-based approach

Acknowledges existing inequalities and marginalization in society with the goal of advancing human rights for all.[13]

"Nothing Without Us"

Refers to an approach that meaningfully involves persons with disabilities in the development of all Government systems, policies, programs, and services.[14] This also includes meaningfully involving advocates of persons with disabilities (for children or those who can't speak for themselves).

Intersectionality and diversity

Government systems, policies, programs, and services must consider the various traits, experiences, and identities that individuals possess, the different ways that persons interact with their environments and the multiple and intersecting forms of marginalization and discrimination that they experience.[15]

Distinctions-based approaches

Recognizes the unique and differing histories, interests and priorities of First Nations, Inuit, and Métis Peoples[16], regardless of residence.

Life-course approach

Attempts to improve the health and well-being of populations at all life stages (including children, youth, adults and older adults) whilst acknowledging that past and present experiences are shaped by dynamic social, economic, and cultural factors.[17]

Collaboration

Offers a possibility to learn from others through the sharing of knowledge, best practices, data, and research. This approach benefits policy development by integrating an array of expertise and perspectives, thus maximizing the chance that policy will be effective and broadly implemented.[18]

THE GUIDING PRINCIPLES consider the essential roles that advocates, caregivers and families play in the lives of Autistic people across the life-course in Canada. These roles can include providing an extensive range of supports and care, especially for Autistic children or adults with complex support needs.

In the context of the Framework, an advocate is someone who represents the rights and interests of a person with autism. In some instances the Autistic person may be unable to communicate for themselves, for example, due to their age or communication-related barriers, in which case an advocate can help make sure the Autistic person's interests are protected. An advocate may or may not be an Autistic person's family member or caregiver.

The needs of Autistic people are unique to each person and evolve over the life-course, as do the needs of caregivers and family members.

FRAMEWORK PRIORITY AREAS AND MEASURES

The *Framework for Autism in Canada* (Framework) outlines five priority areas: screening, diagnosis, and services; economic inclusion; data collection, public health surveillance, and research; public awareness, understanding and acceptance; and tools and resources.

The Priority Areas below have been outlined in the following structure:

- **Vision:** For each priority area, a vision statement sets out a desired future to support Autistic people in Canada, their families and caregivers. It confirms the direction for change needed, to address the barriers faced by this community.
- **Opportunities and best practices:** For each priority area, information regarding possible multi-jurisdictional and aspirational policy directions to address existing needs and barriers is provided. These high-level opportunities and best practices were identified by stakeholders and various partners including Autistic people in Canada, their advocates, families and caregivers, through a synthesis of consultations, including the 2022 and 2024 National Autism Conferences and the Canadian Academy of Health Sciences' report. For a detailed list of opportunities and best practices, identified in consultations with stakeholders, see Appendix A. These opportunities and best practices are intended to guide future action across sectors, federal departments, and various levels of government.
- **Framework measures:** For each priority area, one or more federal-specific Framework measures have been identified. Additional measures are outlined in the section "Moving Forward: Reporting to Parliament", which provide mechanisms to ensure that federal funds for Autistic people and their families are used responsibly and transparently. These measures fall within the Minister of Health's mandate and have been identified in response to the requirements of the Act. The measures provide support for Autistic people, their families, and caregivers in Canada.

PRIORITY AREA 1:
Screening, diagnosis and services

VISION STATEMENT:

A Canada where Autistic people, their families, advocates and caregivers have access to timely, consistent and accessible screening, diagnosis and neuro-affirming services throughout the life-course.

Encouraging the timely and equitable access to screening, diagnosis, and services (e.g., health, including mental health, education, and social services) are often among the top needs highlighted by Autistic people, their families, advocates, and caregivers. Each province or territory has developed its own approach for providing diagnostic assessments and services and there is a wide variety of services, supports and funding models across the various jurisdictions in Canada. Although there are best and promising practices to learn from in Canada, this variability can also contribute to inequities and regional diagnostic and service shortfalls.[3]

As the CAHS's Assessment on Autism Report describes, autism services and supports in Canada can include, but are not limited to:

- Screening,
- Diagnostic assessment,
- Information and referrals,
- Early intervention,
- Behavioural supports,
- 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[3]

There are many challenges faced by Autistic people and their families when seeking screening, diagnosis, and services. The CAHS report identified a number of these challenges including[3]:

- Inconsistent diagnostic policies and practices.
- Long wait times for diagnosis and other services.
- Difficulty consistently accessing therapeutic services.
- High financial impacts for families, including out-of-pocket costs and a lack of healthcare and other sectors' workforce capacity to meet the demand for autism services across the lifespan.

Many families, advocates, and caregivers of Autistic people in Canada find it difficult to access autism supports and services for the Autistic people in their lives. Stakeholders often indicate that accessing a diagnosis can be complex, due to challenges with navigating the healthcare system. In Canada, an autism diagnosis can be accessed through a publicly funded assessment, or private (paid for out of pocket) assessment. Stakeholders have indicated that there is often inconsistent and insufficient access to publicly funded autism diagnoses, supports and services across Canada. Inequities in access to these important services is often related to differences in income, geography, language, race and ethnicity, age, sex, and gender.[3][19]

When considering the ways in which screening, diagnosis and services can be improved moving forward, it is important to recognize that trust and communication are two key components, along with needs-based and strengths-based approaches. It is also critical to acknowledge the need to support Autistic family members, advocates, and caregivers in a system with inadequate supports. Finally, it is important to consider the unique needs of Autistic parents who have Autistic children and the ways in which they can be unfairly judged and stigmatized as parents and caregivers. These negative experiences can influence the supports and services that Autistic parents receive and impact their level of trust in service providers.[3]

> *"Adopting a lifespan, person- and family-centered 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."*[3]

Opportunities and best practices

Stakeholders, including Autistic people, families, and caregivers in Canada, have identified a number of opportunities and best practices aimed to improve access to healthcare, diagnosis, support, and services for Autistic people. Key recommendations include developing national guidelines for diagnostic and service pathways; making navigation of autism supports more accessible; increasing the capacity of the autism workforce; and expanding telehealth services.[3]

Supports and services must incorporate programs specific to various important developmental periods and life-stages of those with autism, including needs-based and strengths-based pathways to supports and services, through to adulthood and older adulthood. There is a need for improved access to individualized, culturally sensitive screening, diagnosis and services for children in preschool and early childhood, particularly for those with autism traits and co-occurring conditions. For school-aged children and adolescents, best practices involve providing consistent support across various settings, building inclusive educational guidelines, and implementing evidence-based approaches to enhance social skills and self-regulation. Families and caregivers should be supported through family-centered service models, mental health support, peer-support and respite programs, with specific assistance for Autistic parents. For Autistic people in adulthood, opportunities include life-stage-specific supports designed to reduce crises and aid with important life-transitions, increased mental health services, peer-support, and self-advocacy training. Improved diagnostic pathways for Autistic adults is also needed. Overall, these opportunities and best practices could promote equitable access to services, improve quality of life, and foster inclusion for Autistic people across their lifespan.[3], [19]

Framework measures

In order to provide timely and equitable access to screening and diagnosis for autism spectrum disorder the Minister of Health will implement and report on the following Framework measures with respect to screening, diagnosis, and services for autism in Canada:

1. Utilize the Government of Canada's convening power, to improve information sharing across federal, provincial, and territorial jurisdictions in key priority areas including approaches to improve wait times and promote equitable access to screening, diagnosis and autism services.
    a. Working with federal, provincial and territorial partners, the Public Health Agency of Canada (PHAC) will advance opportunities to develop and update national guidelines for screening, diagnosis and services. PHAC will also collaborate to assess the current and future outlook of human resources in healthcare and allied health professions delivering autism services.
2. Establish a National Autism Network that will have a mandate to put in place advisory committees with representation of Autistic people, their advocates, families, and caregivers to ensure that their lived experiences inform actions to address wait times and inequitable access to screening, diagnosis and services.

PRIORITY AREA 2:
Economic inclusion

VISION STATEMENT:

A Canada where Autistic people have tailored financial supports and access to education, employment, and housing throughout the life-course.

Economic inclusion involves addressing the determinants of financial stability and security for Autistic people and their families in Canada. Currently, many people with autism and their families encounter economic obstacles that make it difficult for them to fully participate in society.[3] The costs associated with autism are high for individuals, families, and society.[3] Average annual costs for an Autistic child with co-occurring intellectual disability are significantly higher compared to those without an intellectual disability.[3] As heard during the National Autism Conference in November 2022, financial stability is an important social determinant of health for Autistic people and their families. It was also stated that financial stability for Autistic people can be impacted by a variety of factors, such as access to mental health and other support services; early intervention and diagnosis in childhood; accessible and affordable housing in a safe community; sustainable employment; and financial literacy. Financial stability is also directly tied to quality of life, which tends to be lower for Autistic people in Canada.[19]

Autistic people have valuable skillsets that governments, businesses, and society can greatly benefit from. Statistics show that Autistic people of working age in Canada and their families are under-represented in the labour market. For example, Autistic adults over 15 years of age have an employment rate of only 14.3%.[3] Parents of those with autism may also encounter specific barriers surrounding employment.

Beyond the Autistic population, financial security is recognized as an urgent priority amongst persons with disabilities more broadly in Canada. Canada's Disability Inclusion Action Plan (2022) describes the following as part of the current Canadian context[20]:

- Persons with disabilities in Canada are less likely to experience financial security and more likely to live in poverty than persons without disabilities.
- Persons with disabilities have heightened costs associated with disability.
- Persons with disabilities are under-represented in the Canadian labour market.
- Many persons with disabilities are unemployed or under-employed.

Additional supports for Autistic people, and their families, would contribute to both their financial stability and security, and improvements to their overall quality of life.

“**IN THE SPACE OF FINANCIAL STABILITY**… it's [about] a comfortable home; health; meaningful relationships; safety in the community; work, either paid, unpaid, or a combination of both; access to leisure activities; a sense of security about the future; and being part of the community. But… for any of those points to happen there has to be financial stability around that person.” (Financial Stability Panel, National Autism Conference, 2022)

Opportunities and best practices

In the context of the Framework, the priority area of Economic Inclusion focuses on many of the key economic factors impacting Autistic people in Canada, their families and caregivers, such as taxation, benefits, employment, financial literacy and planning, post-secondary education pathways, and appropriate housing.[3]

Stakeholders have identified opportunities to alleviate the financial burden for Autistic people, their families and caregivers by modernizing and improving the eligibility and access to federal taxation and benefits, and other federal programs. Stakeholders identified the need to support employment opportunities by providing better skills training and work experience programs for Autistic Canadians. They also indicated that the employment environment could be improved through initiatives to create autism-inclusive workplaces mentorship opportunities and equitable employment practices. The need for financial planning services across the life-course was also identified by stakeholders; as was the need for programming to support the transition from education to employment, disability accommodations and financial support in post-secondary institutions. Finally, there is a need for investments in safe, sustainable housing options and supports for Autistic people across the life-course.[3][19]

Framework measures

The Minister of Health will implement and report on the following Framework measures with respect to economic inclusion for Autistic people in Canada and support for caregivers of Autistic people:

1. Engage with the Minister of Finance, Minister of National Revenue, and Minister of Employment, Workforce Development and Official Languages, to support the identification, development, and implementation of ways to improve programs within the responsibility of these Ministers, which may include tax measures, benefits, and other government programs provided to Autistic people in Canada, their families and caregivers.

2. Establish a National Autism Network that will put in place advisory committees tasked with identifying additional financial supports to improve the social determinants of health and determine what tools could provide better support for Autistic people in Canada, their families, and caregivers.
    a. The network will also have a mandate to support information-sharing and outreach to autism-focused organizations with the objective of increasing awareness and uptake of tax measures, benefits and other government programs that may be available to Autistic people, their families, and caregivers.
3. Engage the Minister of Diversity, Inclusion, and Persons with Disabilities on the Disability Inclusion Action Plan to address priorities for Autistic people in Canada.

PRIORITY AREA 3:
Data collection, public health surveillance and research

VISION STATEMENT:

A Canada where public health surveillance and research support action to improve health outcomes for Autistic people.

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006), it is an "express priority" for national governments to collect and disaggregate statistical and research data for the purpose of developing and implementing policies and practices to meet the needs of Autistic people of all ages and their families.[3]

Public health surveillance and research, core functions of the Public Health Agency of Canada (PHAC), support the Government of Canada's health promotion and chronic disease prevention programming by providing timely and relevant information on the health of the Canadian population. Public health surveillance refers to the ongoing, systematic collection, analysis, interpretation, and dissemination of health-related data essential to planning, implementation, and evaluation of public health practice. In contrast, research refers to activities designed to develop or contribute to generalizable knowledge i.e., theories, principles, relationships, or the information on which these are based, that can be confirmed or refuted by recognized methods of observation, experiment, and inference. Surveillance and research are connected, as it is often through surveillance that research questions emerge (and vice versa).

When prevalence data is contextualized with additional information on service use, co-occurring conditions, and socioeconomic variables, more meaningful data on equitable access and overall needs can be generated, which ultimately can help inform service planning and targeted approaches to reducing inequities.[3]

The Government of Canada also has a role in facilitating research and innovation to understand autism; to support the development of new screening and diagnostic tools, standards of care, and best practices to support the social inclusion of people with disabilities.

To date, data about Autistic people in Canada has been collected through:

- The National Autism Spectrum Disorder Surveillance System;
- The Canadian Health Survey on Children and Youth (CHSCY);
- The Canadian Survey on Disability (CSD); and
- Integrated hospital, health systems or jurisdictional datasets developed through research partnerships between Canadian universities or research institutes.

While these datasets have helped to advance Canada-specific autism knowledge, there are some limitations. For instance, data collection in support of public health surveillance and research often operates within a short-term funding environment and as a result, may be easily disrupted by lack of funding, with longitudinal data collection being particularly costly, thus, difficult to establish and maintain. A "functional" disability approach (which focuses on specific body functions instead of diagnostic labels like autism) has been adopted in some pan-Canadian surveys (e.g., CSD) limiting the availability of information about the experiences of Autistic people in Canada.[3] In addition, population-based surveys often exclude key sub-groups and integrated datasets may over-represent particular groups or jurisdictions and therefore, may not be reflective of the true diversity of Canada's geographic, economic, and cultural diversity.

In addition to these data limitations, it is important to keep sensitivity regarding stakeholders' perspectives in mind. Their involvement will help foster greater buy-in and understanding about the public health surveillance and research process.

Opportunities and best practices

To build trust and ensure that data is being collected and used in a way that maximally benefits the lives of Autistic people in Canada, stakeholders identified a number of opportunities and best practices. These include creating opportunities for meaningful collaboration with Autistic people and their families in the collection and use of data, in reporting of findings to ensure language preferences of the Autistic community are respected, in making decisions and setting research priorities, and in engaging groups that have historically been excluded from autism research.

Stakeholders also identified opportunities to improve sharing of information, including increased coordination across multiple sectors and levels of government to create opportunities for innovation and address strategic priorities. They highlighted best practices to expand the infrastructure for data collection and sharing in Canada, including the harmonization of data elements across jurisdictions, so that more consistent and comprehensive information could be used to guide policy development and service delivery for Autistic people.[3][19]

Furthermore, stakeholders identified opportunities to expand the scope of autism research and data collection to fill gaps in the areas of social inclusion, diagnosis, supports and services, and economic inclusion.[3][19]

Framework measures

To promote and improve data collection, public health surveillance and research on autism spectrum disorder in Canada, the Minister of Health will implement and report on the following Framework measures:

1. Support national autism surveillance, including the development of new data and reporting on indicators beyond prevalence (such as demographics, diversity and equity, co-occurring conditions and Indigenous health), as well as all jurisdictions and age ranges (children, youth, adults), where possible.
2. Support autism research through the federal health portfolio.
3. Establish a national research network that would support information sharing and collaboration across sectors and jurisdictions, enable improved data collection and promote research on autism.
4. Engage the Minister of Diversity, Inclusion, and Persons with Disabilities on the Disability Inclusion Action Plan to address priorities for Autistic people in Canada.

PRIORITY AREA 4:
Public awareness, understanding and acceptance

VISION STATEMENT:

A Canada where Autistic people have all their needs met in an environment where they feel safe and accepted, including when accessing services and supports.

Autistic people are entitled to the same rights, protections, and benefits of the law as any other person. The Canadian Charter of Rights and Freedoms prohibits unjustified discrimination by public entities on the basis of disability. The Canadian Human Rights Act and provincial and territorial human rights codes prohibit discrimination by public or private entities, including on the basis of disability, in specified contexts. This principle is also described in international human rights instruments to which Canada is a signatory or party, including the United Nations' Declaration of Human Rights (1948), the United Nations Declaration on the Rights of Indigenous Peoples (2007), the Convention on the Rights of Persons with Disabilities (2010), and the Convention on the Rights of the Child (1991).[3] Societal factors often inhibit Autistic people from feeling included in society in a meaningful way, contributing to challenges that interfere with their ability to achieve a high quality of physical and mental well-being.[3] Stigma and discrimination are major public health issues as they produce social inequalities and reduce the quality of life of Autistic people, their family members, and supporters.[3]

Autistic people are often subjected to stigma and discrimination, which leads to barriers accessing and maintaining a high quality of education, employment, a stable and sufficient income, housing, healthcare, social services, safety, dignity, and self-determination. An inability to achieve these basic foundations has been associated with poorer mental health and higher rates of suicide.[3]

The CAHS report identified the following factors as major reasons for negative societal attitudes towards people with autism[3]:

- A lack of targeted, long-term, and systematic autism acceptance and awareness raising strategies.
- A lack of knowledge and understanding of autism by the public and in the health and social service workforce.
- A lack of positive and realistic images of Autistic people in society, including negative framing of media messages about autism.
- Historically devalued narratives and perspectives of Autistic people.

IMPORTANTLY, AUTISM AWARENESS in not in itself sufficient to address societal shortfalls in inclusivity. Autism acceptance must also play a role, which involves embracing autism in a neuro-affirming way, across the spectrum. Many view autism awareness and education as a starting point for autism acceptance.

Opportunities and best practices

To combat negative stereotypes and help increase public awareness, understanding, and acceptance of autism, stakeholders identified a number of opportunities and best practices, including creating national acceptance campaigns to raise awareness and combat stereotypes, implementing anti-bullying programs in schools, and creating inclusive educational and employment settings. There is a need for mandatory, high-quality, standardized autism training for an array of service providers, including those in healthcare social services, and public safety; with training programs developed in partnership with Autistic people and focused on evidence-based, culturally responsive supports. Additionally, governments can aid through regulatory guidance and improvement standards. To foster workplace inclusion, widescale professional training and efforts to promote inclusive hiring practices is important.[3][19]

Framework measures

The Minister of Health will implement and report on the following Framework measures with respect to public knowledge, understanding and acceptance of autism while accounting for intersectionality, to foster inclusivity:

1. Undertake a national autism knowledge, understanding and acceptance campaign. The campaign will focus on key sectors including healthcare, education, employment, community services, and public safety, while accounting for intersectionality and autism across the spectrum, to foster inclusivity in all aspects of Canadian society.
2. With a focus on information for Autistic people and caregivers, provide and disseminate information regarding autism through the Government of Canada's webpage and communications, including on World Autism Awareness Day and for Autism Awareness Month in Canada.
3. Engage the Minister of Diversity, Inclusion, and Persons with Disabilities on the Disability Inclusion Action Plan to address priorities for Autistic people in Canada.

PRIORITY AREA 5:
Tools and resources

VISION STATEMENT:

A Canada where accessible and evidence-informed tools and resources are available to support Autistic people their families, advocates and caregivers, across the life-course.

Autistic people and their caregivers benefit tremendously when they have access to information and support through evidence-based, culturally relevant, credible, up to date, and accessible tools and resources.[3] Increasing access to information about autism, supports, services, and best practices is important to support the health, safety, and well-being of Autistic people and their caregivers.[19] Outdated, incomplete, or difficult to navigate tools and resources can sometimes add an extra layer of complexity.[19] Challenges in accessing information can contribute to emotional strain, stress and additional costs for Autistic people and their caregivers.[3][19]

Accessibility and equity are important considerations when creating evidence-informed tools and resources. There are sub-groups of people within the autism community that are often overlooked in the development of these resources. These sub-groups include newcomers to Canada, language minorities (including OLMCs), Indigenous peoples, and individuals from racialized communities. These individuals are often less likely to get needed diagnoses, supports and services and experience additional challenges seeking the information they require.[3]

Additionally, Autistic people and their families in rural or remote areas often have difficulty accessing diagnostic and support services and may be forced to pay high costs and spend time travelling long distances to seek care.[3] Research also suggests that girls, women and individuals assigned female at birth can face additional barriers to accessing information and supports because they are more likely to be mis-, un-, or under-diagnosed and/or receive later diagnoses.[3]

Opportunities and best practices

Stakeholders and various partners, including Autistic people in Canada, their families and caregivers, identified a number of opportunities and best practices to enhance self-advocacy, systems navigation, access to autism supports, and overall well-being for Autistic people and their caregivers. Key recommendations include providing comprehensive information on autism supports, financial assistance, and protections against discrimination, creating tools for accessing individualized services, and offering resources to foster self-advocacy. Emphasis is placed on improving digital literacy, addressing digital inequities, and leveraging platforms, such as AIDE Canada, to provide reliable, accessible information, especially in rural areas. The development of tools and resources should be inclusive, culturally relevant, and involve Autistic people and their caregivers from diverse backgrounds. [3][19]

Framework measures

To provide sustained, accessible and culturally relevant resources on best available evidence-based information to support Autistic persons, their families and caregivers, the Minister of Health will implement and report on the following Framework measures:

1. Provide access to updated information on the Government of Canada's webpage with sustained, accessible and culturally relevant resources, with a focus on providing information for Autistic people and caregivers.
2. Work with provinces and territories to strengthen the provision of evidence-based information on autism, including effective treatments, and ineffective or harmful treatments, to ensure consistency of information across Canada.
3. Support online platforms with evidence-based information regarding autism to support Autistic people, their families, and caregivers.
4. Support regular updates to clinical practice guidelines to ensure that the most recent research evidence to improve care for Autistic people is being integrated.
5. Establish a National Autism Network that will have a mandate to put in place advisory committees with representation of Autistic people, their advocates, families, and caregivers to provide experience and expertise on the additional resources and tools needed, from a social determinants of health perspective, to provide better support for Autistic people in Canada, their families, and caregivers.

MOVING FORWARD

The *Framework for Autism in Canada* (Framework) provides a common policy direction to guide collective efforts on autism. Governments in Canada, as well as the many partners, organizations, and people whose work touches on autism-related initiatives, are invited to use the Framework to help advance autism priorities in a way that is aligned with their respective mandates and adapted to their community contexts. Every person in Canada can contribute to making communities inclusive of people on the autism spectrum, their advocates, families, and caregivers.

Given the significant and important work ahead to implement the Framework, the Government of Canada's National Autism Strategy Secretariat will continue to provide a leadership and convenor role to support ongoing engagement and coordination of national autism initiatives. The opportunities and best practices identified in the Framework provide a roadmap to guide future interdepartmental and intergovernmental collaboration on autism priorities while the specific federal measures identified confirm areas where the Government of Canada can move forward, to begin addressing priorities at the federal level. The National Autism Strategy Secretariat will establish a new National Autism Network, including people with lived and living experience across the country which will bring partners together to support progress and efforts to address priority areas for action on autism.

Distinctions-based approaches to implementation

Though the Framework is meant to be a broad policy direction, it also recognizes that Indigenous communities and individuals have distinct understandings and lived experiences of autism. While moving toward implementation, the Government of Canada will continue to take an Indigenous-led approach to engaging with First Nations, Inuit, Métis, and Urban-Indigenous Peoples. This ongoing engagement will inform the way forward while exploring distinctions-based and Indigenous-led approaches to addressing autism-related priorities.

Reporting to parliament

As required by the Act, within five years (2029) of publishing the Framework, the Minister of Health will table a report in Parliament sharing progress on implementation of the Framework, as well as its effectiveness. This report will evaluate the effectiveness of the Framework measures within the Minister of Health's jurisdiction, explain the reason for which any Framework measure was not implemented, and provide a timeline for its implementation. The report will also describe collaborative efforts with autism stakeholders, Indigenous partners, provincial, territorial, and local governments.

Framework measures

The Minister of Health will implement the following Framework measures with respect to ensuring accountability in the use of federal funds for autism, and monitoring the implementation and effectiveness of the measures outlined in the Framework under the Minister of Health's responsibility:

1. Report on the progress of the Framework annually through the Departmental Results Report to highlight federal efforts to advance the Framework measures, including reporting on federal funds allocated to implementing measures under each of the priority areas in the Framework.
2. Include aggregated results of the five years of annual Departmental Results Reports in the legislated report to Parliament on the Framework for Autism in Canada (2029), including reporting on federal funds allocated to implementing the Framework measures under each of the priority areas in the Framework.
3. Develop performance indicators to measure the effectiveness of the Framework and to support policy and informed decision-making that will benefit Autistic people in Canada, their families, and caregivers.

The federal government also intends to establish and work with a National Autism Network composed of experts, including people with lived and living experience, advocates, families and caregivers to provide ongoing input on the development of autism policies and programs. This network will integrate existing collaborative networks and will be involved in the development of benchmarks and indicators for autism initiatives, as well as measures to ensure accountability for Framework implementation.

An autism strategy for Canada

The Framework and will be complementary, mutually reinforcing documents that outline both the autism priorities for Canada, as well as a plan to address the priority areas for action. While the Framework sets out guiding principles related to national autism policy and programs, the Strategy will support the implementation of the Framework. The Strategy will serve as a multi-year strategic plan that outlines specific short- and medium-term initiatives at the federal level that will be used to address key priority areas. The Strategy will be updated on a regular basis, as the needs and priorities for Autistic people in Canada evolve over time. It will be a tool for the Government of Canada to continue advancing autism priorities, in collaboration with key partners and stakeholders.

APPENDICES

APPENDIX A: Detailed list of opportunities and best practices

These high-level and aspirational opportunities and best practices were identified by stakeholders and various partners, including, Autistic people in Canada, their families, advocates, and caregivers through a synthesis of consultations, such as the 2022 National Autism Conference, the CAHS report, as well as other engagement activities.

PRIORITY AREA 1: Screening, diagnosis and services

The CAHS report identified numerous practices, supports and strategies that could help to improve the quality, equity, and timeliness of access to healthcare services for Autistic people and their caregivers, including[3]:

- Developing national guidelines and consensus statements for diagnostic and service pathways.
- Making the navigation of autism supports and services more accessible.
- Growing the capacity of the autism workforce, including the training of professionals who are equipped to work with diverse groups.
- Increasing the reach of telehealth and other e-health services.

In addition to these more general strategies, there are specific opportunities for action that can help to address needs for adequate services across the life-course, all the way from preschool to older adulthood. These supports and services must incorporate programs specific to various important developmental periods and life-stages of those with autism, including through adulthood and older adulthood. Importantly, these supports and services must also be accessible, neuro-affirming, and culturally sensitive.

Preschool and early childhood:

To support positive developmental outcomes, even before confirmation of a formal diagnosis, stakeholders indicated that there is a need to:

- Provide timely access to screening, diagnosis, and services for children, particularly those with autism traits and co-occurring conditions.[3]
- Enable service providers in early learning and childcare settings to implement screening and inclusive strategies effectively.[3]

To acknowledge the diversity of needs among Autistic people and promote flexibility, timely access, and culturally appropriate options for support and intervention, there are opportunities to:

- Adopt a model of delivering supports and services tailored to individual characteristics, enhancing communication, cognition, and other adaptive skills.[3] "Services may involve family supports, speech-language therapy, occupational therapy, psychological or behavioural therapy, as well as early childhood education and social work services."[3]
- Adopt new services and build the capacity of autism service providers to meet the needs of those belonging to diverse cultural groups and those whose first language is not the regional majority language, including Official Language Minority Communities (OLMCs).

School-aged children and adolescents

To ensure school-aged Autistic children and adolescents have effective supports and services, best practices would suggest:

- Providing consistent support across various settings (e.g., homes, preschools, daycares, schools, and recreation centres), through collaboration among a range of partners (e.g., healthcare providers, families, educators).[3]

The CAHS report indicated that to support school-aged children and adolescents, especially during and after times of transition, such as leaving high school:

- Supports should "span medical, psychosocial, educational, and technology-based services."[3]
- Focus on "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."[3]
- "Cultivate the development of autism-informed, inclusive educational guidelines [for Canada] … [to help] promote the adoption of best practices across Canada."[3]

The CAHS report also suggested that to improve the educational experiences of Autistic students, and their families, approaches could:

- Offer a broad range of accommodations that include evidence-informed instructional and support strategies.
- Provide safe, predictable, and sensory-friendly environments.
- Promote the professional development of education staff.
- Meaningfully integrate Autistic students with non-Autistic peers across academic and non-academic activities and environments.[3]

To improve skills and coping mechanisms, and create safe and inclusive school environments, opportunities for action include[3]:

- Providing evidence-based approaches that could help Autistic people develop social skills, communication skills, improved self-regulation, along with the management of mental and physical health.
- mplementing anti-bullying programs tailored to specific needs of Autistic students, where students and their families can receive support and thrive.

To ensure that families and caregivers are supported, the CAHS report included best practices to:

- Provide family-centred service models that ensure parents and other family members are also being supported. This can include mental health and counselling supports, respite programs, education on systems navigations, and workshops on stress-management, problem solving and coping skills.[3]
- Provide specific supports tailored to Autistic parents with Autistic children who face unique challenges. This can include peer support groups with other Autistic parents or Autistic adults.[3]

Through to adulthood and older age

To address the evolving and often increasing complexity of support needs for Autistic people in adulthood, particularly during life-stage transitions, stakeholders indicated that there are opportunities to:

- Implement life-stage-specific supports to help reduce the chances of family or individual crisis from occurring, reduce the unnecessary use of emergency services, and improve quality of life and financial stability.[3]
- Provide locally available adult autism supports to foster economic and social inclusion and enable families to provide ongoing adequate support at home.[3]

There are opportunities and best practices that could help to improve social and economic inclusion, as well as the overall health and well-being of Autistic people, including:

- Creating and implementing standardized guidelines and practices for health and education transitions to adulthood.[3]
- Increasing availability of autism-specific supports pertaining to mental health, peer support, and self-advocacy training to improve quality of life, autonomy and help to ease the difficulties often associated with the transition into adulthood.[3]
- Providing "up to date, geographically, and developmentally relevant information and hands-on support, particularly during life transitions" for parents and family members of Autistic people.[3]

To help combat the stigma often experienced by families and caregivers, stakeholders indicated that there is a need to[3]:

- Provide additional supports for parents and caregivers of people on the autism spectrum. For instance, peer support groups that can help them learn about some of the challenges and solutions associated with these periods of change.
- The CAHS report indicated that there are opportunities to foster family engagement, recognizing it as the primary factor in achieving a successful transition[3], when appropriate, by[3]:
- Expanding services for Autistic parents, in partnership with them as end-users.

The CAHS report identified additional opportunities and best-practices that may be beneficial for Autistic adults, including[3]:

- Mental health supports that are accessible, neuro-affirming, culturally sensitive and trauma-informed.
- Peer support and mentorship models.
- Resources and supports for adults diagnosed later in life.
- Self-advocacy training.

PRIORITY AREA 2: Economic inclusion

In the context of the Framework, the priority area of Economic Inclusion focuses on many of the key factors contributing to the financial stability and security of Autistic people in Canada and their families, such as tax measures, benefits, employment, financial literacy and planning, post-secondary education pathways, and appropriate housing.

Government programs and services including tax measures and benefits

To better promote financial stability and support the financial well-being of persons with disabilities, many of whom have complex support needs, and their families, stakeholders who have been engaged on the Framework have identified the following objectives:

- Help to alleviate the financial burden on caregivers potentially through enhancement of existing tax measures and benefits.[19]
- Offset "common out-of-pocket costs associated with autism such as home modifications, transportation, therapeutic products, and day supports", [3] including by improving eligibility and access to tax measures, benefits, and other federal programs for Autistic people in Canada, their families and caregivers.

To improve programs and benefits for Autistic people, and promote financial stability, stakeholders have also indicated that the following should be taken into consideration[19]:

- Modernize and improve accessibility of federal government programs and services for persons with disabilities, including those with autism.
- Streamline the ESDC and CRA tax credit and benefit systems, ensuring they are flexible.

Employment

To support employment opportunities for Autistic people and their families, the stakeholders indicated best practices to:

- Implement supportive workplace policies through unions, employee assistance plans, and human resource departments.[3]
- Provide access to employment skills training, as well as job coaches.[19]
- Provide employment readiness and work experience programs, which will better prepare students for finding employment in the long-term.[3]

To improve the employment environment for Autistic people, stakeholders also indicated that the following should be considered:

- Ensure businesses are paying the same wages for Autistic employees as they are for non-Autistic employees in Canada.[19]
- Highlight the importance of autism acceptance in the workplace, including ensuring that training is provided to employers and coworkers to understand the needs and strengths of Autistic workers.[19]
- Encourage Autism-inclusive workplaces, and promote them through a variety of approaches, including evidence-based guidelines for human resources and employers, employer awards, incentives for training and long-term inclusive hiring practices.[3]
- Identify, support, and scale promising employment initiatives and best-practices in different regions.[19]

Financial literacy and planning

To improve financial stability for Autistic people and their families, the CAHS report included best practices to:

- Provide resources such as access to trusted financial planning services or financial literacy programs to support financial planning for the future and empower Autistic people and their families to make well-informed decisions.[3]
- Develop financial planning services using a person-centred approach to raise awareness about the Registered Disability Savings Plan and other federal or provincial/territorial tax measures.[3]

To support Autistic people who depend upon their aging caregivers for financial stability and housing, panelists at the National Autism Conference indicated there is an opportunity to[19]:

- Focus more on financial planning across the life-course, particularly for adults and older Autistic people.

Post-secondary education pathways

Many Autistic people have the capacity to participate in post-secondary education, however; due to inadequate support, their graduation rate still falls behind non-Autistic and other disabled students.[3]

To improve graduation rates and support the financial stability of many Autistic people, there are opportunities to:

- Diversify "current education-to-employment pathways to include trades and technical programs and on-the-job training with commensurate supports and accommodations."[3]

To ensure that appropriate targeted supports are in place, participants in the National Autism Conference also identified opportunities to[19]:

- Collect data regarding the number of Autistic students accessing and completing post-secondary education in Canada, to enable system-level changes, and to help them reach their full potential in academia.

To recognize neurodiversity as an essential and often overlooked dimension within post-secondary equity, diversity, and inclusion frameworks, there are opportunities to[3]:

- Implement targeted post-secondary assistive programs and services.
- Increase access to disability accommodations and financial supports.

Housing

To support financial stability and maintain suitable housing for Autistic people in Canada, stakeholders identified the following objectives:

- Provide ongoing supports to choose, plan for, access, maintain, and manage housing19, ideally occurring through "person-centred planning, navigation, and skill-building approaches."[3]
- Provide "stable community linkages, promotion of neighborhood and landlord acceptance, accessibility of and eligibility for affordable housing, and proactive community planning".[3]
- Invest in building suitable housing options for Autistic people in Canada.[19]

To meet the changing housing needs of Autistic people across the life-course, opportunities identified during the National Autism Conference include:

- Implement future planning to ensure housing needs continue to be supported through housing policies, such as long-term care for older Autistic adults, and aging-in-place options as appropriate.[19]
- Provide safeguards and regulations to ensure safe and appropriate housing for those who require congregate living settings.[19]
- Ensure that sustainable design, opportunities for community participation, and maximizing person-environment fit are considered when creating housing options for Autistic people with complex needs.[3]

- Increase opportunities for legal representation regarding housing rights for Autistic people and their families in Canada.[19]
- Provide access to better data regarding housing for Autistic people to help determine the current housing situation and needs of the Autistic population, enabling forward planning.[19]

PRIORITY AREA 3: Data collection, public health surveillance, and research

Increased consultation and collaboration to inform data collection, public health surveillance, and research

Expanding the scope of evidence-based research and openly sharing data with the autism community has been widely recommended throughout various autism policies internationally.[3]

To build trust and ensure that data is being used in a way that maximally benefits the lives of Autistic people in Canada, stakeholders identified the following best practices:

- Create opportunities for "meaningful collaboration with Autistic people and their families in the collection and use of data." [3]
- Carefully consider the diverse perspectives of Autistic people and their families to improve impact; for example, when considering language choices.3 (p. 258)
- Provide opportunities for Autistic people and their families to help make decisions and set research priorities.[3]
- Recognize and acknowledge that at times, Autistic people have not always felt respected or heard during research.[19]
- Engage with groups that are historically excluded from autism research, such as adolescents, older adults, women and girls, racialized people, Indigenous people, non-speaking Autistic people, and Autistic people with intellectual disabilities.[19]
- Consider best practices and principles on inclusive and participatory research approaches which include "respectful engagement, direct and intentional inclusion, accessibility and accommodations, individualized approaches, flexible options and being attentive and responsive".[3]
- Create a standard set of measurable indicators or outcomes, in consultation with Autistic people and other stakeholders.[19]

While incorporating more voices in research is important, so too is the need to ensure collaboration and sharing of information. Stakeholders indicated that this could be improved through:

- Increased "coordination amongst different levels of governments, ministries, industries, and philanthropic and non-profit organizations" to create opportunities for innovation and address strategic priorities.[3]
- Creating a national repository of research, to share data that is accessible to researchers across the country. This would help advance understandings of research completed to date and highlight gaps for further research.[19]

Expanded scope of data collection for public health surveillance and research purposes

Expanding infrastructure for data collection and sharing in Canada would offer consistent and more comprehensive information that could help guide policy development and service delivery for Autistic people.[3]

To expand the infrastructure for data collection and sharing in Canada, stakeholders suggested best practices could include:

- Supporting the harmonization of data elements across jurisdictions in Canada.
- Encouraging open communication and building trust and capacity between jurisdictions in Canada to promote data sharing.[3]
- Establishing mechanisms for documenting autism diagnoses/cases outside of the medical field.[3]

To date, most of the research about autism has focused on the causes, prevention, and characterization of autism. While this type of research is helpful to understanding the neurological differences and genetic conditions associated with autism, a broader perspective is needed.

Stakeholders identified opportunities to expand the scope of research on autism and fill gaps in the areas of social inclusion, diagnosis, supports and services, and economic inclusion:

- Conduct research on the day-to-day needs of Autistic people in Canada across the entire lifespan, for example through longitudinal studies.[3]
- Collect data on the social determinants of health as they relate to Autistic people.[21]
- Invest in training and career development of the next generation of autism researchers in Canada, with an emphasis on developing training and mentorship opportunities for Autistic researchers.[3]

PRIORITY AREA 4: Public awareness, understanding and acceptance

To combat negative stereotypes and help increase public awareness, understanding, and acceptance of autism, the CAHS report indicated opportunities to[3]:

- Create national "knowledge-raising campaigns, positive media portrayals, education and training, and lasting peer engagement [opportunities] with Autistic people."
- Implement anti-bullying programs in schools across Canada, with a focus on understanding autism and creating inclusive educational settings for Autistic students.

It was also identified through stakeholder engagement that in order to improve the delivery of care and support for Autistic people and their families, there is a need for high-quality, standardized autism training for an array of service providers, including those in healthcare, social services, and public safety. These training opportunities should be mandatory in nature.[3]

The CAHS report listed the following components to consider when developing autism training programs for service providers[3]:

- Develop and implement programs in partnership with Autistic people, their families and end users.
- Focus on evidence-based, culturally-responsive supports, and services.
- Have varied training opportunities that correspond to the roles of the staff, and their interactions with Autistic people.
- Incorporate independent evaluation and quality assurance.
- Involve partnerships amongst organizations and governments (e.g., across health, education, and social sectors).

The CAHS report also indicated that there are opportunities for governments in Canada to assist with the provision of regulatory and statutory guidance, improvement standards, and mandatory autism training for government, education, and healthcare professionals.[3]

To increase autism knowledge, understanding, and acceptance to foster inclusion in the workplace, stakeholders indicated that there is a need for:

- Widescale, professional training tailored to diverse types of interactions with Autistic people.[3]
- More specialized training 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."[3]
- Increased efforts to foster autism inclusivity in the workplace, for example through the "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 practice, and incentives for longer-term inclusive hiring practices".[3]

PRIORITY AREA 5: Tools and resources

Stakeholders indicated that there are opportunities to help Autistic people and their caregivers self-advocate, better navigate the systems in place, improve access to autism supports and improve their overall well-being:

- Provide information on autism, best practice guidelines, and locally available supports and services, including details on wait times.[3]
- Provide information about financial assistance, protections against discrimination on the basis of disability in the context of housing, and how to navigate financial and housing support systems.[19]
- Create navigational tools that can help facilitate access to appropriate individualized services.[3]
- Improve access to tools and resources with information about protections against discrimination, on the basis of disability and human rights more generally, and supports which can help foster self-advocacy.[19]

To empower Autistic people to use the internet safely to access tools and resources, there are opportunities to:

- Provide information on digital literacy skills.[19]
- Develop programs to address digital inequities, with an emphasis on bridging the digital divide in remote and rural areas.[3]

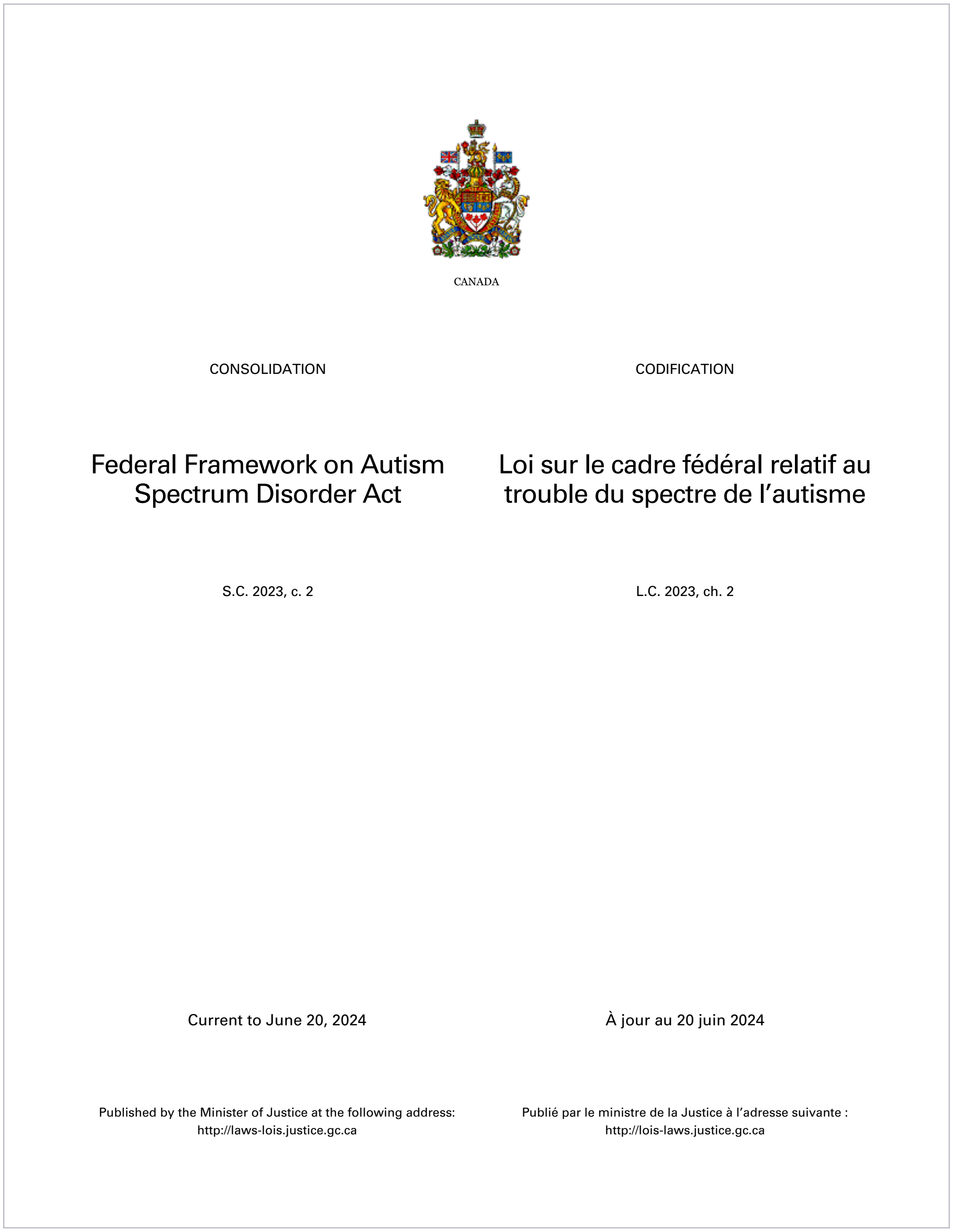
An online tool launched in Canada in 2020 and highlighted in the 2022 CAHS report, is the Autism and/or Intellectual Disability Knowledge Exchange Network (AIDE Canada), which received funding from PHAC.[3] AIDE Canada offers a platform to easily access reliable and evidence-informed information and resources on autism and intellectual disabilities. The goal of the website is to help reduce regional disparities in accessing services, supports and resources on autism and other intellectual disabilities, with a focus on improving access in rural and remote areas. The CAHS report notes that “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”.[3]

Stakeholders indicated that in order to reflect the complexity of needs and range of experiences of Autistic people:

- Tools and resources should be culturally relevant and accessible.[19] This includes making sure that tools and resources are available in multiple languages.
- The development process of these tools and resources should include the participation of Autistic people and their caregivers, including those from diverse backgrounds.[3][19]

APPENDIX B: Federal Framework on Autism Spectrum Disorder Act

Visit the Justice Laws website to see the *Federal Framework for Autism Spectrum Disorder Act*.



CANADA

CONSOLIDATION

Federal Framework on Autism Spectrum Disorder Act

S.C. 2023, c. 2

Current to June 20, 2024

Published by the Minister of Justice at the following address:
http://laws-lois.justice.gc.ca

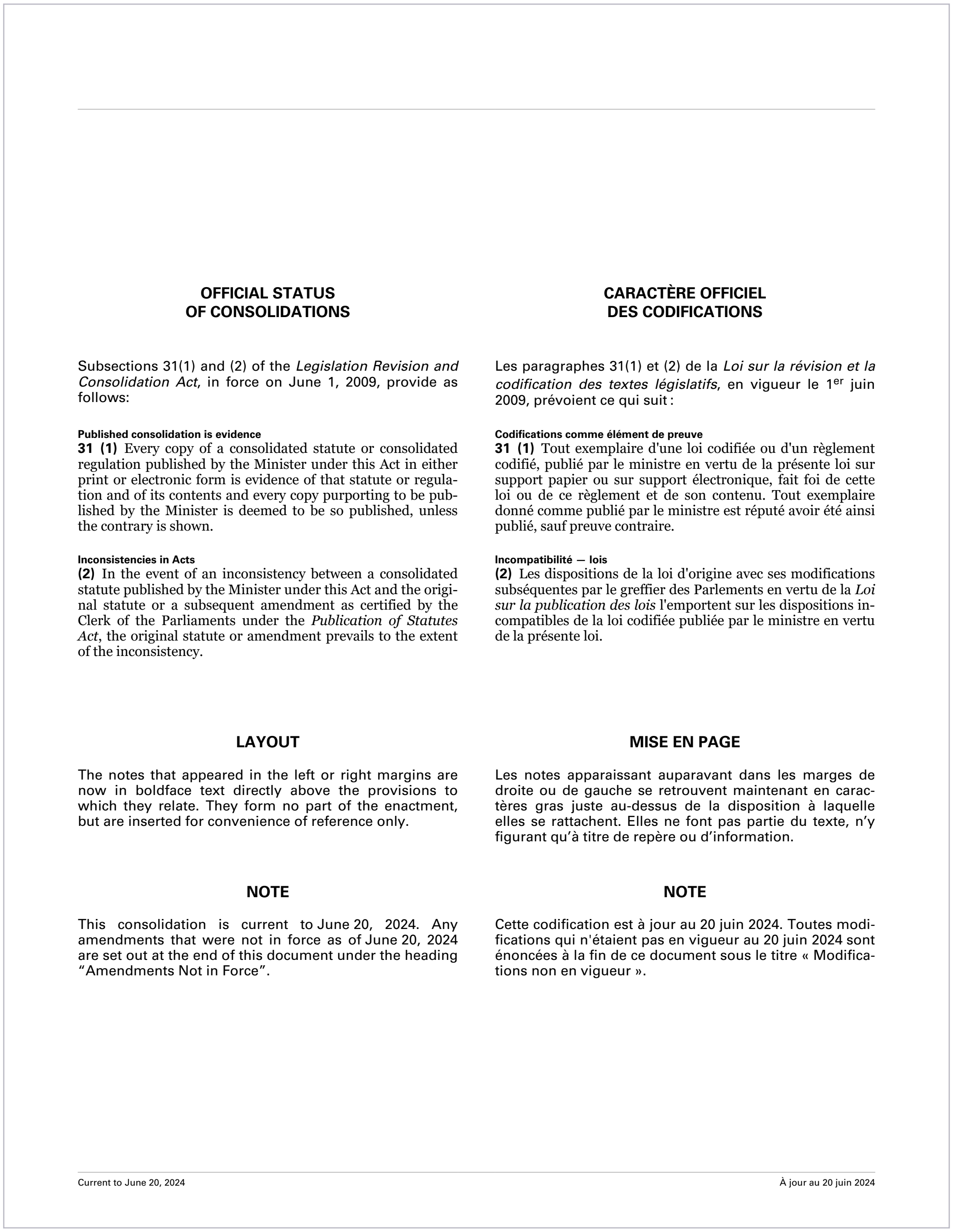
CODIFICATION

Loi sur le cadre fédéral relatif au trouble du spectre de l'autisme

L.C. 2023, ch. 2

À jour au 20 juin 2024

Publié par le ministre de la Justice à l'adresse suivante :
http://lois-laws.justice.gc.ca



OFFICIAL STATUS OF CONSOLIDATIONS

Subsections 31(1) and (2) of the *Legislation Revision and Consolidation Act*, in force on June 1, 2009, provide as follows:

Published consolidation is evidence
31 (1) Every copy of a consolidated statute or consolidated regulation published by the Minister under this Act in either print or electronic form is evidence of that statute or regulation and of its contents and every copy purporting to be published by the Minister is deemed to be so published, unless the contrary is shown.

Inconsistencies in Acts
(2) In the event of an inconsistency between a consolidated statute published by the Minister under this Act and the original statute or a subsequent amendment as certified by the Clerk of the Parliaments under the *Publication of Statutes Act*, the original statute or amendment prevails to the extent of the inconsistency.

LAYOUT

The notes that appeared in the left or right margins are now in boldface text directly above the provisions to which they relate. They form no part of the enactment, but are inserted for convenience of reference only.

NOTE

This consolidation is current to June 20, 2024. Any amendments that were not in force as of June 20, 2024 are set out at the end of this document under the heading “Amendments Not in Force”.

CARACTÈRE OFFICIEL DES CODIFICATIONS

Les paragraphes 31(1) et (2) de la *Loi sur la révision et la codification des textes législatifs*, en vigueur le 1er juin 2009, prévoient ce qui suit :

Codifications comme élément de preuve
31 (1) Tout exemplaire d'une loi codifiée ou d'un règlement codifié, publié par le ministre en vertu de la présente loi sur support papier ou sur support électronique, fait foi de cette loi ou de ce règlement et de son contenu. Tout exemplaire donné comme publié par le ministre est réputé avoir été ainsi publié, sauf preuve contraire.

Incompatibilité — lois
(2) Les dispositions de la loi d'origine avec ses modifications subséquentes par le greffier des Parlements en vertu de la *Loi sur la publication des lois* l'emportent sur les dispositions incompatibles de la loi codifiée publiée par le ministre en vertu de la présente loi.

MISE EN PAGE

Les notes apparaissant auparavant dans les marges de droite ou de gauche se retrouvent maintenant en caractères gras juste au-dessus de la disposition à laquelle elles se rattachent. Elles ne font pas partie du texte, n’y figurant qu’à titre de repère ou d’information.

NOTE

Cette codification est à jour au 20 juin 2024. Toutes modifications qui n'étaient pas en vigueur au 20 juin 2024 sont énoncées à la fin de ce document sous le titre « Modifications non en vigueur ».

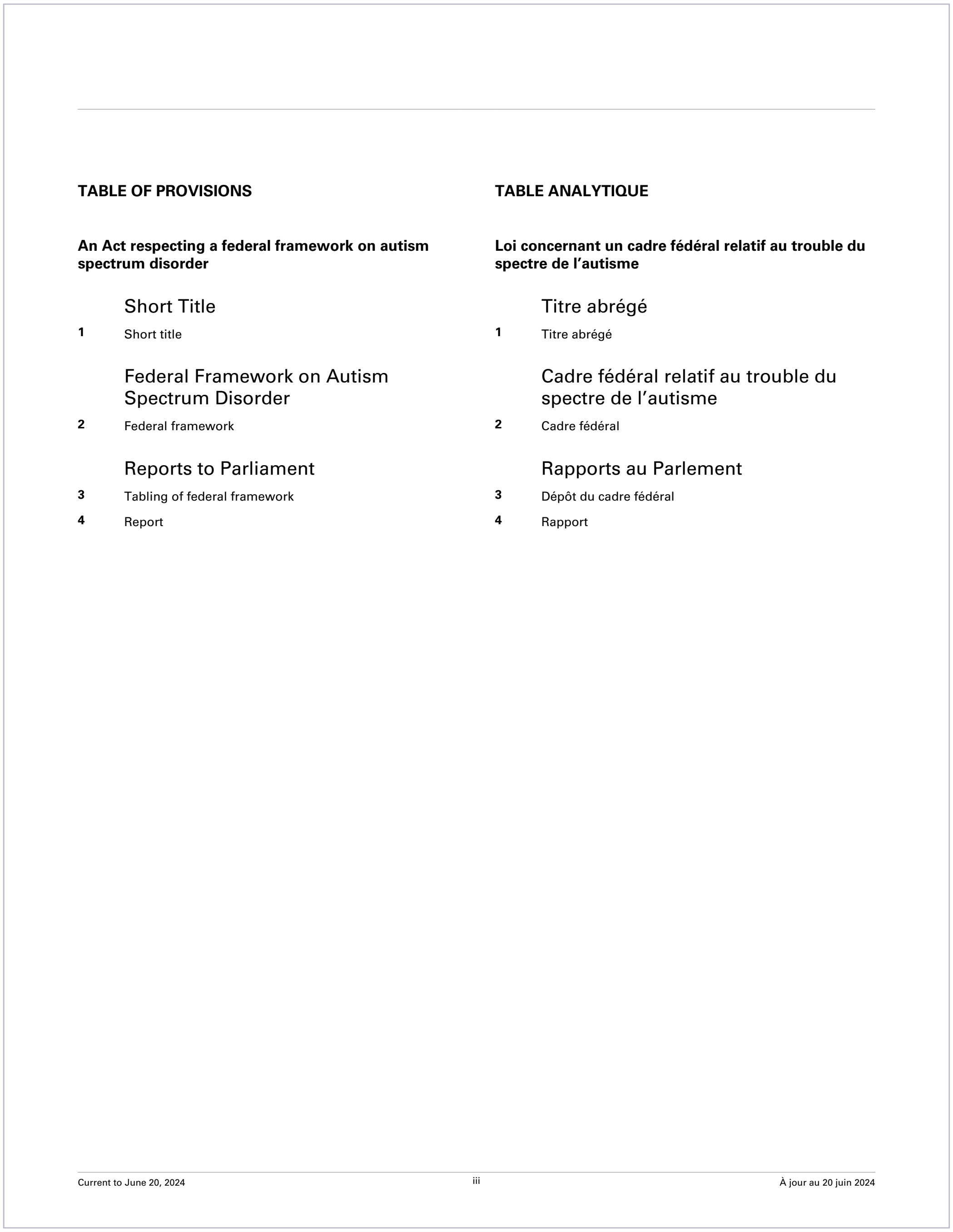
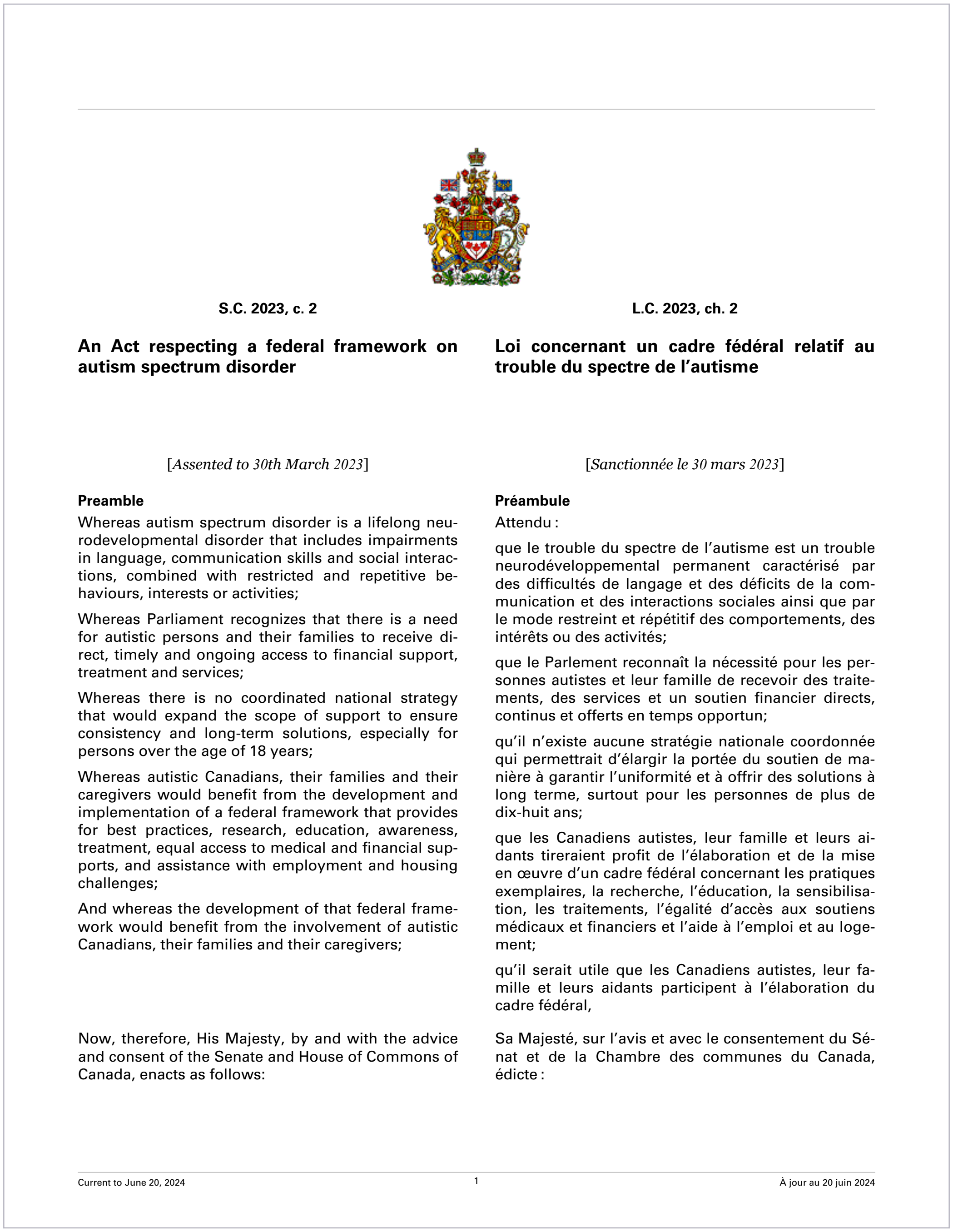


TABLE OF PROVISIONS	TABLE ANALYTIQUE
An Act respecting a federal framework on autism spectrum disorder	**Loi concernant un cadre fédéral relatif au trouble du spectre de l'autisme**
Short Title	Titre abrégé
1 Short title	**1** Titre abrégé
Federal Framework on Autism Spectrum Disorder	Cadre fédéral relatif au trouble du spectre de l'autisme
2 Federal framework	**2** Cadre fédéral
Reports to Parliament	Rapports au Parlement
3 Tabling of federal framework	**3** Dépôt du cadre fédéral
4 Report	**4** Rapport

Current to June 20, 2024 iii À jour au 20 juin 2024



S.C. 2023, c. 2

An Act respecting a federal framework on autism spectrum disorder

[*Assented to 30th March 2023*]

Preamble

Whereas autism spectrum disorder is a lifelong neurodevelopmental disorder that includes impairments in language, communication skills and social interactions, combined with restricted and repetitive behaviours, interests or activities;

Whereas Parliament recognizes that there is a need for autistic persons and their families to receive direct, timely and ongoing access to financial support, treatment and services;

Whereas there is no coordinated national strategy that would expand the scope of support to ensure consistency and long-term solutions, especially for persons over the age of 18 years;

Whereas autistic Canadians, their families and their caregivers would benefit from the development and implementation of a federal framework that provides for best practices, research, education, awareness, treatment, equal access to medical and financial supports, and assistance with employment and housing challenges;

And whereas the development of that federal framework would benefit from the involvement of autistic Canadians, their families and their caregivers;

Now, therefore, His Majesty, by and with the advice and consent of the Senate and House of Commons of Canada, enacts as follows:

L.C. 2023, ch. 2

Loi concernant un cadre fédéral relatif au trouble du spectre de l’autisme

[*Sanctionnée le 30 mars 2023*]

Préambule

Attendu :

que le trouble du spectre de l’autisme est un trouble neurodéveloppemental permanent caractérisé par des difficultés de langage et des déficits de la communication et des interactions sociales ainsi que par le mode restreint et répétitif des comportements, des intérêts ou des activités;

que le Parlement reconnaît la nécessité pour les personnes autistes et leur famille de recevoir des traitements, des services et un soutien financier directs, continus et offerts en temps opportun;

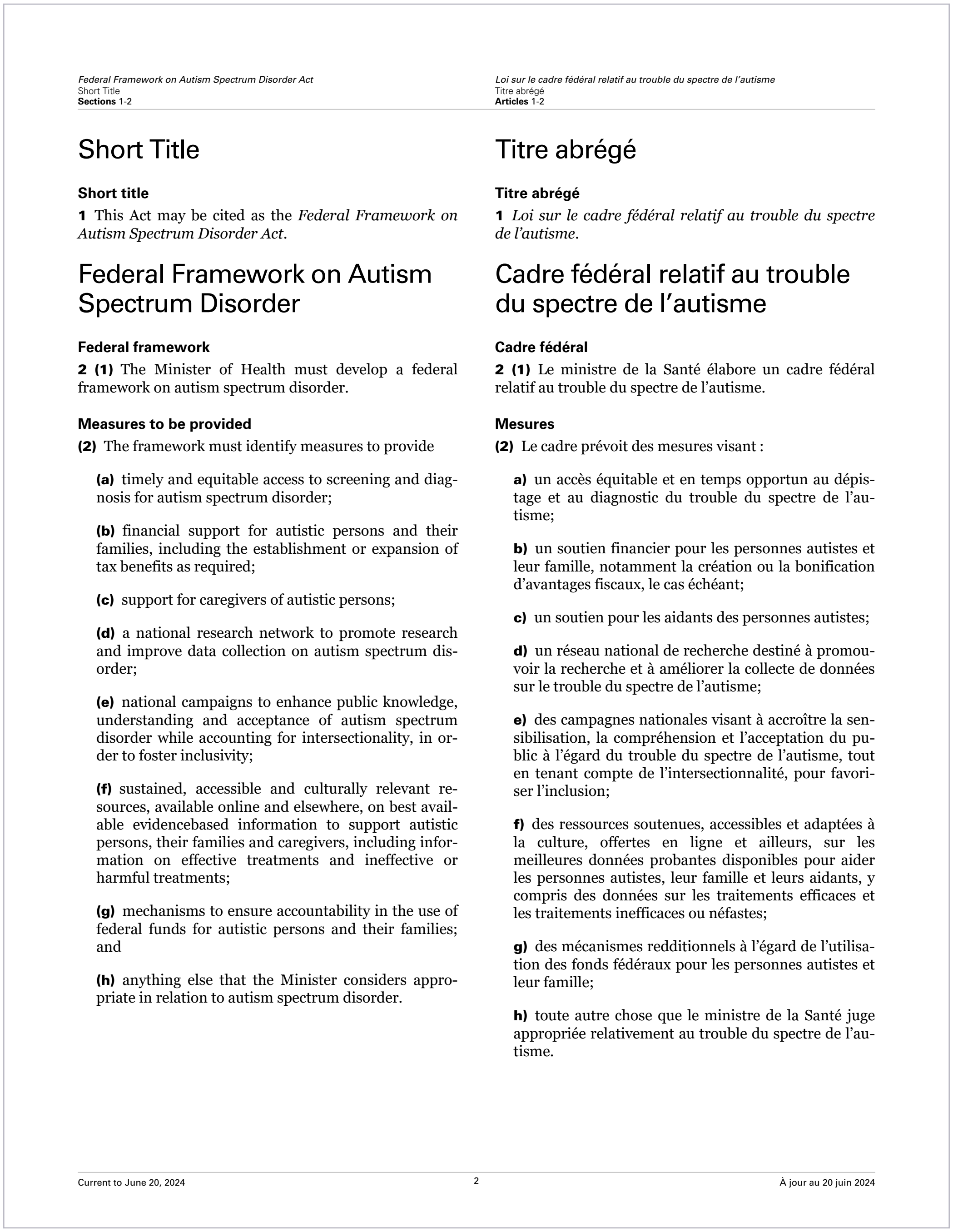
qu’il n’existe aucune stratégie nationale coordonnée qui permettrait d’élargir la portée du soutien de manière à garantir l’uniformité et à offrir des solutions à long terme, surtout pour les personnes de plus de dix-huit ans;

que les Canadiens autistes, leur famille et leurs aidants tireraient profit de l’élaboration et de la mise en œuvre d’un cadre fédéral concernant les pratiques exemplaires, la recherche, l’éducation, la sensibilisation, les traitements, l’égalité d’accès aux soutiens médicaux et financiers et l’aide à l’emploi et au logement;

qu’il serait utile que les Canadiens autistes, leur famille et leurs aidants participent à l’élaboration du cadre fédéral,

Sa Majesté, sur l’avis et avec le consentement du Sénat et de la Chambre des communes du Canada, édicte :

Current to June 20, 2024 1 À jour au 20 juin 2024



Short Title

Short title

1 This Act may be cited as the *Federal Framework on Autism Spectrum Disorder Act*.

Federal Framework on Autism Spectrum Disorder

Federal framework

2 (1) The Minister of Health must develop a federal framework on autism spectrum disorder.

Measures to be provided

(2) The framework must identify measures to provide

(a) timely and equitable access to screening and diagnosis for autism spectrum disorder;

(b) financial support for autistic persons and their families, including the establishment or expansion of tax benefits as required;

(c) support for caregivers of autistic persons;

(d) a national research network to promote research and improve data collection on autism spectrum disorder;

(e) national campaigns to enhance public knowledge, understanding and acceptance of autism spectrum disorder while accounting for intersectionality, in order to foster inclusivity;

(f) sustained, accessible and culturally relevant resources, available online and elsewhere, on best available evidencebased information to support autistic persons, their families and caregivers, including information on effective treatments and ineffective or harmful treatments;

(g) mechanisms to ensure accountability in the use of federal funds for autistic persons and their families; and

(h) anything else that the Minister considers appropriate in relation to autism spectrum disorder.

Titre abrégé

Titre abrégé

1 *Loi sur le cadre fédéral relatif au trouble du spectre de l'autisme.*

Cadre fédéral relatif au trouble du spectre de l'autisme

Cadre fédéral

2 (1) Le ministre de la Santé élabore un cadre fédéral relatif au trouble du spectre de l'autisme.

Mesures

(2) Le cadre prévoit des mesures visant :

a) un accès équitable et en temps opportun au dépistage et au diagnostic du trouble du spectre de l'autisme;

b) un soutien financier pour les personnes autistes et leur famille, notamment la création ou la bonification d'avantages fiscaux, le cas échéant;

c) un soutien pour les aidants des personnes autistes;

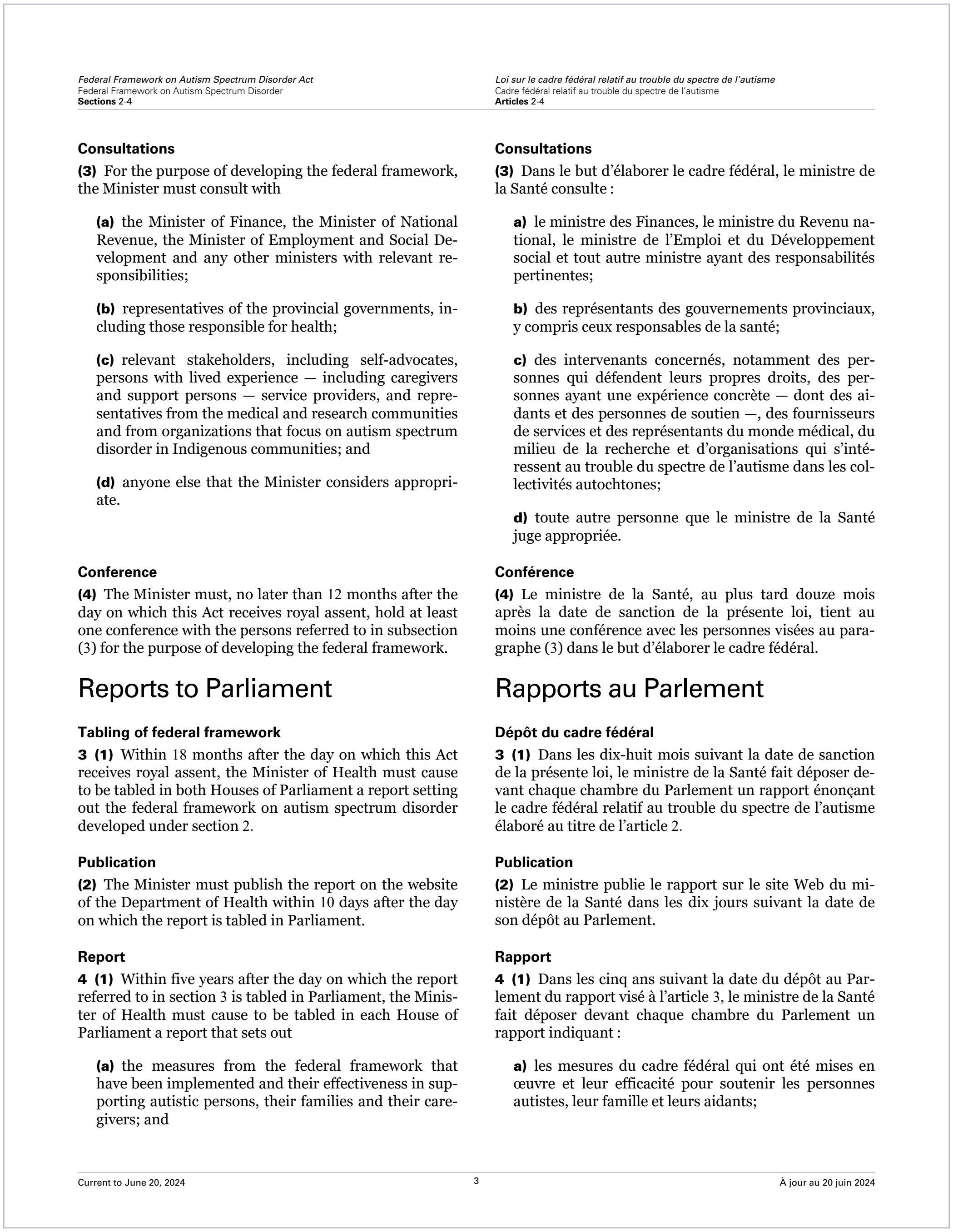
d) un réseau national de recherche destiné à promouvoir la recherche et à améliorer la collecte de données sur le trouble du spectre de l'autisme;

e) des campagnes nationales visant à accroître la sensibilisation, la compréhension et l'acceptation du public à l'égard du trouble du spectre de l'autisme, tout en tenant compte de l'intersectionnalité, pour favoriser l'inclusion;

f) des ressources soutenues, accessibles et adaptées à la culture, offertes en ligne et ailleurs, sur les meilleures données probantes disponibles pour aider les personnes autistes, leur famille et leurs aidants, y compris des données sur les traitements efficaces et les traitements inefficaces ou néfastes;

g) des mécanismes redditionnels à l'égard de l'utilisation des fonds fédéraux pour les personnes autistes et leur famille;

h) toute autre chose que le ministre de la Santé juge appropriée relativement au trouble du spectre de l'autisme.



Consultations

(3) For the purpose of developing the federal framework, the Minister must consult with

(a) the Minister of Finance, the Minister of National Revenue, the Minister of Employment and Social Development and any other ministers with relevant responsibilities;

(b) representatives of the provincial governments, including those responsible for health;

(c) relevant stakeholders, including self-advocates, persons with lived experience — including caregivers and support persons — service providers, and representatives from the medical and research communities and from organizations that focus on autism spectrum disorder in Indigenous communities; and

(d) anyone else that the Minister considers appropriate.

Conference

(4) The Minister must, no later than 12 months after the day on which this Act receives royal assent, hold at least one conference with the persons referred to in subsection (3) for the purpose of developing the federal framework.

Reports to Parliament

Tabling of federal framework

3 (1) Within 18 months after the day on which this Act receives royal assent, the Minister of Health must cause to be tabled in both Houses of Parliament a report setting out the federal framework on autism spectrum disorder developed under section 2.

Publication

(2) The Minister must publish the report on the website of the Department of Health within 10 days after the day on which the report is tabled in Parliament.

Report

4 (1) Within five years after the day on which the report referred to in section 3 is tabled in Parliament, the Minister of Health must cause to be tabled in each House of Parliament a report that sets out

(a) the measures from the federal framework that have been implemented and their effectiveness in supporting autistic persons, their families and their caregivers; and

Consultations

(3) Dans le but d'élaborer le cadre fédéral, le ministre de la Santé consulte :

a) le ministre des Finances, le ministre du Revenu national, le ministre de l'Emploi et du Développement social et tout autre ministre ayant des responsabilités pertinentes;

b) des représentants des gouvernements provinciaux, y compris ceux responsables de la santé;

c) des intervenants concernés, notamment des personnes qui défendent leurs propres droits, des personnes ayant une expérience concrète — dont des aidants et des personnes de soutien —, des fournisseurs de services et des représentants du monde médical, du milieu de la recherche et d'organisations qui s'intéressent au trouble du spectre de l'autisme dans les collectivités autochtones;

d) toute autre personne que le ministre de la Santé juge appropriée.

Conférence

(4) Le ministre de la Santé, au plus tard douze mois après la date de sanction de la présente loi, tient au moins une conférence avec les personnes visées au paragraphe (3) dans le but d'élaborer le cadre fédéral.

Rapports au Parlement

Dépôt du cadre fédéral

3 (1) Dans les dix-huit mois suivant la date de sanction de la présente loi, le ministre de la Santé fait déposer devant chaque chambre du Parlement un rapport énonçant le cadre fédéral relatif au trouble du spectre de l'autisme élaboré au titre de l'article 2.

Publication

(2) Le ministre publie le rapport sur le site Web du ministère de la Santé dans les dix jours suivant la date de son dépôt au Parlement.

Rapport

4 (1) Dans les cinq ans suivant la date du dépôt au Parlement du rapport visé à l'article 3, le ministre de la Santé fait déposer devant chaque chambre du Parlement un rapport indiquant :

a) les mesures du cadre fédéral qui ont été mises en œuvre et leur efficacité pour soutenir les personnes autistes, leur famille et leurs aidants;

(b) with respect to any measure included in the federal framework that was not implemented, the reason it has not been implemented and the timeline for its implementation.

b) dans le cas des mesures du cadre fédéral qui n’ont pas été mises en œuvre, la raison pour laquelle elles ne l’ont pas été et l’échéancier prévu pour leur mise en œuvre.

APPENDIX C: Informing the Framework

Key themes from the Canadian Academy of Health Sciences' (CAHS) Report, Autism in Canada: Considerations for future public policy development

The CAHS report described five thematic areas to consider for future policy development:

1. Intersectionality and Diversity
2. Social Inclusion
3. Diagnosis, Supports, and Services
4. Economic Inclusion
5. Positioning for Impact (data collection and sharing, research, and collaboration)

Below is a high-level summary of their findings as they relate to the five priorities of the Framework. This is not intended to be an exhaustive summary. For additional information, see the full CAHS report.[3]

PRIORITY AREA 1: Screening, diagnosis and services

Timely and equitable access to autism diagnoses, supports and services must be available for Autistic people and for their families. The theme Diagnosis, Supports, and Services relates to the Framework's first priority. The CAHS report recommends a life-course approach that considers the needs of Autistic people and their family members at various life stages. Young children should be able to access early publicly funded diagnostic assessments that will allow them to benefit from supports during this important developmental period. The report recommends using a stepped approach to diagnosis and services, which helps to deliver supports and services to the child and their family in accordance with their specific needs. Supports and services for school-aged Autistic children and adolescents can improve academic success, life and social skills, and mental health, while preventing bullying and other forms of exclusion. Continued supports and services that help students transition into adulthood could help improve mental and physical wellbeing of Autistic adults. Additionally, there is a need for increased supports and services for older Autistic adults, for example, autism-specific long-term care options.

The CAHS report emphasized the importance of supports and services that promote social inclusion through community participation, addressing discrimination, fostering physical and emotional safety, and leveraging technology. Importantly, evidence-based research should inform these services. Increased translational efforts could help bridge research into practice.

PRIORITY AREA 2: Economic inclusion

Improving economic inclusion for Autistic people involves removing barriers to financial stability; and creating pathways for inclusive education opportunities, meaningful employment and autism-inclusive housing options. The theme Economic Inclusion relates to the Framework's second priority. The CAHS report describes several opportunities to increase economic inclusion for Autistic people: financial stability could be promoted by offsetting common out-of-pocket expenses; encouraging labour market participation through workplace policies and provisions; offering financial planning and literacy supports; and reforming access to disability benefits and tax measures. Incorporating neurodiversity into post-secondary equity and inclusion frameworks and adopting more autism-specific accommodations and financial supports could help remove barriers to post-secondary education. Promoting autism acceptance in the workplace, providing autism-specific supports and accommodations, and encouraging equitable access to work opportunities could improve employment pathways for Autistic people. Finally, there is a need to develop autism-inclusive housing models that consider the unique needs of Autistic people across Canada.

In accordance with the CAHS report's theme Positioning for Impact, increased data collection on autism enrollment rates in post-secondary education in Canada, and on the housing needs of Autistic people could inform targeted systems-level changes.

PRIORITY AREA 3: Data collection, public health surveillance, and research

Data collection and sharing, research, and collaboration are important enablers for meaningful change and will help inform future autism policies. The theme Positioning for Impact relates to the Framework's third priority. The CAHS report recommends that research projects expand their scope beyond investigating the causes and characterization of autism, and instead focus on research that investigates the day-to-day needs of Autistic people across the life span. Additionally, future research should prioritize meaningfully collaborating with people on the autism spectrum and their families, while building the capacity of autism researchers, and including Autistic researchers in the research process.

Several other themes from the CAHS report relate to the Framework's third priority, as there are critical gaps to fill in data collection, public health surveillance, and research, notably within the themes of Social Inclusion, Economic Inclusion, and Diagnosis, Supports, and Services.

PRIORITY AREA 4: Public awareness, understanding and acceptance

Initiatives that promote social and economic inclusion and educate the public on all aspects of autism can help increase public awareness, understanding and acceptance of autism. The theme Social Inclusion is most related to the Framework's fourth priority. This theme entails addressing discrimination and promoting a sense of belonging and acceptance, while fostering physical and emotional safety, and ensuring that Autistic people have equitable opportunities to fully participate in the community. The CAHS report notes that knowledge-raising campaigns, positive-media portrayal, and standardized education and training programs can help boost autism acceptance and inclusion in Canada.

The themes Diagnosis, Supports, and Services and Economic Inclusion are also relevant in informing the fourth priority. Particularly, supports and services that encourage public acceptance and inclusion over the life-course such as anti-bullying campaigns for school-aged children, autism-specific post-secondary education supports, and developing autism-inclusive employment pathways.

PRIORITY AREA 5: Tools and resources

Tools and resources can help those with autism and their families access invaluable supports and services, improving their health, safety, and well-being. This priority relates to every theme outlined in the CAHS report. For example, the theme Intersectionality and Diversity should be considered when developing tools and resources with equity in mind, as some groups have more difficulty accessing diagnostic supports and services. Secondly, providing tools and resources on financial assistance, housing rights, and navigating financial and housing support systems can promote Economic Inclusion; and providing tools and resources on peer support, behaviour and communication strategies, digital literacy skills, accessibility services and rights can promote Social Inclusion. Additionally, the use of these tools and resources can help connect Autistic people to diagnostic services and other useful programs (Diagnosis, Supports, and Services). Lastly, tools and resources must be evidence-informed to ensure that the findings from high quality research are translated into practice (Positioning for Impact).

It is important to note that the cross-cutting theme of Intersectionality and Diversity informed all five priorities. The CAHS report highlights that the challenges and needs of Autistic people intersect with a wide range of identities such as race, ethnicity and language, gender and sexual orientation, diversity of family structure, geography, socioeconomic status, and diversity of support needs. The report also recommends that Indigenous-led, culturally relevant, localized approaches are necessary to address the unique experiences of Canada's Indigenous population. Concepts respecting and acknowledging intersectionality and diversity should be incorporated into every aspect of autism policy, including developing diagnostic and screening services, creating culturally relevant tools and resources, collecting data that relates to diverse populations, and designing inclusive research projects.

Key themes from the 2022 National Autism Conference

The Government of Canada's 2022 National Autism Conference[19], invited participants from across Canada to discuss further a number of issues identified in the CAHS report.

The Conference included seven thematic panels:

1. Safety and Security
2. Financial Stability
3. Employment
4. Equity, Diversity, and Inclusion
5. Housing
6. Health Human Resources
7. Research, Data and Evaluation

Below are some key messages related to the Framework's 5 priorities discussed by panelists during this national event. This is not intended to be an exhaustive summary.

PRIORITY AREA 1: Screening, diagnosis and services

In acknowledgement of the considerable provincial and territorial roles and responsibilities in this space, panelists were directed to focus on the federal roles and responsibilities. The Health Human Resources panel discussed ways to bolster the capacity of healthcare and allied health professionals delivering autism screening, diagnosis and/or services. Panelists highlighted that Autistic people could benefit from earlier interventions along with greater access to mental health supports. They emphasized a need for up-to date professional training on autism through continuing education and communities of practice informed by Autistic people and their families. Reducing barriers to hiring neurodiverse practitioners could also support the future workforce. The panel also noted a need for clarity and consensus around standards of autism care, notably national guidelines for diagnosis (wait-times) to reduce the barriers to autism services.

During panel discussions on Financial Stability; Equity, Diversity, and Inclusion; and Health Human Resources, panelists indicated that there is a need for financial support for early intervention and diagnosis in childhood. Panelists also highlighted that there needs to be an increased awareness about the consequences of late diagnosis/misdiagnosis, especially for women.

PRIORITY AREA 2: Economic inclusion

Financial stability is an important social determinant of health for Autistic people and their families and is related to quality of life. In the Financial Stability panel, the conference heard that Autistic people and their families need direct financial assistance as well as support navigating complex tax systems. Families are challenged by recurring out of pocket expenses, difficult choices to leave employment to provide care, and a stark loss of disability benefits when Autistic children reach adulthood. Speakers called for a systems-thinking approach to the tax credit and benefit system; one that both understands complex needs and that autism is a lifelong condition.

The Financial Stability panel underscored that this issue is related to many other determining factors, including access to mental health and other support services, early intervention and diagnosis in childhood, suitable housing, sustainable employment, and financial literacy. Panelists emphasized the need for future planning for the financial stability and housing of Autistic adults and older adults.

The Employment panel noted that many Autistic people lack access to meaningful and appropriate employment that pays an adequate income, meets their skills and qualifications, and offers appropriate accommodations. They observed, however, that in various regions there are already employment initiatives with best or promising practices that could be supported and scaled up. The conference heard that autism-specific and general disability supports could improve the experiences and success of Autistic people in post-secondary education. That said, employment pathways could also better recognize competencies and training outside of traditional schooling.

The Housing panel emphasized that affordable and appropriate housing solutions will require flexibility to the changing needs across the lifespan of Autistic people, their aging families, and caregivers. They also highlighted a need to implement safeguards for those who require congregate living, and access to legal representation for Autistic people and their families.

PRIORITY AREA 3: Data collection, public health surveillance, and research

Re-assessing the infrastructure and inclusivity of data collection, public health surveillance, research, and evaluation will allow for a better, more unified representation of the diversity of Autistic people in Canada. The Research, Data and Evaluation panel noted the need for funding to ensure autism research extends beyond a medical understanding of autism and towards more psycho-social research, including participatory research methods. The panel indicated that to rebuild trust with the Autistic community, research needs to be conducted in partnership with Autistic people from the start and include various demographic groups. This includes finding ways to include Autistic people with intellectual disabilities or communication differences. With much research focused on Autistic children, more knowledge is needed about experiences across the lifespan. Panelists indicated that standardizing data collection and public health surveillance across all provinces and territories, and developing a national repository of autism research, would ensure that the data is unified and can easily be accessible to all researchers across Canada. Panelists also discussed what the federal government's role could be in setting benchmarks in program evaluation standards by ensuring measurable indicators, tools, and outcomes.

PRIORITY AREA 4: Public awareness, understanding and acceptance

Harmful stereotypes are a driver of discrimination, diminished opportunities, and experiences of social isolation for Autistic people. Stereotypes contribute to safety and mental health concerns, and a lack of confidence that Autistic people can trust others to support them. The Safety and Security panel identified autism awareness and acceptance training for professionals as a critical need to address a knowledge and training gap, and to enable positive interactions with first responders and authority figures in educational and medical settings. Panelists expressed a need to change the narrative around autism, starting with a shift in supports and services from a deficit-based model to a strengths-based approach.

Similarly, the Employment panel noted that greater workplace awareness and acceptance of neurodiversity could enable a shift in recruitment, retention, and advancement practices. Human Resources professionals could complete training to better recognize the opportunities in the autism workforce and how employers and coworkers could accommodate.

The Research panel offered opportunities to improve upon the base of knowledge informing public understanding of autism. Notably, a greater acknowledgement of the double empathy problem and a better collection of narratives from under-represented Autistic populations will be important.

The Equity, Diversity and Inclusion panel emphasized the need for various engagement strategies to provide a voice for different Autistic populations (including Autistic people who are non-speaking; Indigenous; culturally and racially diverse; women and non-binary; late diagnosed; and located in rural and remote communities). To help explain differences across the spectrum, they pointed to a need for a national communication campaign, training for professionals and funding for entertainment and media. Panelists suggested the creation of a training guide for race-based policing could support equitable treatment of Autistic people, and safe and positive interactions. An Indigenous-led assessment on autism could present insight for autism policy in other communities.

PRIORITY AREA 5: Tools and resources

All seven panels of the conference discussed access to tools and resources for Autistic people and their caregivers. The Safety and Security panel discussed a need to equalize and implement tools to promote safety online and in physical communities (e.g., digital literacy training, self-advocacy skills, and rights information). As Autistic people transition into adulthood, there is a growing need for tools and resources that facilitate meaningful employment, access to technology, and continuous financial and housing support throughout their lives, especially in marginalized areas (as highlighted in discussions from the Financial Stability, Employment, and Housing panels). Tools, resources, and supports should further be participatory, easily accessible, culturally specific, and address the needs of different demographic groups and marginalized areas (Equity, Diversity, and Inclusion; Health Human Resources; and Research, Data and Evaluation panels).

APPENDIX D: Roles and responsibilities in Canada relating to autism

All governments in Canada, across many stakeholders and sectors, have a role to play in providing supports for people on the autism spectrum. The promotion and protection of health is an area of shared jurisdiction in Canada.

The **federal government has a role** in promoting and protecting the health of people in Canada, while respecting provincial and territorial areas of jurisdiction. The Government of Canada's responsibilities include:

- Setting national principles so that quality healthcare is available to all people in Canada.
- Data collection and public health surveillance of autism in Canada.
- Developing policies and guidelines and supporting implementation through awareness and education.
- Facilitating research and innovation to understand autism and support the development of new screening and diagnostic tools and standards of care.
- Developing and administering federal programs and measures including financial supports and tax relief.
- Facilitating community-based programming aimed at improving the health and well-being of Autistic people, their caregivers and families.
- Collaborating and engaging with provinces and territories, Indigenous and international partners, and other sectors regarding autism.
- Delivering and funding healthcare services for Indigenous populations (including First Nations people living on-reserve, and Inuit communities).
- Ensuring accountability in the use of federal funds for programs and measures reaching Autistic people and their families by reporting through the Departmental Results Reports.

Provincial and territorial governments also have responsibilities in relation to promoting and protecting health within their jurisdictions, including:

- Healthcare settings, health insurance, and the delivery of health programs and services.
- Establishing policies, guidelines, and standards for healthcare settings.
- Supporting medical education; implementing programs for persons with disabilities.
- Supporting research and academic initiatives and collecting data used for surveillance.
- Facilitating community-based programming.
- Establishing certification programs for health service providers.
- Providing supports and services to persons with disabilities, including Autistic people in Canada.

APPENDIX E: Current autism initiatives in Canada

The purpose of this appendix is to provide examples of current initiatives in Canada supporting Autistic people, which have been considered in the development of this Framework. They cover initiatives at various levels, including those led by the Government of Canada, provincial and territorial governments, as well as international initiatives. It is not meant to be an exhaustive list.

There are many other initiatives offered by stakeholders and organizations in the public and private sectors to support Autistic people across Canada, their families, and caregivers. The variety of current initiatives emphasizes the value of having services and supports available for Autistic people across the life-course, and to address the wide variability of needs in this population.

Federal government

National Autism Surveillance

The Public Health Agency of Canada works with FPT partners to provide reliable estimates of the number of Autistic people in Canada, and to assess whether there are changes over time. Surveillance of autism also allows comparison of the number of Autistic people in different areas of the country, as well how the lives of Autistic people and their families are impacted.

Autism and Intellectual Disabilities Knowledge Exchange Network (AIDE Canada)

AIDE Canada provides access to online resources, including an inventory of services, supports, employment opportunities and local programming for families across the country. Six AIDE Canada locations across the country provide a point of access for those in Canada to obtain resources and supports on autism.

Autism Spectrum Disorder (ASD) Strategic Fund (2018-2023)

The ASD Strategic Fund invests in community-based projects that pursue innovative program models, help reduce stigma, and integrate health, social and educational components to better serve the complex needs of Autistic people in Canada and their families.

Disability Inclusion Action Plan (DIAP), 2022

Canada's DIAP is a comprehensive, whole-of-government approach to disability inclusion. It aims to improve the social and economic participation of persons with disabilities in Canada across four pillars: financial security, employment, accessible and inclusive communities, and a modern approach to disability. DIAP's second pillar of *Employment, Employment Strategy for Canadians with Disabilities* was launched on July 11, 2024, with the purpose of closing the employment gap between persons with disabilities and those without. It is a key action of the DIAP and contains a range of measures organized around three goals:

- Individuals | help them find and maintain good jobs, advance in their careers or become entrepreneurs;
- Employers | help them to diversify their workforces by creating inclusive and accessible workplaces; and
- Enablers | increase the supply, capacity, and reach of individuals and organizations that support disability inclusion and accessibility in employment.

Opportunities Fund (OF) for Persons with Disabilities

Helps persons with disabilities prepare for, obtain, and maintain employment, advance in their careers or pursue entrepreneurship. The OF also assists employers in hiring persons with disabilities and creating inclusive and accessible workplaces.

Enabling Accessibility Fund (EAF)

Provides funding to support the capital costs of construction and renovation projects that improve physical accessibility and safety for persons with disabilities in Canadian communities and workplaces. The EAF also supports projects that reduce barriers for those with autism.

The Housing Solutions Lab (Housing through an Autism Lens)

The Housing through an Autism Lens Solutions Lab will develop a pathway to independent and fulfilling living for Autistic adults. It will determine the right mix of services that support Autistic adults at different stages in their lives. Participants will then co-create housing solutions that recognize and match the housing and independent living needs of Autistic adults.

Canadian Institutes of Health Research (CIHR), Autism Research Investments

CIHR funds autism-related research through its open, investigator-led programming which can be searched in the CIHR Funding Decisions Database.

> #### CIHR Anti-Ableism Action Plan
>
> CIHR is co-developing an Action Plan with the External Advisory Committee on Accessibility and Systemic Ableism. This plan will identify, prevent and remove barriers to participation in CIHR health research funding for persons with disabilities and ultimately aims to eliminate systemic ableism in Canada's health research funding system.

Through Canada's Strategy for Patient-Oriented Research (SPOR), CIHR and its partners are investing in CHILD-BRIGHT, an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. The network's many projects include:

> "Ready 2 Work", an online vocational/employment readiness platform developed alongside self-advocates who operate vocational programs for young people with autism; and
>
> "MEGA TEAM", which is evaluating whether a take-home video game can improve executive functioning in children with autism.

Provinces and territories

All provinces provide autism-specific funding for a range of investments focused on supports and services (including education-based supports for pre-school and school-aged children). While the three territories do not have autism-specific funding, they do have supports for broader disability services, including autism.

Many provinces and territories have current (or previous) Action Plans, Strategies or Frameworks to address autism-specific supports in their jurisdictions, while others have developed approaches for disabilities and/or mental health more broadly.

These initiatives include, but are not limited to:

- **Alberta:** Valuing Mental Health: Next Steps (PDF)
- **British Columbia:** B.C.'s Accessibility Plan for 2022/23 to 2024/25 (PDF)
- **Manitoba:** Thrive! A five-year plan for helping Manitobans with autism spectrum disorder and their families (2011)
- **New Brunswick:** Disability Action Plan
- **Newfoundland and Labrador:** Autism Action Plan 2019-2022 (PDF)
- **Northwest Territories:** Equity, Accessibility, Inclusionand Participation—NWT Disability Strategic Framework: 2017 to 2027 (PDF)
- **Nova Scotia:** Autism Spectrum Disorder Action Plan, 2011 (PDF)
- **Nunavut:** n/a
- **Ontario:** Ontario Autism Program: capacity action plan (2021)
- **Prince Edward Island:** Recommendations Toward A Prince Edward Island Autism Action Plan: Another Piece of the Puzzle (2009); Guide to Early Years Autism Services (2012)
- **Quebec:** Autism Spectrum Disorder Action Plan 2017-2022 (PDF)
- **Saskatchewan:** The Saskatchewan Disability Strategy (download); Framework and Action Plan for Autism Spectrum Disorders Services in Saskatchewan 2008 (download); Cognitive Disability Strategy
- **Yukon:** Forward together: Mental Wellness Strategy 2016 to 2026

International efforts

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international treaty that was adopted in 2006 to help protect the rights of people with disabilities around the world. Canada and 183 other state parties have accepted the legal obligations contained in the UNCRPD.

World Health Assembly Resolution WHA73.10

In May 2014, the Sixty-seventh World Health Assembly adopted a resolution entitled Comprehensive and coordinated efforts for the management of autism spectrum disorders, which was supported by more than 60 countries. The resolution urges the World Health Organization (WHO) to collaborate with Member States and partner agencies to strengthen national capacities to address autism and other developmental disabilities.

WHO Comprehensive mental health action plan 2013–2030

The plan calls on countries to address the current significant gaps in early detection, care, health services and rehabilitation for mental and neurodevelopmental conditions, which include autism. It also calls for countries to address the social, economic, educational and inclusion needs of people living with mental and neurological disorders, and their families, and to improve surveillance and relevant research.[22]

APPENDIX F: Identified research gaps and opportunities

The CAHS report entitled Autism in Canada: Considerations for Future Public Policy Development identified many of the current autism research gaps in the areas of social inclusion, diagnosis, supports and services and economic inclusion, as outlined in the below chart.[3] This is not intended to be an exhaustive list, but rather to provide examples of the research opportunities, based on gaps in available research regarding autism in Canada.

Social Inclusion	Diagnosis, Supports, and Services	Economic Inclusion
• 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.	• 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.	• 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.[23] • 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.

Social Inclusion	Diagnosis, Supports, and Services	Economic Inclusion
• Development and evaluation of strategies aimed at shaping attitudes and changing behaviour among frontline service providers as well as first responders. • Data on the prevalence 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 neurodiversity within priorities and metrics.	• 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.	• Longitudinal research of higher education approaches and outcomes (e.g., long term; quality of outcomes) for Autistic people and their family members. • Evaluation of the effects of different housing arrangements and design on outcomes for Autistic adults.[24] • 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.

APPENDIX G: Glossary

Many definitions used for the purposes of the *Framework for Autism in Canada* (Framework) are available from the Canadian Academy of Health Sciences' report, *Autism in Canada: Considerations for future public policy development*.

For the purposes of the Framework, the following definitions are used:

Accommodations: 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.

Autism: Autism (also known as autism spectrum disorder or ASD) is a lifelong neurodevelopmental condition. Autistic people may communicate and connect with other people differently, have sensory processing differences, or focus intensely on certain interests or activities. Autistic people may also have other physical, intellectual, learning, or mental health conditions which can introduce complexities and challenges. Since everyone has different experiences and characteristics, the type and extent of supports needed can vary considerably and should be adapted to individual needs.

Autism acceptance: Embracing autism in a neuro-affirming way—as a difference, not a disorder. Autism acceptance involves 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. Autism acceptance works to change public attitudes and behaviours towards Autistic people.

Autism awareness: 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.

Caregiver: A caregiver is defined as a person who provides care and support to an Autistic person, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbour, or volunteer. Support provided by a caregiver may include assisting with the activities of daily living.

Complex support needs: 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.

Culturally relevant: A way to describe something, for example supports and services, that aim to respect and understand a culture's values, beliefs, and traditions.

Developmental disability: 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. Thinking includes reasoning, organizing, planning, making judgements, and anticipating consequences. Doing includes learning and applying various daily living skills.

Double Empathy Problem: A theory that mutual misunderstandings can arise between an Autistic and non-Autistic person due to differences in how each experience the world, express emotions and communicate. Consistent with the neurodiversity perspective, this framing views a (two-way) empathy divide to be due to cross-type differences, rather than a deficit in the social interaction and communication skills of Autistic people.

Evidence-based: The thorough, clear, and careful use of existing evidence, for example, in developing guidelines, implementing interventions, and making decisions about the types of care that an individual receives. In today's healthcare systems, Western perspectives on evidence-based medicine are often the most relied on, whereas Indigenous knowledge and evidence is often dismissed as lacking conclusive evidence or excluded entirely. There is a need to consider evidence gathered through traditional Indigenous methods as valid, and to integrate Indigenous and Western knowledge in the healthcare system to better serve Indigenous populations.[25]

Family member: A parent/guardian, grandparent, sibling, spouse, or other non-paid supporter of an Autistic person. This broad understanding of family is applied because defining "who is family" is deeply personal and cultural. The term parent is used when referring specifically to that relationship. Unless otherwise specified, a family member may be an Autistic person or a non-Autistic person.

Identity-first language: 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.

Inclusion: 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.

Indigenous: "Indigenous Peoples" is a collective name for the original Peoples of North America and their descendants. "Aboriginal Peoples" was formerly used. The Canadian Constitution recognizes three groups of Aboriginal Peoples: First Nations, Inuit, and Métis. These are three distinct Peoples with unique histories, languages, cultural practices, and spiritual beliefs.

Intellectual disability: Refers to significant impairments in both intellectual and adaptive functioning. Some Autistic people have a co-occurring intellectual disability.

Life skills: Abilities that people need to manage and adapt to daily demands and challenges. These abilities include 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: An approach to interacting with Autistic and other neurodiverse people that 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: People who face systemic disadvantages because they are not white. The term racialized is used 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: Work by Autistic people to improve their situation. This includes Autistic people expressing their own personal interests, needs, and rights, and Autistic-led initiatives that improve situations for Autistic people.

Self-determination: Acting on one’s own free will, preferences, choices, and interests; not forced to do things by other people or by circumstances.

Services: A type of support for Autistic people. Could include health, education, social services, or employment support.

Service provider: 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.

Social model of disability: A view that individual limitations (physical, sensory, intellectual, or psychological) are not the cause of disability; rather it results from a mismatch between a person and their environment. It is a societal failure to take account and be inclusive of these individual needs.

Stepped approach: In a stepped approach to assessment and diagnosis, 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.[3]

Supporters: 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.

Surveillance: Public health surveillance refers to the ongoing, systematic collection, analysis, interpretation, and dissemination of health-related data essential to planning, implementation, and evaluation of public health practice.

Trauma-informed: An understanding of how distressing life experiences or events affect people and how to provide support that is appropriate and accessible and does not cause more trauma. 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.

2SLGBTQIA+: 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 “+” is inclusive of people who identify as part of sexual and gender diverse communities, who use additional terminologies.

REFERENCES

* Although consulted, provincial and territorial government endorsement has not been sought. This Framework, including its appendices, has been prepared by the Public Health Agency of Canada in accordance with the Act, and does not necessarily reflect the views of provinces and territories.

[1] Public Health Agency of Canada. Autism: About, causes and co-occurring conditions [Internet]. Government of Canada. 2020. Available from: www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd.html

[2] Public Health Agency of Canada. Autism spectrum disorder: Highlights from the 2019 Canadian health survey on children and youth [Internet]. Government of Canada. 2022. Available from: www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-canadian-health-survey-children-youth-2019.html

[3] Canadian Academy of Health Sciences. Autism in Canada: Considerations for future public policy development—Weaving together evidence and lived experience [Internet]. Ottawa (ON): The Oversight Panel on the Assessment on Autism, CAHS; 2022. Available from: https://cahs-acss.ca/wp-content/uploads/2022/04/CAHS-Autism-in-Canada-Considerations-for-future-public-policy-development.pdf

[4] Togher K, Jay S. Disclosing an autism diagnosis: A social identity approach. Autism Res [Internet]. 2023, 16(10), 1934-1945. Available from: https://doi.org/10.1002/aur.2990

[5] Cooper K, Smith LGE, Russell A. Social identity, self-esteem, and mental health in autism. Eur. J. Soc. Psychol [Internet]. 2017, 47:844–854. Available from: https://doi.org/10.1002/ejsp.2297

[6] Hurlbutt K, Chalmers L. Adults With Autism Speak Out: Perceptions of Their Life Experiences. Focus Autism Other Dev Disabl [Internet]. 2002, 17(2):103–111. Available from: https://doi.org/10.1177/108835760201700205010

[7] MacLeod A, Lewis A, Robertson, C. 'Why should I be like bloody Rain Man?!' Navigating the autistic identity. Br. J. Spec. Educ [Internet]. 2013, 40:41-49. Available from: https://doi.org/10.1111/1467-8578.12015

[8] Botha M, Dibb B, Frost DM. "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. Disabil Soc [Internet]. 2022, 37(3):427–453. Available from: DOI: 10.1080/09687599.2020.1822782

[9] Crown-Indigenous Relations and Northern Affairs Canada. First Nations, Inuit and Métis children, youth and families [Internet]. Government of Canada. 2022. Available from: www.rcaanc-cirnac.gc.ca/eng/1662490244764/1662490318016

[10] World Health Organization. Autism [Internet]. 2023. Available from: www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

[11] United Nations. Convention On The Rights Of Persons With Disabilities (CRPD) [Internet]. New York: United Nations; 2006. Available from: https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

[12] National Collaboration Centre for Methods and Tools. Evidence-Informed Decision Making in Public Health [Internet]. 2024. Available from: Evidence-Informed Decision Making in Public Health | National Collaborating Centre for Methods and Tools (nccmt.ca)

[13] Government of Canada. Human rights-based approach [Internet]. 2017. Available from: www.international.gc.ca/world-monde/issues_development-enjeux_developpement/priorities-priorites/human_rights-droits_personne.aspx?lang=eng

[14] Government of Canada. Accessible Canada Act (S.C. 2019, c. 10) [Internet]. 2019. Available from: https://laws-lois.justice.gc.ca/eng/acts/a-0.6/page-1.html#h-1153434

[15] Women and Gender Equality Canada. What is Gender-based Analysis Plus? [Internet]. Government of Canada. 2023. Available from: https://women-gender-equality.canada.ca/en/gender-based-analysis-plus/what-gender-based-analysis-plus.html

[16] Canadian Institute for Health Information. A Path Forward: Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI [Internet]. Ottawa, ON: CIHI; 2020. Available from: www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf#:~:text=Indigenous%20data%20sovereignty%20principles%20assert%20that%20First%20Nations%2C,and%20priorities%20of%20First%20Nations%2C%20Inuit%20and%20M%C3%A9tis

[17] World Health Organization. A life Course Approach to Health [Internet]. 2000. Available from: https://apps.who.int/iris/bitstream/handle/10665/69400/WHO_NMH_HPS_00.2_eng.pdf?sequence=1

[18] Public Health Agency of Canada. A Dementia Strategy for Canada: Together We Aspire. [Internet] Government of Canada. 2019. Available from www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html#s7.1

[19] National Autism Conference. Hosted by the Public Health Agency of Canada (2022, Nov 15–Nov 16). Virtual.

[20] Employment and Social Development Canada. Canada’s Disability Inclusion Action Plan, 2022 [Internet]. Government of Canada, 2022. Available from: www.canada.ca/en/employment-social-development/programs/disability-inclusion-action-plan/action-plan-2022.html

[21] Hotez E, Shea L. Prioritizing Social Determinants of Health in Public Health Surveillance for Autism. Pediatr [Internet]. 2023, 151 (2): e2022059541. Available from: https://doi.org/10.1542/peds.2022-059541

[22] World Health Organization. Comprehensive Mental Health Action Plan 2013-2030. 2021 [Internet]. Available from: www.who.int/publications/i/item/9789240031029

[23] Ally S, Boyd K, Abells D, Amaria K, Hamdani Y, Loh A, Niel U, Sacks S, Shea S, Sullivan WF, Hennen B. Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective. Can Fam Physician [Internet]. 2018, 64(Supplement_ 2):S37-S43. Available from: https://pubmed.ncbi.nlm.nih.gov/29650743

[24] Mandell DS. A house is not a home: The great residential divide in autism care. Autism [Internet]. 2017, 21(7):810-811. Available from: https://doi.org/10.1177/1362361317722101

[25] Rogers BJ, Swift K, van der Woerd K, Auger M, Halseth R, Atkinson D, Vitalis S, Wood S, Bedard A. At the interface: Indigenous health practitioners and evidence-based practice [Internet]. Prince George, BC: National Collaborating Centre for Aboriginal Health, 2019. Available from: www.nccih.ca/docs/context/RPT-At-the-Interface-Halseth-EN.pdf