

A close-up photograph of several hands of different skin tones working together to assemble white puzzle pieces. The hands are positioned around the pieces, with some fingers holding them steady and others placing them into place. The background is a soft, out-of-focus blue. A large, dark red diagonal shape is overlaid on the left side of the image, containing the text 'The Way Forward'.

Autism Action Plan

2019-2022

The Way Forward

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Introduction

Autism Spectrum Disorder (ASD) is a life-long neurodevelopmental condition that affects how individuals relate to people, situations and their environment. ASD is considered a spectrum as the individual impact varies from person to person. Each person living with ASD has unique strengths and needs, as the disorder can impact individuals in a variety of ways. However, the core deficits of ASD include difficulties with communication, social interaction and adaptive behaviour functioning, all of which appear in early childhood.

Vision

To support individuals living with ASD and their caregivers to live full and rewarding lives.

According to the 2018 Public Health Agency of Canada **Report on the National Autism Spectrum Disorder Surveillance System**, approximately one in 57 individuals in Newfoundland and Labrador are living with ASD. Although not all have support needs, the prevalence and spectrum of strengths and needs of the condition support the necessity for a streamlined and responsive approach to providing a comprehensive array of treatments, supports and services.

ASD prevalence among 5–17 year olds
in Newfoundland and Labrador, 2015



Number of Children Identified with ASD
1 in 57

ASD prevalence among 5–17 year olds
in Canada, 2015



Number of Children Identified with ASD
1 in 66

The Government of Newfoundland and Labrador recognizes that there is no one way to address the diverse needs of individuals living with ASD and continues to work to ensure there are evidence-based, comprehensive approaches to support individualized needs across the life span.

The introduction of a three-year Autism Action Plan (Plan) will enhance existing treatments, supports and services for individuals living with ASD and their loved ones, by integrating a more holistic and person-centred approach to service delivery.

This Plan outlines government's commitment to improve the lives of individuals and families living with ASD. The actions outlined in this document are consistent with **The Way Forward: A vision of sustainability and growth in Newfoundland and Labrador**, focusing on delivering better services, greater efficiency and better outcomes.

Background

The United Nations **Convention on the Rights of Persons with Disabilities** (Convention) purpose is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

The Plan aligns with the overarching principles contained within the Convention. It also aligns with the **Provincial Strategy for the Inclusion of Persons with Disabilities, Access. Inclusion. Equality.**

The Plan is grounded in the best evidence currently available for the identification and diagnosis of ASD, and the interventions, services and supports for individuals living with ASD. It seeks to assist individuals, parents, caregivers, health professionals, education professionals, policy makers, community agencies, and ASD specialists in improving the health, educational and social outcomes for individuals living with ASD.

The Plan addresses all aspects of living with ASD, including awareness, diagnosis and assessment, educational programming and other interventions and services that provide support for individuals and their families. It is based on principles of person-centered planning which is essential to ensure treatments, supports and services are based on the specific strengths and needs of each individual.

The actions outlined in the Plan are the result of consultations with individuals living with ASD, family members, health and education professionals, community providers, government agencies and leading researchers in ASD. Implementation creates further opportunities for engagement and networking within and among government departments, community agencies, municipalities and Indigenous governments and organizations.

The Department of Health and Community Services will lead the implementation of the Plan in collaboration with other government departments, Indigenous governments and organizations, regional health authorities, school districts and community groups.

In an effort to deliver on a sound Autism Action Plan for the province, the Government of Newfoundland and Labrador has partnered with world leaders in ASD treatments, and has invested in JASPER (Joint Attention Symbolic Play Engagement Regulation) training. JASPER is an ASD therapy that has shown significant, long-term positive results in children. Clinicians in this province have received extensive training to ensure they can provide JASPER therapy to children.



We have partnered with the National Autism Spectrum Disorder Surveillance System, which collects data to examine and report on prevalence, characteristics and related outcomes. Newfoundland and Labrador is also a member of the Atlantic Canadian Autism in Education Partnership, established to develop a regional approach to ASD training for educators across Atlantic Canada.

Leading up to the development of the Autism Action Plan, there have been multiple stakeholder consultations, and reviews of reports and research studies relevant to individuals living with ASD. As a result, many ideas and concepts for improving ASD services have been proposed and incorporated.

Recent examples include: key stakeholder engagements in the development of **Now is the Time: Premier's Task Force for Improved Educational Outcomes, Towards Recovery: A Vision for a Renewed Mental Health and Addictions System**, the Autism Society Newfoundland and Labrador (ASNL) Needs Assessment (2015), and most recently, the Deloitte Review of ASNL (2018), which held focus groups on the current landscape for ASD services and supports in Newfoundland and Labrador. These consultations repeatedly identified similar systemic issues that need to be addressed through targeted government initiatives.

Governance

A whole-of-government approach, along with a significant combined effort from regional health authorities, Indigenous governments and organizations, school districts, health professionals, community agencies, and individuals and families with lived experience, is necessary to transform the way ASD supports and services are delivered. In recognition of the need to co-ordinate services across the lifespan, and support a cross-departmental collaborative approach, an Autism Action Council (the Council) was created. Members of the Council include: individuals with lived experience, representatives from ASNL, the Newfoundland and Labrador Association for Community Living, health and education professionals, as well as representatives from the Departments of Health and Community Services, Education and Early Childhood Development, Children, Seniors and Social Development, Justice and Public Safety and Advanced Education, Skills and Labour.

The Department of Health and Community Services and the Autism Action Council will oversee the implementation of the Autism Action Plan. The Council will also provide advice to the Minister of Health and Community Services on matters related to ASD.

Implementation

The Autism Action Plan has been developed to support sustainable, systemic changes. Implementation will occur in three phases. The timeline for each action was determined by considering the level of complexity, whether the work has already begun, the urgency of implementation, and system readiness for change.

Actions will be completed as follows:

- **Short-term:** 19 actions to be substantially completed in year one (March 2020)
- **Medium-term:** 22 actions to be substantially completed in year two (March 2021)
- **Long-term:** five actions to be substantially completed in year three (March 2022).

Appendix A includes a list of the short, medium, and long-term actions and responsibility for leading their implementation.

Six Focus Areas

1. Awareness, Acceptance, Diagnosis and Assessment of ASD

Raising ASD awareness across government departments, health authorities, school districts, municipalities and the general public, will bring further understanding of the features of ASD. This will enable individuals living with ASD to lead fuller, richer lives in communities where they are understood and accepted. The anticipated outcomes of increasing awareness are the promotion of positive attitudes about ASD, assistance with earlier diagnosis and increased support for an individual's right to be a contributing member of society.

Research demonstrates improved cognitive and functional outcomes for children who are diagnosed at younger ages and who subsequently receive appropriate early intervention and supports. Raising awareness will increase the likelihood of early identification of ASD, leading to earlier diagnosis and intervention.

Implementation of focus area number one will result in:

- 1.1 Increased public awareness of the core features of ASD.
- 1.2 Increased ASD awareness by delivering sessions to frontline staff who provide services or could potentially provide services to individuals living with ASD.
- 1.3 Routine monitoring for early signs of ASD for siblings of children diagnosed with ASD through surveillance by health professionals.
- 1.4 Increased access to supportive counselling and support groups for families living with ASD.
- 1.5 Availability of a toolkit for individuals and families which provides critical information upon diagnosis.
- 1.6 Improved data collection across the lifespan on the number of individuals living with ASD availing of services and supports through the regional health authorities and in the education system.
- 1.7 Reduced wait times for ASD diagnosis by aligning diagnostic procedures with national standards.
- 1.8 More diagnostic clinics for children and adults within each regional health authority.
- 1.9 New assessment tools targeting the core features of ASD for children and youth to assist with support planning and program development.
- 1.10 New standardized assessment tools for community supports that target individualized support needs for adults living with developmental disabilities including ASD.
- 1.11 Enhanced diagnostic summary reports that outline individual strengths and needs, ASD symptoms, recommendations for intervention and information on support services and materials for individuals receiving the diagnosis of ASD.

2. Support for Individuals, Families and Caregivers Living with ASD

ASD has been described as a 'hidden disability' that may affect many aspects of a person's day-to-day life. Some people living with ASD have significant support needs while others require little or no support. Parents, partners, siblings and caregivers are key people in the lives of a person living with ASD. Those who live with, love and care for individuals living with ASD may also need support to ensure they experience social inclusion to the degree that others may sometimes take for granted.

Individuals, families and caregivers require clinically-sound information from appropriately-qualified professionals, to assist them in making their decisions. They require timely information about assessments, support plans, individualized education plans and available resources. Family and caregiver education is associated with improved outcomes and reduced stress for individuals and their families. In addition, the use of effective teaching methods for individuals with ASD results in more adaptive skills, giving family members increased access to social options and more quality time for one another.

Information and supports will be made available to parents, families and caregivers:

- Information on evidence-based ASD treatments and supports;
- Details about specific teaching strategies to help acquire new skills and behaviours;
- Information on understanding how ASD influences learning and behaviour; and,
- Help in coping with the emotional stress that may result from having a family member who is living with ASD.



A co-ordinated approach to planning and implementing services is necessary to meet the identified needs of an individual living with ASD by establishing linkages and ensuring integration of multiple services.

Creation of a provincial autism services program for children and youth up to age 21, and a supporting abilities program for adults, will ensure seamless supports across the lifespan of persons living with ASD.

Implementation of focus area number two will result in:

- 2.1 Revision of the Supportive Services for Children Program to expand eligibility based on functional need for supports, and include individualized case management for children and youth with complex needs.
- 2.2 Expansion of JASPER treatment to include parent/caregiver mediated training.
- 2.3 Access to information about ASD specifically designed for siblings.
- 2.4 Seamless service provision for children and youth living with ASD up to age 21, through the development of a new Provincial Autism Services Program.
- 2.5 Standardized intake for the Provincial Autism Services Program with system navigation assistance for individuals newly diagnosed.
- 2.6 Education and training in Applied Behaviour Analysis (ABA) for parents and caregivers of children and youth availing of the Provincial Autism Services Program.
- 2.7 Individualized person-centered support plans that are co-developed by individuals, parents and caregivers, educational, and health professionals.
- 2.8 Seamless service provision for adults with developmental disabilities through the creation of a new Supporting Abilities Program.
- 2.9. Eligibility for Community Support Services based on functional need for support rather than intellectual disability – eliminating the IQ70 criteria.

3. Evidence-Based Treatment and Management of ASD: Right Service, Right Place, Right Time

Treatments for ASD should match individualized needs and be grounded in strong evidence of effectiveness. Decisions about the type and intensity of evidence-based interventions should be informed by a skilled team led by clinical experts who will consider an individual's strengths, developmental stage, individual characteristics, treatment goals and family preferences. Spontaneous communication, socialization and play goals must be a priority for all children and youth.

One of the core features of ASD is stereotypical behaviours, which often characterize the disorder. Long-term problems in learning and functioning may arise if behaviours that are ritualistic or obsessive are not addressed. Proactive interventions that focus on skill teaching can reduce the potential of developing behavioural difficulties.

For adults living with ASD, evidence supports the use of behavioural interventions and cognitive behavioural therapy. These interventions will be the focus of treatment options for adults living with ASD.

Implementation of focus area number three will result in:

- 1.1 Evidence-based interventions at home, in the community, in regulated child care, and in school, through the Provincial Autism Services Program. These interventions include, but are not limited to, the JASPER program for children up to age eight, and supporting children beyond grade three through the ABA program for children and youth up to age 21.
- 1.2 Improved access to cognitive behavioural therapy and other evidence-based interventions for children and adults living with ASD and experiencing mental health concerns.
- 1.3 Improved access to developmental health services such as speech language pathology and occupational therapy.
- 1.4 Development and implementation of a health and community services system-wide framework for increasing positive and proactive interventions, minimizing the need for restrictive interventions.
- 1.5 Enhanced protection and support for individuals living with ASD who become part of the criminal justice system.
- 1.6 Revised guidelines for criminal justice system professionals on considerations which may be required when interacting with individuals living with ASD.
- 1.7 Improved victim services to ensure the needs of individuals living with ASD are considered.



4. Education for Children and Youth Living with ASD

All children have the right to a quality education within a safe, caring and inclusive learning environment. Children living with ASD enter early-years programs and the K-12 system with a variety of strengths and learning needs. These factors must be considered when making decisions regarding approaches to teaching and learning.

Early childhood educators and day school staff must be provided with professional learning opportunities to improve their knowledge and understanding of:

- Children and youth living with ASD;
- Evidence-based interventions for children and youth living with ASD; and,
- Appropriate interventions and strategies within early-years programs and school settings for children and youth living with ASD.

Implementation of focus area number four will result in:

- 4.1 Increased access to interventions for children and youth living with ASD to support literacy, numeracy, and social and emotional learning.
- 4.2 Increased knowledge and use of assistive technology to support the communication needs of children and youth living with ASD.
- 4.3 Support for the social inclusion of children and youth living with ASD using appropriate peer-mediated techniques.
- 4.4 Increased access to programming for children and youth living with ASD specific to the core features of ASD.
- 4.5 Improved transition planning at key points for children and youth living with ASD.
- 4.6 Disability awareness and ASD-specific training for professionals providing early-years programs.



5. Living with ASD in the Community

Careful planning is necessary to minimize the anxiety that individuals living with ASD and their families often experience when transitioning to a new learning environment. Planning should be done well in advance of transition as part of a person-centred approach for individuals who require supports.

Lifelong learning should be an option for all people, regardless of ability. Many individuals living with ASD have the potential to have successful experiences in post-secondary education – a potential that should be explored and supported.

Work is considered a primary activity for adults in society, and it is often through work that individuals develop a sense of meaningful purpose. Through careful attention and planning, adults living with ASD can effectively secure and maintain meaningful work.

Recreation is an effective means for promoting independent functioning and life skills, enhancing social inclusion, encouraging education and work, and improving quality of life. Planning for meaningful daily routines and regular recreational activities are important for supporting an individual living with ASD to participate and enjoy a full life.

Implementation of focus area number five will result in:

- 5.1 Increased opportunities for individuals living with ASD to attain skills and qualifications through access to appropriate training programs, social enterprise and youth employment programs.
- 5.2 Increased partnerships with the private sector, not-for-profit and co-operative organizations to encourage social enterprise opportunities, and to support, fund and mentor entrepreneurship for individuals living with ASD.
- 5.3 Partnerships between the Government of Newfoundland and Labrador and community agencies, municipalities, Indigenous governments and organizations, and the private sector, to increase awareness and to develop a range of supports, including life skills networking groups and leisure groups for adults with ASD.
- 5.4 Enhanced promotion of existing programs and employment supports for individuals living with ASD.



- 5.5 Exploration of initiatives aimed at improving transitions to post-secondary.
- 5.6 Increased residential and other supported living options for individuals with significant complex needs.
- 5.7 Enhanced support planning processes which include leisure activities and social skill development.
- 5.8 Increased ASD-specific accessibility initiatives including transportation, visual supports, and communications.

6. Professional Learning and Development in ASD

Those who support individuals living with ASD can help improve outcomes if they have effective professional learning opportunities. All health professionals and educators need ASD specific training and development to be effective in providing support.

Implementation of focus area number six will result in:

- 6.1 Clinical training in evidence-based practices for ASD for all professionals working within the Provincial Autism Services Program, the Supporting Abilities Program and Mental Health and Addiction Services.
- 6.2 Increased professional development opportunities for home therapists and behavioural aides who provide support for individuals living with ASD.
- 6.3 ASD-specific professional development opportunities for primary health care clinicians.
- 6.4 Increased access to ASD-specific awareness sessions for post-secondary students in health, education and social sectors.
- 6.5 A network for professionals providing support to individuals living with ASD to share information across jurisdictions on provincial initiatives and evidence-based research.



Accountability and Performance Monitoring

1. Performance monitoring and accountability are essential to ensure these outcomes are achieved in a timely and effective manner. The progress of the Autism Action Plan will be monitored through the Autism Action Council.
2. An evaluation plan that outlines deliverables and desired outcomes will be developed by the Department of Health and Community Services, in consultation with the Autism Action Council, and will form the basis of annual progress reports on the delivery of the Autism Action Plan. Due to the evolving nature of research and evidence in ASD treatments and best practice in supports, this Plan will be monitored annually.
3. To ensure the Plan continues to align with the most current evidence and research, an evaluation will occur after year two, and the Action Plan will be updated accordingly.

Appendix A

Implementation Timelines

Short-Term Actions (by March 2020)

Action	Responsibility
1.5 Availability of a toolkit for individuals and families which provides critical information upon diagnosis	Health and Community Services (HCS), Regional Health Authorities (RHAs), Community Agencies
1.6 Improved data collection across the lifespan on the number of individuals living with ASD availing of services and supports through the regional health authorities and in school	HCS, RHAs, Newfoundland and Labrador Center for Health Information (NLCHI), Education and Early Childhood Development (EECD), School Districts
1.7 Reduced wait times for ASD diagnosis by aligning diagnostic procedures with national standards	HCS, RHAs
1.8 More diagnostic clinics for children and adults within each regional health authority	HCS, RHAs
1.11 Enhanced diagnostic summary reports that outline individual strengths and needs, ASD symptoms, recommendations for intervention and information on support services and materials for individuals receiving the diagnosis of ASD	HCS, RHAs
2.1 Revision of the Supportive Services for Children Program to expand eligibility based on functional need for supports and include individualized case management for children and youth with complex needs	HCS, RHAs
2.2 Expansion of JASPER treatment to include parent/caregiver mediated training	HCS, RHAs
2.3 Access to information about ASD specifically designed for siblings	HCS, Community Agencies
3.2 Improved access to cognitive behavioural therapy and other evidence-based interventions for children and adults living with ASD and experiencing mental health concerns	HCS, RHAs
3.5 Enhanced protection and support for individuals living with ASD who come into contact with the criminal justice system	HCS, Justice and Public Safety (JPS)
3.6 Revised guidelines for criminal justice system professionals on considerations which may be required when interacting with individuals living with ASD	HCS, JPS
3.7 Improved victim services to ensure the needs of individuals living with ASD are considered	HCS, JPS

4.3	Support for the social inclusion of children and youth living with ASD using appropriate peer-mediated techniques	EECD, School Districts
4.4	Increased access to programming for children and youth living with ASD specific to the core features of ASD	EECD, School Districts
5.3	Partnerships between the Government of Newfoundland and Labrador and community agencies, municipalities, Indigenous governments and organizations and the private sector to increase awareness and to develop a range of supports, including life skills networking groups and leisure groups for adults with ASD	Children Seniors Social Development (CSSD), HCS, Indigenous Governments and Organizations, Community Agencies, Municipalities, Private Sector
5.4	Enhanced promotion of existing programs and employment supports for individuals living with ASD	Advanced Education, Skills and Labour (AESL)
5.5	Exploration of initiatives aimed at improving transitions to post-secondary	AESL
5.7	Enhanced support planning processes which include leisure activities and social skill development	HCS, RHAs
6.2	Increased professional development opportunities for home therapists and behavioral aides who provide support for individuals living with ASD	HCS, RHAs

Medium-Term Actions (by March 2021)

Action	Responsibility
1.1 Increased public awareness of the core features of ASD	CSSD
1.3 Routine monitoring for early signs of ASD for siblings of children diagnosed with ASD through surveillance by health professionals	HCS, RHAs
1.4 Increased access to supportive counselling and support groups for families living with ASD	HCS, RHAs
1.9 New assessment tools targeting the core features of ASD for children and youth to assist with support planning and program development	HCS, RHAs
1.10 New standardized assessment tools for community supports that target individualized support needs for adults living with developmental disabilities including ASD	HCS, RHAs
2.4 Seamless service provision for children and youth living with ASD up to age 21 through the development of a new Provincial Autism Services Program	HCS, RHAs, EECD, School Districts
2.5 Standardized intake for the Provincial Autism Services Program with system navigation assistance for newly diagnosed individuals newly diagnosed with ASD	HCS, RHAs
2.6 Education and training in Applied Behaviour Analysis (ABA) for parents and caregivers of children and youth availing of the Provincial Autism Services Program	HCS, RHAs
2.7 Individualized person-centered support plans that are co-developed by individuals, parents and caregivers, educational, and health professionals	HCS, EECD, CSSD, JPS
2.9 Eligibility for Community Support Services based on functional need for support rather than intellectual disability – eliminating the IQ70 criteria	HCS, RHAs
3.1 Evidence-based interventions at home, in the community, in regulated child care, and in school through the Provincial Autism Services Program. These interventions include, but are not limited to, the JASPER program for children up to age eight, and supporting children beyond Grade three through the ABA program for children and youth up to age 21	HCS, RHAs, EECD, School Districts
3.3 Improved access to developmental health services such as speech language pathology and occupational therapy	HCS, RHAs
4.2 Increased knowledge and use of assistive technology to support the communication needs of children and youth living with ASD	EECD, School Districts
4.5 Improved transition planning at key points for children and youth living with ASD	EECD, School Districts
4.6 Disability awareness and ASD-specific training for professionals providing early-years programs	EECD, Regulated child care

5.1	Increased opportunities for individuals living with ASD to attain skills and qualifications through access to appropriate training programs, social enterprise and youth employment programs	AESL
5.2	Increased partnerships with the private sector, not-for-profit and co-operative organizations to encourage social enterprise opportunities, and to support, fund and mentor entrepreneurship for individuals living with ASD	Tourism, Culture, Industry and Innovation (TCII), AESL, Private Sector, Not-for-profit and Co-operative organizations
5.6	Increased residential and other supported living options for individuals with significant complex needs	HCS, RHAs, AESL
5.8	Increased ASD-specific accessibility initiatives including transportation, visual supports, and communications	CSSD, HCS
6.1	Clinical training in evidence-based practices for ASD for all professionals working within the Provincial Autism Services Program, the Supporting Abilities Program and Mental Health and Addiction Services	HCS
6.4	Increased access to ASD-specific awareness sessions for post-secondary students in health, education and social sectors	HCS, Post-secondary Institutions
6.5	A network for professionals providing support to individuals living with ASD to share information across jurisdictions on provincial initiatives and evidence-based research	HCS, EECD, AESL, JPS, CSSD

Long-Term Actions (by March 2022)

Action	Responsibility
1.2 Increased ASD awareness by delivering sessions to frontline staff who provide services or could potentially provide services to individuals living with ASD	HCS, RHAs
2.8 Seamless service provision for adults with developmental disabilities through the creation of a new Supporting Abilities Program	HCS, RHAs
3.4 Development and implementation of a health and community services system-wide framework for increasing positive and proactive interventions, minimizing the need for restrictive interventions	HCS
4.1 Increased access to interventions for children and youth living with ASD to support literacy, numeracy, and social emotional learning	EECD, School Districts
6.3 ASD-specific professional development opportunities for primary health care clinicians	HCS

This document is available in alternative formats.

Health and Community Services
Government of Newfoundland and Labrador

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