

ANNUAL REPORT

AUTISM COORDINATION ACT
2019-2020

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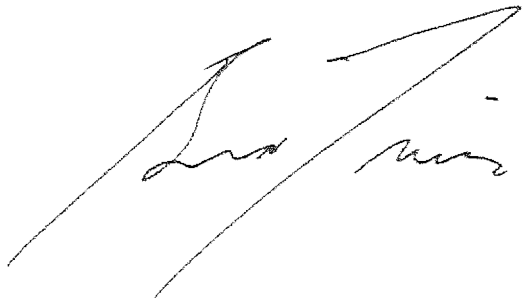
June 23, 2020

The Honourable Antoinette Perry
Lieutenant Governor
Province of Prince Edward Island

May it Please Your Honour:

I have the honour to submit the first Annual Report of the administration of the *Autism Coordination Act*, R.S.P.E.I. 2018, Cap. A-24.1 pursuant to section 7 of the *Act*.

Respectfully submitted,

A handwritten signature in black ink, appearing to read 'Brad Trivers', written over a large, light-colored diagonal stroke that spans across the signature area.

Brad Trivers
Minister of Education and Lifelong Learning

Minister's Message

Strategic Highlights

This report highlights the first full year of the implementation of the *Autism Coordination Act*.

Over the last year, the Autism Coordination Committee was formed and an Autism Coordination Project Lead was assigned to support the *Act* and the Committee itself. An Autism Services working group helped develop a comprehensive work plan; identified areas of improvement and developed a scan of all government and community Autism Spectrum Disorder programs and services available on Prince Edward Island.

Consultations are underway to validate this scan, identify sub-committees, and explore opportunities for improvement within Autism services.



Looking Ahead

In the coming year, the government will continue to seek ways to improve coordination of services and focus on supporting Islanders with Autism Spectrum Disorder and their families.

As Minister responsible for implementation of the Autism Coordination Act, I am committed to exploring ways to improve coordination of services and for providing a continuum of services that aim to maximize inclusion. I am grateful to the valuable work done by the Autism Coordination Committee, community and governmental Autism service providers, and most notably, the tireless efforts of the Autism community.

By continuing our collaboration, we can help ensure those with Autism Spectrum Disorder and their families thrive on Prince Edward Island.

Brad Trivers

A handwritten signature in black ink, appearing to read 'Brad Trivers', written over a large, stylized graphic element consisting of several overlapping diagonal lines.

Minister of Education and Lifelong Learning

Autism Coordination Act Overview

Autism Spectrum Disorder (ASD) is a neurobehavioral disorder that includes impairments in social communication skills combined with the occurrence of rigid and repetitive behaviors.

According to 2003-2015 PEI data (as report by PHAC in 2018) the prevalence of ASD in PEI is 16.9 per 1000 (1 in 59 or 1.7%) – the second highest in Canada. Data shows, among 5-14 year olds, that ASD prevalence has had a large increase from 5.0 per 1000 to 17.7 per 1000 over that same twelve-year period.

Mandate, Vision and Mission

The *Autism Coordination Act (Act)* supports improved coordination of government and community Autism services. It is a Private Members Bill, which received Assent on December 5, 2018.

In July 2019, as required by the Act, Executive Council designated the Education and Lifelong Learning Minister to be responsible for the Act and the Social Policy Deputy Ministers' Committee to be the membership of the Autism Coordinating Committee (Committee).

As noted in the *Act*, the objects and purposes of the Committee are:

- (a) to facilitate and coordinate the planning, development and delivery of services and programs for people with autism spectrum disorders;
- (b) to heighten awareness of the needs and aspirations of people with autism spectrum disorders;
- (c) to encourage persons and groups providing voluntary and professional services to people with autism spectrum disorders;
- (d) to consult with stakeholders on matters that affect people with autism spectrum disorders, including legislation, regulations, policies or programs; and
- (e) to be responsive to the needs and concerns of people with autism spectrum disorders and their caregivers by
 - (i) seeking feedback and advice regarding the improvement of autism programs and services from persons and groups interested in providing voluntary services to people with autism spectrum disorders,
 - (ii) reviewing existing programs and services, and
 - (iii) making recommendations as to how those programs and services may be made more responsive to the needs and aspirations of people with autism spectrum disorders.

The duties of the Committee are to initiate and coordinate government work

- (a) to undertake research to identify and study matters with respect to people with autism spectrum disorders and make recommendations based on the findings of the research;
- (b) to collect and disseminate information to the public with respect to people with autism spectrum disorders;
- (c) to publish reports, studies and surveys with respect to people with autism spectrum disorders;

- (d) to develop legislation, policies or programs to achieve the objects of this *Act*;
- (e) to collaborate with other governments and with community-based organizations on the development and delivery of policies and programs respecting people with autism spectrum disorders;
- (f) to deliver programs and navigation supports for people with autism spectrum disorders or for the benefit of people diagnosed with autism spectrum disorders;
- (g) to review or participate in the review of programs and services delivered to or on behalf of people with autism spectrum disorders by other government departments;
- (h) to promote awareness within the government of issues experienced by people with autism spectrum disorders; and
- (i) to support programs and activities that recognize the contributions of people with autism spectrum disorders to the community.

In carrying out the duties of the Committee, the Committee shall work closely with government agencies and boards, Crown corporations, physical and mental health professionals, registered charities and non-profit organizations.

The Committee may establish the sub-committees that it considers appropriate for the carrying out of its objects and purposes and may delegate to those sub-committees any of its powers, duties or functions.

The Autism Coordinating Committee

The Autism Coordinating Committee, established in July 2019, plays a critical role in the implementation of the *Act*. The Committee has seven members: Deputy Minister of Education and Lifelong Learning; Deputy Minister of Health and Wellness; Deputy Minister of Social Development and Housing; Deputy Minister of Justice and Public Safety, Assistant Deputy Minister of Health and Wellness; Secretary to Treasury Board; and Clerk Assistant of Executive Council Office. The members for 2019-2020 were as follows:

Bethany MacLeod	Committee Chair Deputy Minister, Department of Education and Lifelong Learning
Mark Spidel	Deputy Minister, Department of Health and Wellness
David Keedwell	Deputy Minister, Department of Social Development and Housing
Erin Mitchell/Sherry Gillis/	
Karen MacDonald	Deputy Minister, Department of Justice and Public Safety
Deborah Bradley	Assistant Deputy Minister, Department of Health and Wellness
Cindy Harris	Secretary to Treasury Board
Pamela Trainor	Clerk Assistant to the Executive Council

During the reporting period (July 2019-July 2020), the *Autism Coordination Act* was on the agenda of seven separate Social Policy Deputy Ministers' meetings prior to the formalized meetings of the Autism Coordinating Committee. The Autism Coordinating Committee met on three occasions since forming: February 25, May 19 and June 16, 2020.

In accordance with its mandate under the *Act*, the Committee shall provide updates and report at least annually to the Lieutenant Governor in Council.

Autism Services Working Group

In February 2019, an interim working group was formed to begin work to support the *Act*. The working group had representatives from three departments and both educational authorities (Public Schools Branch and Commission scolaire de langue française).

The working group identified an environmental scan of government Autism programs and services as an activity that could inform initial work to support the *Act*.

The Autism Services Working Group representatives met nine times between February 2019 and December 2019. The working group also met with the Committee on several occasions to provide an outline of the work completed to date, outcomes of the internal scan of programs and services, helped identify future priorities and directions and discussed options for resourcing the *Act*.

Members of the Working Group were as follows:

Danielle Rochon	Early Years Autism Coordinator Department of Education and Lifelong Learning
Dr. Nadine DeWolfe	Psychologist, Supervisor of Pediatric Psychology Services, Health PEI
Lisa Marmen	Student Services Coordinator Commission scolaire de langue française
Susan Chappell	Provincial Manager of Clinical Supports, Social Programs Department of Social Development and Housing
Terri MacAdam	Director of Student Services Public Schools Branch

Autism Coordination Project Lead

The Autism Coordinating Committee identified the need to have a dedicated position to support the *Act* and the Committee itself. This position is the project lead assigned to support cross-departmental efforts to improve coordination of programs and services for Islanders with Autism Spectrum Disorder (ASD). It is the lead resource to the Autism Coordinating Committee, established under the *Autism Coordination Act*.

The Autism Coordination Project Lead reports administratively to the Executive Director of Educational Services within the Department of Education and Lifelong Learning and strategically to the Autism Coordinating Committee. The work completed by this position is guided by a comprehensive work plan mutually developed and approved by the Autism Services Working Group and the Autism Coordinating Committee. The Project Lead began work on February 10, 2020.

Organizational Structure

The Minister of Education and Lifelong Learning and the Autism Coordinating Committee administer the *Autism Coordination Act*. Other members and groups listed below provide information, advice and expertise to help implement the goals and objectives of the *Act*.

The Minister responsible for the Act

The Minister is responsible for the administration of the *Act* and its regulations. In July 2019, as required by the *Act*, Executive Council designated the Education and Lifelong Learning Minister to be responsible for the *Act*.

As per the *Act*: The Minister of Education and Lifelong Learning is responsible for tabling an annual report in the Legislative Assembly, if the Legislative Assembly is sitting when the report is made, or file the annual report with the Clerk of the Legislative Assembly, if the Legislative Assembly is not sitting when the report is made.

The Autism Coordinating Committee

The Autism Coordinating Committee is comprised of seven members: Deputy Minister of Education and Lifelong Learning; Deputy Minister of Health and Wellness; Deputy Minister of Social Development and Housing; Deputy Minister of Justice and Public Safety; Assistant Deputy Minister of Health and Wellness; Secretary to Treasury Board; and Clerk Assistant to the Executive Council.

The Autism Services Working Group

The Working Group is comprised of five members representing three government departments and both educational authorities (Public Schools Branch and Commission scolaire de langue française). The Working Group works with the Autism Coordination Project Lead and provides support and advice to the Committee.

Autism Coordination Project Lead

The Autism Coordination Project Lead is the lead resource to the Autism Coordinating Committee. This position reports administratively to the Executive Director of Educational Services within the Department of Education and Lifelong Learning and strategically to the Autism Coordinating Committee. The work completed by this position is guided by a comprehensive work plan mutually developed and approved by the Autism Services Working Group and the Autism Coordinating Committee.

Autism Coordination Sub-Committee members

As per the *Act*, The Committee may establish sub-committees that it considers appropriate for the carrying out of its objects and purposes. Members of the sub-committees will include government and community stakeholders and those with lived experiences.

See Appendix: Organizational Structure of the *Autism Coordination Act*.

Highlights and Accomplishments

The following objects and purposes are outlined in the *Autism Coordination Act*. Included below are specific actions and initiatives from the past year that are directly supporting the *Act*'s implementation.

Facilitate and Coordinate the planning, development and delivery of services and programs for people with autism spectrum disorders

- **Formation of the Autism Coordinating Committee**

In July 2019, Executive Council designated the Social Policy Deputy Ministers' Committee to be the membership of the Autism Coordinating Committee (Committee). Since then, the *Autism Coordination Act* has been on the agenda of 10 meetings (7 Social Policy Deputy Ministers' meetings and 3 Autism Coordinating Committee meetings). The dedicated committee meetings allotted for Autism services help in coordination of services.

- **Formation of the Autism Services Working Group and the development of a provincial scan of Autism services**

From February 2019 until December 2019, the working group met monthly to discuss government Autism Spectrum Disorder services and developed a draft scan of programs and services. This scan provided initial suggestions and identified opportunities for program and service delivery improvements. The working group also identified overarching themes, which were presented to the Committee.

The validation of the scan of programs and services is still ongoing. The Project Lead is meeting with other government and community service providers to continue to validate the scan.

- **New staffing to support the *Act***

As of February 10, 2020, there has been a full time employee (Autism Coordination Project Lead) dedicated to support the *Act* and the Committee itself. The Committee, along with members of the working group, developed and approved Terms of Reference, developed a job

description and an extensive work plan. The project lead will coordinate and facilitate discussions between the various government departments providing Autism services and with community stakeholders to help ensure the objectives of the *Act* are implemented.

- **Launch of 211 PEI**

211 PEI is a free information and referral service that launched in the spring of 2020. It is available to support all Islanders and helps individuals and families make the connection to community, government and non-urgent health services. Members of the working group and the Project Lead met with staff of 211 PEI to discuss how the service could help individuals and families navigate Autism Spectrum Disorder programs and services across PEI. 211 PEI is available 24/7/365 through its website and help line and through email on weekdays between 8:00am – 8:00pm.

- **Increased inter/intra governmental communication of Autism services and programs**

Monthly meetings between working group members, Autism Coordinating Committee members and the Project lead has helped increase communications and information sharing between and within departments.

Consult with stakeholders on matters that affect people with autism spectrum disorders

- Autism Services Working Group and the Autism Coordination Project Lead met with numerous stakeholders over the last year. These meetings included both government and community stakeholders such as staff within Department of Health and Wellness; Department of Education and Lifelong Learning; Department of Social Development and Housing; Department of Justice and Public Safety; Health PEI; Skills PEI; Holland College; Autism Society; Stars for Life; and individuals and families with lived experiences. These were opportunities to make connections, seek feedback, identify gaps in services, gather ideas for improvement, enhance communication between stakeholders, and to develop a pathway for future communications/processes.
- Through consultation with community and government stakeholders, there was a preliminary identification of sub-committees. These sub-committees will provide valuable input on priority items.

Promote and provide Autism Spectrum Disorder training and education

- Over the last year, Public Schools Branch Autism Consultants have been presenting strategies and program supports to Canadian Union for Public Employees and Prince Edward Island Teachers' Federation staff to increase capacity.
- Over 80 staff (teachers, administrators, educational assistants, speech language pathologists and school psychologists) have enrolled in an online training program, *ASD & Behavioural Interventions*. 123 staff completed the online training in the first semester of the 2019-2020 school year.
- AccessAbility Supports staff within the Department of Social Development and Housing received a certificate in Collaborative Care Management.

Future Direction and Priorities

The *Autism Coordination Act* supports improved coordination of government and community Autism services across the entire lifespan of an individual.

The Autism Coordinating Committee, with input from the working group, other government representatives and community stakeholders have identified the following overarching themes that will help guide future work. Over the next year, priority items will include:

1. Identify resources to support the Autism Coordination Act

Staffing and resources are needed to complete a consultative process (government, community, family) to add/expand/confirm suggested themes and opportunities and to complete the work outlined within the *Act*. There needs to be an analysis and/or creation of a coordinated process/pathway, which is family-centered, from the identification of concern, diagnosis, to when accessing services.

2. Support families to navigate and access government/community programs, resources, and supports

- Continue validating the scan of programs and services so that all Autism resources are identified. This scan will identify services and programs across the lifespan (early years, K-12, post-secondary, workforce, adults and senior services) and across government and community service providers as well. This scan will help identify where there are gaps and overlaps in services.
- Develop a Communications Strategy to help address the following:
 - Raise awareness of existing programs and services
 - Simplify navigation process for individuals and families who are trying to access programs, services and supports
 - Increase public awareness of Autism Spectrum Disorder
 - Promote inclusion and diversity
- Identify Early-intervention supports for individuals and families

3. Support Inter/Intra-Departmental and Community Collaboration

The ongoing dialogue with the community is a critical aspect of the *Autism Coordination Act*. The relationship of collaboration and information sharing between the government and community service providers and those with lived experiences will make it possible to improve delivery of and access to Autism services.

- Continue to meet with government and community stakeholders on a regular basis to gain feedback, identify priority themes and opportunities for improvements
- Continue to validate scan of Autism programs and services within government and community service providers
- Form sub-committees (with government, community and those with lived experiences as members) to provide input and expertise to support the implementation of the *Act*

4. Identify COVID-19 impacts on Autism services and programming

A current and continued focus of the Committee will be identifying COVID-19 impacts on programs and services. As the global pandemic continues to unfold, it will be important to identify how Autism services have been impacted and what types of supports may be needed for individuals and families affected by COVID-19.

In response to COVID-19 and the potential impacts on wait-times for accessing services, early intervention options are currently being explored as a possible support for families.

5. Support opportunities to increase Education and Training

- Identify and support training opportunities for adults with Autism Spectrum Disorder looking to enter the workforce and/or post-secondary education
- Increase awareness of Autism Spectrum Disorder through training and workshops to front line workers in the education, health, and justice and public safety sectors

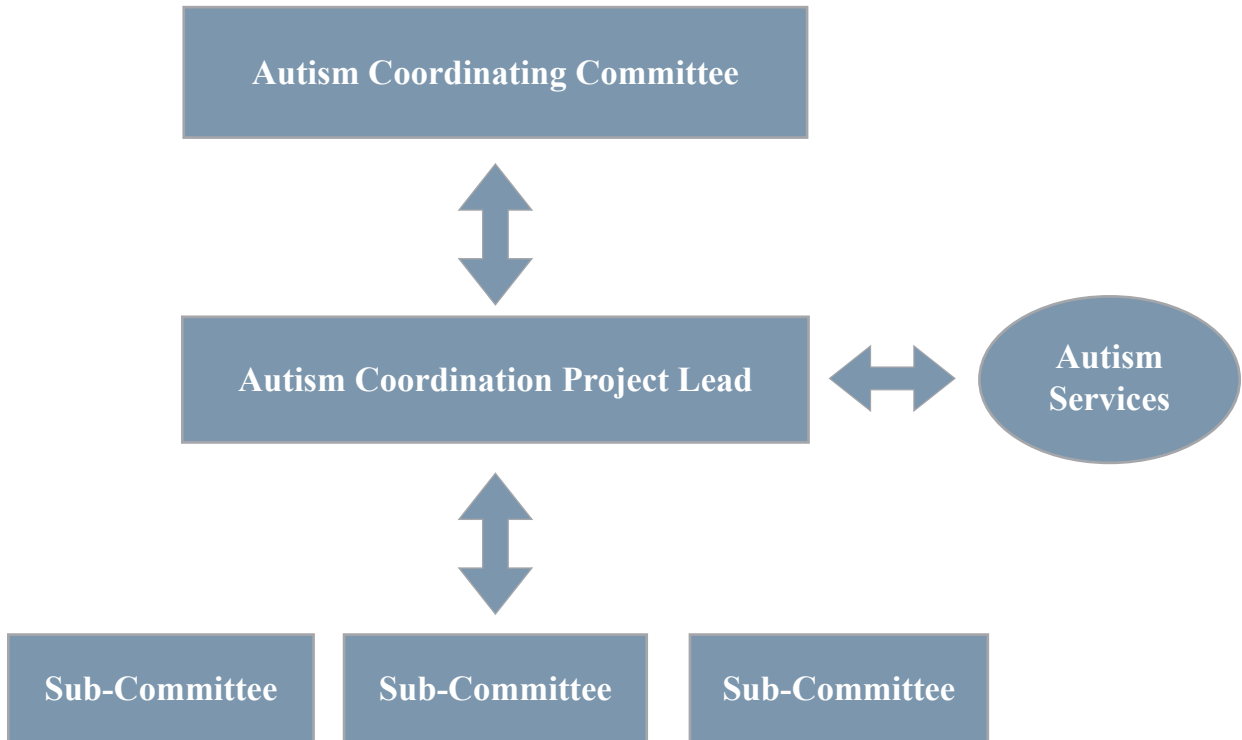
6. Explore ways to support individuals and families during transitions

Changes in routine can be especially challenging for those with an Autism Spectrum Disorder diagnosis. During major life transitions, it is critical that supports be identified and available for individuals and families. Some common life transitions may include: when a child moves from early years to the school system; transitioning from elementary school to junior high; leaving school system after grade 12; entering the workforce and/or post-secondary; moving into adult housing; or accessing seniors services/ nursing homes.

Autism services must consider the entire lifespan of an individual. Services and programming should reflect how an individual's need for supports might change during their lifetime. It is important that services and supports be identified and/or developed for these transitions so that families have access to supports when they need them most.

Appendix

Appendix A: Organizational Structure of the *Autism Coordination Act*.



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