

Autism Spectrum Disorder

Action Plan

Autism Spectrum Disorder Action Plan



CONTENTS

Introduction and Background

| | |
|---|---|
| What is Autism Spectrum Disorder?..... | 2 |
| What have we learned?..... | 2 |
| What is the Action Plan and why do we need one? | 3 |
| What are the Government’s Focus Areas? | 3 |
| What will the Action Plan encompass? | 4 |

Action Plan

| | |
|---|---|
| What government is doing | 4 |
| New Actions Government will take to Address Lifespan Needs for Persons with Autism | 6 |

Evaluation

| | |
|--|---|
| Are we making a difference? | 9 |
| Assign evaluation responsibilities | 9 |
| Evaluate indicators of success | 9 |

Appendix A

| | |
|---|----|
| Current government initiatives addressing the lifespan needs of individuals with ASD | 10 |
|---|----|

Appendix B

| | |
|-----------------------------------|-------------------|
| Areas needing further study | Inside back cover |
|-----------------------------------|-------------------|

INTRODUCTION AND BACKGROUND

Government is committed to making health care better for families in every region of the province. The actions outlined in this plan will work toward this goal, while providing the best support possible for individuals and families living with Autism Spectrum Disorder.

In the development of this plan, the ministers of Education, Community Services and Health and Wellness invited staff from their respective departments to collaborate with the Autism Society of Nova Scotia, the Autism Society of Cape Breton, the Annapolis Valley Autism Support Team, and the Provincial Autism Centre to examine the needs of people and families living with an Autism Spectrum Disorder (ASD). This collaboration led to the development and submission of a report on lifespan needs for persons with ASD.

The Autism Management Advisory Team (AMAT) was made up of the following representatives:

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| Kym Hume | Department of Education (chair) |
| Lorna MacPherson | Department of Community Services, Director, Services for Persons with Disabilities |
| Faizal Nanji | Department of Health and Wellness, Director, Adult Mental Health |
| Norm Donovan | Valley Autism Support Team (VAST) |
| Michelle Gardiner | Autism Society of Cape Breton (ASCB) |
| Tracey Avery | Autism Society of Nova Scotia (ASNS) |
| Cynthia Carroll | Provincial Autism Centre (PAC) |
| Vicki Harvey | Researcher, administrative support |

The government of Nova Scotia acknowledges the tremendous time, effort and expertise of AMAT in the development of its report entitled Lifespan Needs for Persons with Autism Spectrum Disorder. The work of this committee and its report will contribute to improving and enhancing programs and services for persons with Autism Spectrum Disorder in Nova Scotia.

The AMAT report contains recommendations compiled after the team researched effective practices and analyzed surveys and interview findings. The report has been reviewed by staff from the departments of Education, Health and Wellness, Community Services and Justice.

What is Autism Spectrum Disorder?

Autism Spectrum Disorder is a complex neurological disorder of development affecting all facets of a person's life. There is considerable variation of symptoms, ranging from mild to severe, across the spectrum. Communication and social interaction are considered primary areas of deficit. Individuals with ASD have difficulty processing and acting upon information from people and the environment, which can result in atypical behavioural responses. No single cause has been identified and it is a lifelong condition with symptoms appearing in early childhood.

At one time ASD was considered a rare disorder, but it is now recognized as one of the most common developmental disorders affecting children. The current prevalence rate according to the Centers for Disease Control and Prevention is 1:110 (2009). In the last 10 years the number of children diagnosed with ASD has increased 400 percent. It has not yet been determined whether this increase is due to better, broader diagnosis or increased risk factors for the development of ASD. Supporting these children into adulthood poses a major challenge for families as well as health, education and community services.

Providing intervention to children with autism at a very young age is key to maximizing their potential and quality of life. Research clearly shows that early intervention treatment services can greatly improve a child's development, better preparing the way for successful transition into school and the wider community. Not only does early intervention improve outcomes for children with ASD, it is a cost effective way of doing so.

What have we learned?

In 2010 the Autism Management Advisory Team published *Lifespan Needs for Persons with Autism Spectrum Disorder*. We have learned from that report that individuals with ASD require comprehensive supports across their lifespan. We have learned that what is important to families is early diagnosis and intervention, reliable and up-to-date information relating to ASD, knowledgeable and well-trained educators, emergency response personnel and respite staff, and access to resources and services specific to their needs. We have learned that although there are many good services and programs currently in place, there are also gaps. When reviewing the information gathered, we were guided by an intergovernmental approach while remaining mindful of living within our means as a result of the fiscal climate. As suggested by the Autism Management Advisory Team, we are supporting a phased-in approach.

Currently, the government responds in a number of areas to address the needs of persons with Autism Spectrum Disorder through programs in multiple departments and agencies. We understand there is no singular approach to addressing the needs across the lifespan and recognize the need for multiple departments and agencies to work collaboratively.

What is the Action Plan and why do we need one?

Government recognizes the complex lifespan needs of persons with autism. Government also recognizes the vital importance of early intervention to the quality of life for individuals with a diagnosis of autism. The action plan recognizes the need for enhanced early intervention services for children and the impact these services will have over their lifespan. The government also recognizes the need for further supports throughout the lifespan for individuals with autism.

The action plan is designed to support sustained change through a phased-in approach. It is supported by current and new investments to strengthen government, community, and individual capacity to address the lifespan needs of persons with autism. Some work in this plan is new, some is currently underway, and other work has been refocused or rounded out to address a particular gap.

Our action plan also creates opportunities for ongoing dialogue and networking between government and community groups. Working together, we can improve the programs and services for persons with autism.

There are five key focus areas resonating throughout *Autism Management Advisory Team Report on Lifespan Needs for Persons with Autism Spectrum Disorder*. These focus areas have guided our response in addressing issues that impact individuals with autism and their families.

What are the Government's Focus Areas?

The five key focus areas are:

- Intervention and Support Services for Families with Preschool Children Diagnosed with ASD
- Supports for School-Aged Children with a Diagnosis of ASD
- Supports for Adults with ASD and Their Families
- Skills Training and Awareness
- Partnerships to Support Programming and Services

What will the Action Plan encompass?

Over the past 10 years, the province of Nova Scotia has recognized that the prevalence of ASD is increasing. Government is committed to ensuring that resources and programs are available to benefit individuals with ASD. Given Nova Scotia's current fiscal realities, government will build on what is in place and develop an Action Plan for sustainability of current programming and services as well as continued enhancements. While some work will be done immediately, other work requires further study.

Government is committed to the implementation of this action plan through informed best practice, evidence-based research, and the appropriate allocation of available financial resources. We will also monitor and track progress. This action plan is a commitment to support the lifespan needs for persons with ASD.

ACTION PLAN

This action plan identifies existing government programs and services that support people with autism and outlines new action government will take in the five focus areas.

What government is doing

Intervention and Support Services for Families with Preschool Children Diagnosed with ASD

Government is

- providing the Early Intensive Behavioural Intervention (EIBI) program in the eight District Health Authorities and the IWK Health Centre (DHA/IWK):
 - The current funding of \$4 million serves 50 percent of the eligible preschool-aged children diagnosed with ASD.
 - 185 have been serviced since the introduction of the program in 2005.
 - 50 new children per year are offered admission into the program.
 - The program offers one year of intensive treatment, followed by sporadic consultation sessions as required.
- offering diagnostic capacity for children and youth:
 - Each DHA/IWK has an established autism assessment process or access to an assessment process.
- providing 17 Early Intervention Programs (EIPs) across the province supporting families of children from birth to school entry who have, or are at risk of having, developmental delay and thereby meeting the program eligibility:
 - The 17 EIPs currently serve approximately 670 families, with approximately 135 families on wait-lists.
 - The current budget for EIPs is approximately \$2.5 million. As EIPs are not 100 percent funded, each has entered into a service agreement with the Department of Community Services with a fund-raising component to their approved annual budgets.

Supports for School-Aged Children with a Diagnosis of ASD

Government is

- distributing a \$200,000 grant to the eight school boards on a claims basis for professional development of teaching personnel, including resource teachers, learning centre teachers, school psychologists, speech-language pathologists, and autism lead team members
- distributing a \$213,000 Early Identification and Intervention Services grant to school boards to facilitate transition of students with ASD into grade primary
- employing a full-time provincial autism consultant
- supporting all school boards to have autism support teachers/specialists to support program planning teams in schools and the training needs of staff
- supporting Access to Community Education and Employment (ACEE) in partnership with the Halifax Regional School Board, the Nova Scotia Community College, and Independent Living Nova Scotia as well as the Strait-to-Work program in Port Hawkesbury in partnership with the Strait Regional School Board and the Nova Scotia Community College
- funding DHAs/IWK to provide a diagnostic assessment for school-aged children suspected of having ASD
- providing funding for the Regional Development Program grants to support activities that respond to the goals and priorities of communities including responding to traditionally underserved populations; autism organizations that meet the eligibility guidelines may apply for these grants
- providing support for individuals with ASD through the Direct Family Support program if they have developmental delays and exhibit severe acting-out behaviours
- offering summer camp opportunities through the Provincial Autism Centre and Reachability
- providing summer respite funding for eligible children with disabilities through the Direct Family Support for Children program
- providing support to Regional Respite Services programs in the four regions of the province. These programs help families plan respite care for their children by assisting them in identifying and accessing the supports they require.

Supports for Adults with ASD and Their Families

Government is

- providing support for individuals with ASD through the Direct Family Support program
- providing residential services to support the needs of individuals with disabilities based on current capacity and applying the new wait-list policy and priority placement process
- addressing the recommendations from the *Report of Residential Services (2008)*, with a focus on sustainable funding
- providing support to adults with ASD through Adult Service Centres
- providing funding through the DHAs/IWK for mental health services to family members, as requested

Skills Training and Awareness

Government is

- continuing to support Access to Community Education and Employment (ACEE) in partnership with the Halifax Regional School Board, the Nova Scotia Community College, and Independent Living Nova Scotia as well as the Strait-to-Work program in Port Hawkesbury in partnership with the Strait Regional School Board
- supporting professional development for teaching personnel, including classroom, resource, and learning centre teachers, speech-language pathologists, school psychologists, and autism lead team members
- supporting DirectioNS (a provincial umbrella association of vocational and day-program service providers) to provide vocational and day-program options

Partnerships to Support Programming and Services

Government is

- supporting DirectioNS on funding options to consider increased vocational and day-program options
- collaborating with the Provincial Autism Centre through the centre's membership on the Special Education Programs and Services (SEPS) Committee

New Actions Government will take to Address Lifespan Needs for Persons with Autism

The government is launching a range of new actions to address lifespan needs for persons with autism based on informed best practice, evidence based research and recommendations from *Autism Management Advisory Team Report on Lifespan Needs for Persons with Autism Spectrum Disorder*.

Intervention and Support Services for Families with Preschool Children Diagnosed with ASD

- Provide additional funding to ensure that the EIBI program is offered to all pre-school-aged children diagnosed with ASD.
- Provide additional funding to Early Intervention programs to assist in addressing waitlist pressures.
- Review and examine the implications of adjusting the income guidelines for the Department of Community Services Direct Family Support for Children program (ages 3 years to 19 years).
- Explore early identification at the 18-month physician visit using a screening tool that captures the symptoms of ASD.
- Link the Individual Family Service Plans, for those preschool children diagnosed with ASD in receipt of Early Intervention program services, to Autism Treatment Teams in the DHAs/IWK.

- Identify and disseminate information on existing services offered by the DHAs/IWK to families.
- Work with the DHAs/IWK to identify the current referral process for regular health assessments and identify gaps in this process.

Supports for School-Aged Children with a Diagnosis of ASD

- Maintain a full-time provincial autism consultant to support the public school autism strategy and to provide leadership in coordinating the professional development needs identified by school boards.
- Maintain the provision of autism specialists or consultants as part of school board staffing allocations.
- Engage in discussion with education faculties at universities in the province regarding course content on ASD.
- Maintain dedicated funding to school boards to support the provision of resources and professional development aligned with the programming needs of students with ASD.
- Support transition planning as a required component of the individualized program planning process outlined in the *Special Education Policy*.

Supports for Adults with ASD and Their Families

- Identify capacity in District Health Authorities for autism assessments and intervention for the adult population.
- Identify subject matter experts to explore what assessment tools are available for adults with ASD and to determine what training would be required to become qualified at administering them.
- Work through the recommendations from the *Report on Residential Services* (2008) with a focus on sustainable funding and updating wait-list policies and procedures.
- Continue to provide support to current providers of life-skills training (e.g., ACEE, Strait-to-Work) in partnership with the Departments of Education and Community Services.
- Explore initiatives with Employment Support Services to bring business and social enterprise together.
- Work with the established funding committee involving the Adult Service Centres to consider increased vocational and day-program options.
- Offer ASD information support for Disability Resource Facilitators at the Nova Scotia Community College.

Skills Training and Awareness

- Review the *Physician Toolkit* (available at www.autismcentral.ca) to determine its relevance for Nova Scotia physicians.
- Identify gaps in current Continuing Medical Education and provide ASD Continuing Medical Education credits in partnership with other service providers.
- Maintain funding to support professional development for teaching staff in the area of ASD.

- Expand *Standards for Mental Health Services in Nova Scotia* and any future developments of clinical practice guidelines to include Autism Spectrum Disorder.
- Discuss, in consultation with the Provincial Autism Centre, appropriate training for first responders and 911 call takers, develop a training session on ASD, and obtain ministerial approval of training as required.
- Provide the police roll-call schedule to representatives from the Nova Scotia Autism Council so the Council can present sessions on ASD awareness to various police agencies.

Partnerships to Support Programming and Services

- Collaborate with the autism community to ensure that information resources are available for families
- Collaborate with partners to develop an information resource for families.
- Work with the DHAs/IWK to ensure that information about mental health crisis services is made available to families.
- Explore, through Human Resources at the Department of Health and Wellness, the possibility for enhancing training on ASD for health professionals with the Atlantic Advisory Committee for Health Human Resources.
- Explore, with the Mental Health Commission of Canada, the possibility of including ASD in the curriculum of the Mental Health First Aid program.
- Collaborate with post-secondary educational facilities to explore enhanced postsecondary education opportunities for students with special needs.
- Develop, in partnership with the Provincial Autism Centre, a checklist for families of what to look for in a respite worker.
- Expand the partnership with Employment Support Services regarding the Labour Market Agreement for Persons with Disabilities program to facilitate more job placements.
- Explore partnerships with Sport Nova Scotia and link with the Active Start program to develop programming specific to after-school and school breaks as well as for recreational and leisure programs.
- Explore sport and recreation options to increase opportunities for physical activity, sport, and recreation in the after-school time period.
- Explore partnerships to support the community use of schools to enable physical activity, sport, and recreation offered by municipalities and local physical activity, sport, and recreation groups and organizations to offer programs outside curriculum time.
- Continue the educational partnership with the Nova Scotia Educational Leadership Consortium to develop a module on ASD for educators.
- Explore the option to collaborate with other Atlantic provinces and the Atlantic Provinces Special Education Authority (APSEA) to develop a “centre of excellence” that could support the Department of Education and school boards in enhancing the expertise of their staff in delivery of services to students with ASD.

- Meet with the Nova Scotia Autism Council to discuss their safety needs and determine next steps.
- Facilitate the sharing of a voluntary registry with police, should one be developed by a non-government organization.
- Monitor Project Lifesaver.

EVALUATION

Are we making a difference?

We will monitor and track progress in our efforts to address programming and services for individuals with ASD across their lifespans.

Assign evaluation responsibilities

For actions identified in the plan, government will ensure that evaluation plans are in place to effectively measure whether anticipated results from proposed actions are being achieved.

Evaluate indicators of success

We will evaluate the overall success of this action plan by measuring the following indicators of success:

- More children served through the EIBI program.
- Increased collaboration between EIBI and schools for children entering Grade Primary.
- More families served through Early Intervention programs.
- More families served through Direct Family Support.
- Increased availability of information resources to support individuals with ASD and their families.
- Coordinated training initiatives that meet needs.
- Update of action plan outcomes 2012–13.

APPENDIX A

Current government initiatives to address lifespan needs for persons with ASD

1. Diagnostic capacity for children and youth exists throughout the province. Each District Health Authority (DHA) has an established autism assessment process, or access to an assessment process.
2. Funding is provided to the DHAs/IWK to provide a diagnostic assessment for schooled children suspected of having ASD.
3. Support is provided for all school boards to have Autism Support Teachers/Specialists to support program planning teams in schools and the training needs of staff.
4. Regular health assessments are available through general practitioners or pediatricians across the province. If necessary, people may also be referred to a speech-language pathologist, occupational therapist, etc.
5. People with ASD have access to a wide range of health professionals through the DHAs/IWK, including psychiatrists, psychologists, social workers, and occupational therapists. Speech-language pathologists can be accessed through the Nova Scotia Hearing and Speech Centres.
6. DHAs/IWK Mental Health programs provide behavioural treatment where clinicians with specialized training are available. Physical health needs are dealt with through physicians and medical clinics. Communication needs are addressed through the Nova Scotia Hearing and Speech Centres and speech-language pathologists employed in all school boards.
7. Mental Health Crisis support services are available in all DHAs/IWK. The 811 information and referral line is answered by nurses who can direct families to local mental health crisis services and emergency departments. A Mental Health Mobile Crisis Team operates in the Halifax Regional Municipality.
8. Mental Health services are available in all DHAs/IWK to address mental health issues experienced by families.
9. The Provincial Autism Centre is currently engaged in ASD education and awareness. The Department of Education Autism Consultant and autism teams in all school districts conduct ASD education.
10. The DHAs/IWK complete ASD diagnostic assessments, and comprehensive medical testing is requested if necessary. Every effort is made to see ASD referrals and communicate the result of the assessment to families in a timely manner.
11. EIBI is available in the eight DHAs/IWK. Currently, 50 percent of the pre-school population are being seen through the EIBI program. Published research confirms the provincial EIBI model to be effective (Smith, I., R. Koegel, L. Koegel, D. Openden, K. Fossum, and S. Bryson. Effectiveness of a Novel Community-Based Early Intervention Model for Children with Autistic Spectrum Disorder. *American Journal on Intellectual and Developmental Disabilities* 115(6): 504–523). Parent training is offered through EIBI.

12. The Department of Education's *Special Education Policy 2.2* establishes a program planning process for school boards to support the learning needs of individual students. Policy 2.6 provides for the development of individual program plans based on an assessment of student strengths and challenges. The individual programming needs of students with ASD are addressed through this process.
13. The Department of Education distributes a \$200,000 grant to boards on a claims basis for professional development of teaching personnel, including resource teachers, learning centre teachers, school psychologists, speech-language pathologists, and autism lead team members. School board proposals are submitted yearly and reviewed by Student Services in the Department of Education.
14. The Department of Education distributes a \$213,000 Early Identification and Intervention Services grant to school boards to facilitate transition of students with ASD into grade primary.
15. A full-time Provincial Autism Consultant has been hired as of the 2010–11 school year. The Provincial Autism Consultant chairs the Provincial Education Autism Advisory Team committee meetings. The committee meets several times a year to identify and coordinate professional development among the school boards and support the Department of Education autism initiatives.
16. All school boards have autism support teachers/specialists or consultants to support program planning teams in schools and the training needs of staff.
17. All school boards have speech-language pathologists as part of their staffing allocation. The Department of Education's *Special Education Policy 1.3* applies a recommended ratio of 1:2000 for speech-language pathologists.
18. As part of the *Special Education Policy*, all school boards currently support transition from high school for students with Autism Spectrum Disorder. This service is provided through positions in Student Services; i.e., student services coordinators, program planning teachers, and transition teachers.
19. Educators are supported in professional development through a Department of Education grant, school boards professional development funding, Nova Scotia Teachers Union professional development grants, and the Provincial Education Autism Advisory Team.
20. The Department of Education, through *Special Education Policy 1.3*, provides a Special Education grant to school boards. Funds may be used to purchase specialized materials. Autism lending libraries are available in some boards to assist with programming support for students with ASD.
21. The Department of Education and the Department of Community Services support Access to Community Education and Employment in partnership with the Halifax Regional School Board, the Nova Scotia Community College, and Independent Living Nova Scotia as well as the Strait-to-Work program in Port Hawkesbury in partnership with the Strait Regional School Board and the Nova Scotia Community College.
22. The Provincial Autism Centre supports employment through Autism Works, an on-site support program for employees and employers based on the TEACCH model.

23. The Department of Education is collaborating with Acadia University to explore enhanced post-secondary education opportunities for students with special needs.
24. The Department of Education works in partnership with Nova Scotia Community College to ensure that students with Individual Program Plan credits are given special consideration to access programs at Nova Scotia Community College.
25. Universities across the province offer information about ASD in their faculties of Education and Psychology and at the School of Human Communication Disorders at Dalhousie University.
26. Supports for individuals with ASD are available through the Department of Community Services' Direct Family Support program if they have developmental delays and exhibit severe acting-out behaviours.
27. The Department of Community Services provides residential services to support the needs of individuals with disabilities, based on current capacity and wait-list priority placement.
28. A summer camp is offered through the Provincial Autism Centre, and the Department of Community Services is partnering with Reachability to offer overnight camps.
29. Summer respite funding is available for eligible children with disabilities through the Department of Community Services' Direct Family Support for Children program.
30. The Department of Health and Wellness, through its Physical Activity, Sport and Recreation responsibility centre, provides funding for the Regional Development Program. This program is designed to support activities that respond to the goals and priorities of communities and the Physical Activity, Sport and Recreation responsibility centre's priority areas, including increasing physical activity, sport and recreation opportunities, capacity building, gender equity, volunteer development, physical activity levels of children and youth, fair and safe activities, and responding to traditionally underserved populations. Autism organizations that meet the eligibility guidelines may apply for these grants.
31. The Departments of Education and Community Services provide life-skills training through the ACEE and Strait-to-Work programs and the Adult Service Centres.
32. The Provincial Autism Centre is developing a life-skills support model and is piloting life-skills modules at the Centre.
33. The Department of Community Services provides support to adults with ASD through Adult Service Centres.
34. The Department of Community Services works with DirectioNS to provide vocational and day-program options.

APPENDIX B

Areas needing further study

Government will undertake further study to

- monitor wait-times for school-aged diagnostic assessments and provide additional training, as resources allow, to increase capacity
- explore the need for behavioural analysts as an additional resource for children, youth, and adults with significant or severe behavioural challenges
- determine the status of the Behavioural Intervention program at the Nova Scotia Community College
- investigate funding options for identified training regarding best-practice assessment tools to diagnose adults with ASD
- consider partnering with universities in the province to offer course work in Autism Spectrum Disorder
- work, within the budget process, to update the wait-list policies and procedures to address priority placement needs for residential services
- explore options to expand spaces for leisure/recreational programming for children with disabilities, within available resources