

# CHOOSING NOW

INVESTING IN  
NOVA SCOTIANS  
LIVING WITH AUTISM

A Collaborative Framework Approach to Building  
Sustainable Supports and Services Across the Lifespan



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# Executive Summary

In 2010 Nova Scotia was poised to be a national leader in autism supports. That year, the government released the *Autism Management Advisory Team Report on Lifespan Needs for Persons with Autism Spectrum Disorder* (AMAT Report).<sup>1</sup> The report meticulously detailed recommendations to support Nova Scotians with autism through each stage of life — from early intervention to supports in adulthood.

When this report was published, Nova Scotia had the opportunity to lead the country in Autism awareness, acceptance and service delivery. Sadly, the opportunity was not seized.

Progress to address the lifespan issues identified in the AMAT report has been minimal. Demand for autism supports continues to grow, and Autism Nova Scotia is working tirelessly to respond. Although every effort is made to ensure that solutions for support are robust, sustainable and systemic, the programs and services the organization has been able to build are often piecemeal. Autism Nova Scotia's capacity is being strained just as demand and need are growing to new heights.

Today in Nova Scotia, many families and individuals living with autism spectrum disorder are in crisis. Some are desperately trying to access mental health support, while others are in crisis because of barriers to health care delivery. Families and individuals are struggling in the face of gaps in the education system, shortage in funding for family respite, lack of transition to employment programs and employment support, as well as limited residential supports. The challenges people with ASD and their families face are real, significant, and costly.

In the almost six years since the provincial AMAT group delivered recommendations to government, the prevalence of autism has increased from 1 in 110 to current surveillance indicating a prevalence of 1 in 68.<sup>2</sup> This means that if prevalence rates remain the same, there may be as many as 13,900 Nova Scotians on the Autism Spectrum.

Put simply, our awareness of the needs of individuals with autism is increasing rapidly, but the supports and resources are not keeping pace. The band-aid approach is not working. Given recent concerns around Nova Scotia's demographic pressures, it is simply not an option to leave thousands of citizens — Autistic individuals and their families and caregivers — out of full participation in society and the economy because of a lack of supports.

This document is both an overview of a problem and a proposal for a solution. It explains the work that AutismNS is doing to support people with ASD and their families, and the work it is doing to fill critical gaps in support. It also proposes how AutismNS, working closely with government and other key system service delivery players, could create a more sustainable system of support.

## A note on Autism Language

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Throughout this document you will see Autism Spectrum Disorder, and how it applies to individuals and their families, referenced in a number of ways.

Language within the Autism community is evolving as more is understood about the condition and how it impacts individuals and the lives they lead.

Autism Nova Scotia represents a large and vibrant community — supporting individuals directly as well as providing supports for families and caregivers.

The self-advocates who contribute to Autism Nova Scotia have varied preferences when it comes to how they would like to be identified. Some prefer identity-first language and wish to be called, “Autistic” while others would rather people use “person-first” language such as “on the Autism Spectrum” or “Individual with Autism”.

One thing that we are very adamant about is that it is up to the individual themselves to determine how they wish to be identified.

That is why you will notice we include these different representations throughout the Choosing Now document, in the hopes that our members can all relate, and see themselves within this report.

There are some terms that we, as a community, are working to move away from — such as “high functioning” and “low functioning”. How well an individual functions has long been qualified by ability to use ver-

bal language and their IQ levels. This not only places unfair assumptions about individuals who are non-verbal, or those who have learning disabilities — but it also creates barriers, often insurmountable, against Autistic individuals who may have high IQs but face significant challenges, for example, with social communication and problem-solving skills.

In 2016, the magazine, *The Atlantic* published a story on the outdated use of the high/low functioning labels stating, “Even being tagged as high-functioning can have unfortunate consequences. Any person, regardless of whether they have autism, functions better in some areas of life than in others, whether that’s making and keeping friends, learning and remembering information, taking care of themselves, communicating, solving problems or paying attention. Saying a person with autism is high-functioning implies they are competent in all of these areas, but that’s simply not true...In practical terms, either label can be limiting: It might prevent one child from participating in activities she wants to do, or exclude another from getting the services he needs.”<sup>3</sup>

The references to functioning levels are only used in this document when directly part of sourced information. At all other times, we do our best to avoid these terms as we believe they do not adequately reflect the great attributes, and the significant challenges, that are faced by individuals on the Autism Spectrum.

# Introduction and Background of this Report

Autism Spectrum Disorder is a complex neurodevelopmental disorder that affects a person's ability to communicate and interact, both with other people and with their environment.<sup>4</sup> At one time autism was thought to be a rare condition, but it is now recognized as one of the most common developmental disorders. Prevalence rates have soared from 1 in 2,500 during the 1960s to 1 in 110 in 2009 and now sit as high as 1 in 68.<sup>5</sup> Whether the prevalence of ASD diagnoses remains the same or continues to increase for the foreseeable future, the needs of this population and their families will affect all government departments, and will continue to necessitate new community services and programs.

The increase of people diagnosed with ASD has compelled parents, self-advocates, educators, employers, community employment support agencies, and a host of community sector stakeholders to call for a more robust system of responsive and proactive supports, education, and services. They are calling for resources that can help this population achieve their potential through full community, economic and social inclusion.

As the prevalence and number of people with ASD has grown in Nova Scotia, the Autism community in the province has responded by trying to develop clear, evidence-based plans for how to best support their wide array of needs. In 2010, the Nova Scotia Autism Management Advisory Team (AMAT) published *Autism Management Advisory Team Report on Lifespan Needs for Persons with Autism Spectrum Disorder* (AMAT Report).<sup>6</sup> The report identified top priorities as:

- Early diagnosis and intervention;
- Well-trained educators;
- Health professionals and respite workers; and
- Needs-specific resources and services.

In response, the Nova Scotia government called together a working group that developed the *Autism Spectrum Disorder Action Plan*.<sup>7</sup> It set out key priorities and identified gaps in services and programs across the province and across sectors. The Action Plan acknowledged five key areas of future government investment and support:

1. Intervention and support service for families with preschool children diagnosed with ASD;
2. Support for school-aged children with a diagnosis of ASD;
3. Supports for adults with ASD and their families;
4. Skills training and awareness; and
5. Partnerships to support programming and services.

The vast majority of government attention and investment for autism services, both before and after the AMAT report and subsequent Action Plan in 2011, has been focused on early intervention:

- In 2001 the Early Identification and Intervention Services project, a three-year pilot, was given \$2 million per year to enhance services such as early intervention, speech and hearing. Funding was placed into base budgets after the pilot term.
- In December of 2004, Nova Scotia instituted Early Intensive Behavioural Intervention (EIBI) as a \$4 million yearly commitment for preschool-aged children diagnosed with ASD. The fund is, importantly, not accessible to children and families once a child is in the school system.
- In 2011, an additional \$4 million was invested in EIBI, to remove the random selection process and ensure all children with a diagnosis of ASD accessed treatment before age six.<sup>8</sup>
- In 2015, an additional \$1 million was invested to address the long wait lists, making the annual government expenditure on ASD-specific services \$11 million.
- In 2016, an additional \$3.6 million was invested in EIBI.

There is much evidence proving that investment in early intensive interventions can greatly improve a child's development, lead to successful transitions into school, and build support for people with ASD in the community and employment across their lifespans.

However, as important as investment in early intervention is, there are a suite of supports and services beyond those targeted at preschool-age children which people with ASD, their families, and Nova Scotian communities as a whole require for people with ASD to realize their full potential. Also, there is currently a cohort of Autistic adults in Nova Scotia that did not receive early intervention (EIBI), and that require supports.

The Nova Scotia Government has made some small but very important investments in other areas of support. Yet much of the ASD-specific support and service infrastructure in Nova Scotia has been left to the ASD community, with the coordinating support of Autism Nova Scotia (AutismNS), to deliver with little to no financial support from the provincial government.

As this report outlines, the rapid growth of AutismNS as a charitable organization and community resource, as well as the expansion of its work into new areas of services and supports, are symptomatic of two major shifts in our landscape:

1. A growing awareness of additional issues that people with ASD confront *over their lifespan*, along with a growing recognition of the various and very diverse manifestations of autism; and
2. A growing recognition of the need for a *flexible continuum of supports* for people across this broader (and further broadening) spectrum of individuals with autism.<sup>9</sup>

The growing prevalence and profile of ASD has led to increased awareness among Canadians — and Nova Scotians are no exception — of the challenges that people with ASD confront in their daily lives, and the potential for a more holistic approach to inclusion. Far from being overwhelmed by the needs before us, Nova Scotians across the private, public and community sectors are calling for better education, services, and expert support assistance that can help people with ASD realize their full potential at home, in school, in the workplace, and in their communities. This requires a collaborative multi-sector and cross-discipline approach.

AutismNS is the leading community-based organization in Nova Scotia that supports individuals with autism, while also supporting their families, educators, employers, employment agencies, healthcare professionals and researchers throughout the province. Over the last five years, AutismNS has expanded rapidly to try and meet the demand for more and new kinds of support, programs and services in areas such as employment, education, respite care coordination, expanded family support, system navigation support, social and life skills training, autism appropriate housing, and a host of others (See Appendix: Organizational Structure).<sup>10</sup>

This increased demand and growth is placing a tremendous strain on AutismNS's current resource base — yet the organization has been rising to the challenge, developing a well-respected, multi-sector, and collective impact approach to service, program and support delivery.

As shown throughout this document, AutismNS strives to create effective and efficient systems in collaboration with other stakeholders that leverage existing community capacity and avoid duplicating efforts. Through careful collaboration and program development, AutismNS has established scalable models for education, employment, social and life skills supports and services that have a real potential to be transfer-

able to other disability groups. Moreover, AutismNS is constantly working to identify and map clear pathways through all of the effective supports that are available, thus providing guidance through complex systems and resources that are navigable for people with ASD and their families.

AutismNS's steadfast focus, collaborative model, and many achievements have earned Nova Scotia's Autism community a esteemed reputation on the national

level. However, AutismNS's ability to do this work is greatly constricted by its funding, and the increasing need from families, health professionals, community employment agencies, front line health care workers and first responders, education professionals and para-professionals, employers, not-for profits, and others is stressing the organization's ability to be a consistent intervention support. Despite the stress on resources, AutismNS's vision for service and support systems remains clear, but they can't do it alone.

## Funding of Autism Societies Across Canada: a Comparison

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The issues described in each section of this proposal outline much of the work that AutismNS is doing in the provincial community, helping identify gaps in services, offering extensive programs to help build the quality of life and self-determination of people with ASD, helping with system navigation, and helping build a collaborative network of partners and service providers that,

by any measure, gets formidable results for its staff to outputs ratio. And yet, as the following chart reveals, AutismNS does so with little funding support from the provincial government. The chart below draws from the membership of societies in the national organization, Autism Canada, presenting the government support received by autism societies or resource centres.<sup>11</sup>



Table 1: Comparison of Autism Society Funding Sources, Staff Details, and \$/Person with ASD by Province in 2015

ORGANIZATION	GOVERNMENT	OTHER	TOTAL EXPENDITURE*	STAFF	\$/PERSON WITH ASD (GOVERNMENT / TOTAL)	POTENTIAL # INDIVIDUALS WITH ASD (based on 2015 population and an incidence rate of 1 in 68)
Autism Nova Scotia	\$64,800 (5%)	\$1,135,200 (95%)	\$1,200,000	15 Full-time 7 Part-time 3 Casual 1 Internship 26 Summer	\$3 / \$57	13,868
Autism Society of Newfoundland and Labrador	\$759,970 (45%)	\$928,852 (55%)	\$1,688,822	25 Full-time 4 Part-time 13 Summer	\$65 / \$144	7,762
Autism Society of Prince Edward Island	0	\$60,000 (100%)	\$60,000	1 Full time	\$0 / \$18	2,153
Autism Resource Centres (New Brunswick)	\$300,000	NA	NA	Minimum of 10 part time staff	\$18 / NA	11,087
Federation quebecoise de l'autisme	\$153,908 (69%)	\$68,097 (31%)	\$222,005*	3 Full time	<\$1 / \$1	121,524
Autism Society Ontario	\$2,520,000 (42%)	\$3,480,000 (58%)	\$6,000,000	25 Full-time 30 Part-time 1/2 Casual 1/2 Intern 2/3 Summer	\$8 / \$20	202,825
Autism Society of Manitoba		\$5,000 (100%)	\$5,000	None	\$0 / \$0.17	19,021
Autism Resource Centre (Saskatchewan)	\$817,302 (80%)	\$92,222 (20%)	\$1,016,936*	6 Full time 63 Part time	\$49 / \$61	16,671
Centre for Autism Services (Alberta)	\$8,334.56 (16%)	\$43,756 (84%)	\$52,091	1 Part time 1 Contract	\$3 / \$11 Alberta Total	61,713 Alberta Total
Autism Edmonton	\$165,000 (30%)	\$385,000 (70%)	\$550,000	3 Full time 9 Part time 7 Casual 1 Internship 2 Summer		
Autism Calgary	\$85,000 (20%)	\$340,000 (80%)	\$425,000	4 Full Time 4 Part Time 1 Casual 2 Intership 0 Summer		
Autism Society of British Columbia	\$250,800 (66%)	\$167,200 (44%)	\$380,000	4 Full time 6 Part time	\$2 / \$4	68,869
Autism Yukon	\$75,000 (75%)	\$25,000 (25%)	\$100,000	1 Full time	\$90 / \$120	550
North West Territory Autism Society	0	0	0	None	\$0 / \$0	649
Nunavut Territory					\$0 / \$0	543
<b>CUMULATIVE TOTAL</b>	<b>\$5.0 mil (42%)</b>	<b>\$7.0 mil (58%)</b>	<b>\$12,043,067</b>	<b>n/a</b>	<b>\$6 / \$15</b>	<b>527,232</b>

Sources: from Canada Revenue Agency Charitable Returns, 2015; Library of Parliament for NB data; Statistics Canada, CANSIM, table 051-0001

As this cross-jurisdictional scan shows, government funding and support for Autism Nova Scotia is remarkably less, as a percentage of organization expenses, compared to every other province.

This number is even more astounding when one takes into account that, where many provinces have autism *centres*, working alongside separate autism *societies*—and both receive funding—AutismNS is effectively an amalgam of these resource centre and society functions, working with a fraction of the resources. Compare this situation to New Brunswick; there, \$300,000 is invested each year in 10 Autism Resource Centres, which do much of the same navigation support and even program delivery work that AutismNS does in this province.<sup>12</sup> At the same time, the Autism *Society*

in New Brunswick receives additional funding. Centres for Autism Services in Alberta (97%), Ontario (55%), and Saskatchewan (85%) also receive funding above and beyond what is received by the local Autism societies.<sup>13</sup>

However, the Nova Scotia government has generously funded a number of pilot projects developed by AutismNS over the last several years—programs such as our Transition Readiness and Autism Community Employment program, Launch Pad and the Respite Care Database. However, the needs for community capacity, and the value of the services that AutismNS is rendering to the existing ASD support system, is beginning to over-tax the organization. A clear case exists for additional government funding of targeted initiatives.

## Purpose of this Proposal: A Model of Collaborative Service and Support and a Case for Sustainable Funding

The proposal that follows is an effort to outline each of the major issue areas of service or support for people with ASD, their families, and our communities. It follows the same basic structure for each support or service issue, as follows:

- **Position:** A statement of AutismNS's *core principle(s)* in this particular area of support or service;
- **Issue:** Framing the larger social and systemic challenges that Nova Scotia confronts in the area, including an outline of existing supports or services if applicable;
- **Cross-Jurisdictional Comparison:** Where appropriate and needed, this proposal offers a look at best practices in other provinces or countries, with a focus on those that take advantage of collaborative networks and multi-sectoral stakeholders;
- **Outcomes:** The outcome that AutismNS, and its many partners and supporters, are working towards.
- **Recommendations:** Recommendations to government for enhanced support and services for families and individuals living with ASD in the province.

Autism Nova Scotia understands that it must play a coordinating and leadership role in establishing best practices and real supports; it is not enough that the organization merely point in the direction the province must head and wait for others to do the work. AutismNS is fully committed to being a leader and collaborator in the journey, working with all Nova Scotians. Therefore, each “issue” section of this report situates AutismNS at the heart of the work that must be done, but shows how closer collaboration and support from government can help us get there. Taken together, the issues and suggested outcomes in this report will clearly outline how:

- AutismNS acts as a coordinator in a multi-sector approach to support for people with ASD;
- AutismNS's expertise can be leveraged by government to enhance capacity to support people with ASD;
- Government should prioritize and target investment, at a departmental level; and
- AutismNS is already working towards these outcomes, independently or by building collaborative networks of service and support providers.

## Understanding Autism: A Background on Unique and Complex Needs

The issues and ideal system outcomes outlined in this report are informed by an understanding of ASD that comes from research and experience. This section will help readers grasp the basics of the understanding that underlies the proposals and challenges identified in the rest of the report.

### THE BASICS

People with ASD exhibit a wide range of behavioural challenges stemming from difficulty in verbalizing thoughts, managing anxiety, dealing with change, participating in group activities, understanding and navigating conversation and social interaction—which all lead to problems coping with what many of us take for granted as everyday, routine activities.<sup>14</sup> ASD is diagnosed typically around the age of three years old, and is almost five times more likely to be diagnosed in males than females.<sup>15</sup> It presents as (and is diagnosed by assessing) core deficits in social communication/ social interaction and restricted, repetitive patterns of behaviours, interests or activities.<sup>16</sup> As the name “spectrum” suggests, the way that these deficits present can vary across a broad spectrum in several core areas.

In other words, because autism is a *spectrum disorder*, the way it presents is extremely diverse, varying from person to person. For example, 25% of people with ASD do not talk (are nonverbal), while others may have limited verbal skills and use 1-2 word utterances, and still others are able to speak well.<sup>17</sup> Some people with ASD may seem reclusive and avoid social interaction, whereas others may be very outgoing. The complex range of impacts that can come with ASD could manifest, for example, in someone having limited verbal skills but who is intensely interested in social interaction, or someone who is highly verbal but not interested in people, etc. People with ASD may also experience a spectrum of impacts in sensory sensitivities. Hypersensitivities (when an individual experiences a particular sense more strongly than their peers) may result, for example, in someone who avoids or is averse to certain sounds or types of light. On the other end of the spectrum, there are those who experience varying hyposensitivities (experiencing a particular sense *less* than their peers). People with hyposensitivities may seek out additional stimulation of a particular sense, so they may engage in repetitive or unusual movements/ actions, or patterns of behavior that satisfy their need to experience that sense more strongly.

TABLE 2: Range of impact to skills Adapted from Center for Disease Control and Prevention (2015b)

<b>COMMUNICATION</b>	Nonverbal ————— Verbal
<b>SOCIAL INTERACTION</b>	Not interested in others — A variety of friendships
<b>SENSORY</b>	Not very sensitive (hypo) — Very sensitive (hyper)
<b>MOTOR</b>	Uncoordinated ————— Coordinated
<b>MEASURED INTELLIGENCE</b>	Intellectual disability ————— Gifted
<b>BEHAVIOURS</b>	Mild ————— Intense

Source: Center for Disease Control and Prevention, 2015

## COMMON CHALLENGES

Routines and structure can be very important for people with ASD, though again the extent of this varies across the spectrum, but often means that unexpected changes or differences to a routine can be very upsetting for individuals with ASD.<sup>18</sup> Routines and structures therefore help create predictability and understanding, and can help in alleviating anxiety and negative stress. But this should not be taken to mean that a person with ASD is set in their behavior, or unable to adapt to shifting conditions. Instead, as with all core capacities impacted by ASD—and like everyone in society—people with ASD have strengths in some areas and weaknesses in others. For example: a person with ASD may have a strong ability to enter data into a computer without making very many errors as part of their job; however, the same person could greatly struggle with interacting with their colleagues during lunch.

Understanding that “the spectrum” refers to a spectrum of impacts across a variety of capacities is important because it challenges an often oversimplified notion that the “autism spectrum” refers to a range of ability, with those “more affected” being “lower functioning”, and those who are “less affected” being “higher-functioning.” Importantly, the complexity of impacts means that someone may appear “higher functioning” because of their communication skills, high intelligence, and lack of sensory sensitivities, but they are still highly affected or impacted within a social context by their autism in certain environments.

The high-functioning/low-functioning binary is a common misunderstanding associated with Asperger’s Disorders, which was recently folded into the encompassing diagnosis of ASD.<sup>19</sup> The essential features of Asperger’s Disorders are “severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interest, and activity”.<sup>20</sup> Asperger’s does not typically present with communication deficits and people with Asperger’s are typically considered to be on the “high functioning” end of the autism spectrum. People who self-identify as having Asperger’s also commonly have a very specific area of interest that they know a great deal about. But their struggles with understanding the “hidden curriculum” of social situations (e.g., nonverbal cues), and some behaviours or lack of social skills and executive functioning may lead their peers or co-workers to see them as lacking empathy or being “awkward.” In many ways, someone with Asperger’s syn-

drome can be seen as confronting a larger disability than those having received other diagnoses because of their specific difficulties navigating social situations, which have an adverse impact on things such as employment.

## AUTISM’S CO-DIAGNOSES AND THE WEAK RELATIONSHIP BETWEEN IQ AND ASD

The frequency and variety of disabilities that are co-diagnosed in people with autism makes it additionally complex. Mental health issues are extremely common for people with ASD. For example, recent studies suggest that depression, schizophrenia and psychosis are common, and that anxiety is particularly common, affecting as much as 84% of the population diagnosed with ASD.<sup>21</sup>

Despite the complexity of autism, it is too often wrongly characterized and assessed using IQ profiling to evaluate “severity” or need. The leading view in policy circles up until recently was that as many as 70% of people with ASD had an intellectual disability (IQ<70).<sup>22</sup> Intellectual disability is common, but recent studies suggest that the prevalence of intellectual disability among people with ASD may be considerably lower.<sup>23</sup> Some recent studies have suggested that as few as 30-50% of people with ASD have an intellectual disability. Regardless of the rate, recent evidence suggests that an IQ-focused approach to ASD is a square peg for a round hole—the relationship is weakly correlative, a poor predictor, and certainly an inaccurate tool for assessing both the existence of ASD, and the disabling dimensions of it.<sup>24</sup>

Though autism is commonly co-diagnosed with other disabilities, it is important to understand that it is its own disorder and can create particular alignments of disability that demand tailored accommodations through unique service, support systems and social structures. The American Psychological Association recognizes ASD as a distinct developmental disability, as does the Government of Canada and Nova Scotia.<sup>25</sup>

## Autism Is a Unique Disability and Specialized Support is a Right

Autism is, then, a developmental disorder that results in unique disabilities that have particular and specialized needs. Legislation and regulation in Nova Scotia acknowledges autism's status as a disability with special needs at the school level.<sup>26</sup>

Canada is also a 2010 signatory to the UN Convention on Rights of Persons with Disabilities, which seeks to “promote full and equal employment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.”<sup>27</sup> This means that a strong social and legal case can be made that accommodation of ASD and its special needs

(accommodations, supports, and the services integral to their delivery) are not simply an accommodation ensuring individual welfare, but rather a human right.

Despite the growing body of evidence that autism demands particular supports, services and accommodations, often different from those needed by people with intellectual disabilities, much of the current service system in Nova Scotia and throughout the country is geared towards supporting people with an intellectual disability.<sup>28</sup> As this report highlights on several fronts, AutismNS has developed complimentary, but distinct systems and supports.

## The Cost of Not Acting

Alongside the matter of the human rights of people with ASD, there is a social cost to not acting to support and serve people with ASD throughout the lifespan, and a convincing rationale for how tailored supports and services could help Nova Scotia become a more efficient, sustainable society, by becoming more inclusive.

Failing to address the needs of people with autism has an enormous cost. Using figures from studies in the US and Ontario,<sup>29</sup> it is estimated that the cost of support for a single generation of people with ASD in Canada could range from \$1.4 to \$8.4 billion CDN. Costs are largely being downloaded onto families and individuals, however, which one UK study estimates can cost \$1,325 CDN per week, or \$68,900 CDN per year in out of pocket expenses.<sup>30</sup> Parents are also spending as many as 60 hours a week on care—of which 40 hours would otherwise have been spent on other activities. One study showed that families with children with ASD experienced a 28% decrease in family earnings relative to families of kids with no disabilities.<sup>31</sup> This area of research is just beginning to develop, but evidence is mounting that the loss in productivity and well being in jurisdictions with poor supports for people with ASD is substantial.

And in those instances where assistance beyond family support is needed—particularly among adults—often people are turning to mental health, health, and other

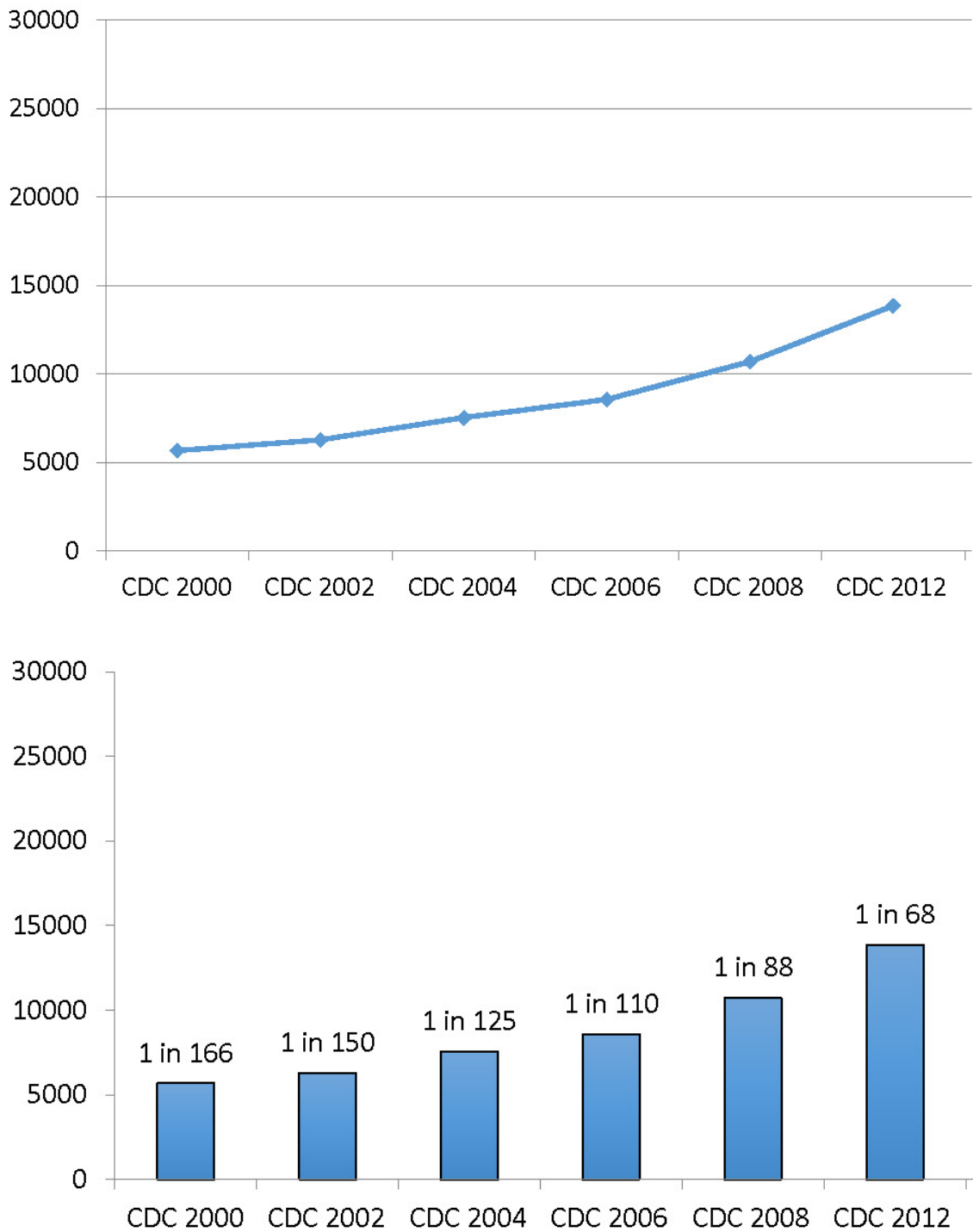
systems that are ill-equipped to work with people with ASD, and that do not recognize and support ASD. This results in additional costs and strain to these systems, as many people become trapped in a cycle of health and community interventions that fail to give them the appropriate tools. And this societal cost tells nothing of the hidden cost that comes from reliance on disability supports and other social service funding by some who simply require basic life, social and employment skills training, and perhaps low intensity ongoing supports. One Ontario study has recently concluded that almost 75% of people with ASD had an annual income below \$30,000, and that the source of income among over 50% of those people was a disability support, while less than 13% had fulltime employment and 6.1% had some form of part-time employment.<sup>32</sup> The cost associated with inappropriate supports is, in many ways, as much a failure as no supports at all. In creating supportive, inclusive and individualized supports that work for people with ASD, Nova Scotia has the capacity to be a society where our goals to support align with our goal to build a more sustainable economy, driving down dependence on costly and often cyclical usage of poorly tailored supports.

For the estimated 21,000 people with autism in Nova Scotia,<sup>33</sup> necessary supports are only beginning to take shape, and are particularly underdeveloped for adults transitioning from the school system. Those leaving

the school system, and their families, are finding what is commonly referred to as a “support cliff” as the wider supports available in school are not replaced, or are filtered by IQ-derived criteria, or are not supported by developmental service providers who lack the

knowledge or training to deal with complex and highly individualized needs.<sup>34</sup> The result is that people with ASD are experiencing a level of social and economic exclusion that many thought our society was well past.

Table 4: Estimated # of Nova Scotians with ASD in 2015—based on changing prevalence rates since 2000<sup>35</sup>





## Choosing Now: Building Sustainable Support through Collaborative Frameworks

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The 2013 Report of the Nova Scotia Commission on Building Our New Economy, or One Nova Scotia Report,<sup>36</sup> and the subsequent work of the OneNS coalition, called on Nova Scotians to address demographic and community sustainability challenges. To achieve these goals, these reports identified important priorities and objectives that could help achieve sustainable prosperity in the province by embracing a new way of coming together in common cause. AutismNS, and the grassroots and national solutions that it is helping build in this province, represent a model of collaborative, cross-sector mobilization, showing “leadership, a clear vision and effective planning that links collaborative effort to larger goals for mutual benefit.”<sup>37</sup>

On this front, AutismNS’s work aligns with several key goals outlined by the initial commission and carried over into the work of the coalition:

1. Labour market development: increase labour force participation to the Canadian rate—particularly by focusing on those groups and cultures that have been historically marginalized from participation;
2. Lower youth unemployment to the national average;
3. Post-Secondary education training: increase population of adults who complete a certificate;
4. Excellence in education and training;
5. A shared commitment to sustainable development and regulatory excellence; and
6. Integrating economic development services and promoting entrepreneurship.

Nova Scotia may face unique challenges in some respects, but AutismNS’s principle that inclusive communities are sustainable and prosperous communities aligns with a way of thinking that is defining the agenda around the world. This way of thinking aligns inclusion with sustainable development. Recent reports by the Canadian Council for International Co-operation have highlighted how the move at the federal and provincial levels towards inclusion aligns with the Sustainable Development Goals (SDGs) that Canada supported at the United Nations post-2015 development summit earlier this

year.<sup>39</sup> These SDGs called for, among other things, equal access to education and full and productive employment, along with the need for accessible schools, transportation and public spaces, and the enhancement of political, social and economic participation by persons with disabilities.<sup>40</sup> The OneNS reports and coalition, as well as the federal government, and a host of other United Nations organizations and member nations, all share the view that *full inclusion of people with disabilities is not only integral to the social and economic sustainability of any society—it represents a real opportunity*. Nova Scotia is no different, and a concerted effort to deliver efficient collaborative supports for people with ASD across their lifespans is one very important part of all Nova Scotians being part of a more sustainable future.

Together, we can choose *now*.

When looking at the broader autism landscape, Nova Scotia is already at the leading edge of grassroots initiatives for support, a strong participant in national programs, and a national leader in building clear systems and services that leverage community collaboration. As this report shows, AutismNS is coordinating, participating in, directing, and supplementing important services that are having a significant collective impact on Nova Scotia’s social, support and economic landscape. We hope that, in this time of transformation, the government sees that AutismNS offers a strong model for support and services. With government collaboration, this model will not only help Nova Scotia catch up to the rest of the country, but will create mechanisms to stably fund programs, services and supports that benefit every Nova Scotian.

# Introduction to the Issues Section

The following section moves through roughly divided areas of needed support and barriers to give readers a very broad understanding of the issues, AutismNS's position on ideal system outcomes, and recommendations for some steps to take towards an ideal system for that given area. Where appropriate, a cross jurisdictional comparison is used to highlight innovations or best practices that inform the recommendations.

## Early Detection and Diagnosis

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### PRE-SCHOOL DIAGNOSIS

Most children who are diagnosed with ASD are between the ages of three and five. For the majority of families in Nova Scotia, parents and caregivers are the first to notice differences or indicators in their child's development, and they then reach out to their family doctor as their first point of contact. In Nova Scotia, after speaking with their family doctor, the doctor then sends a referral to a multi-disciplinary team of professionals qualified to assess and diagnose in their region. The diagnostician(s) then make an appointment with the family at a designated site.<sup>41</sup>

A diagnosis in Nova Scotia is based on a number of tests that offer a profile of the child's strengths and needs. In the current process, a child waits between 1.5 and 2 years for an assessment. These long wait times result in reduced or delayed access to early intervention and supports. As research indicates that earlier interventions yield better outcomes, some families are choosing to pay for expensive private diagnosticians out-of-pocket in order to reduce wait times and access therapies for their child sooner.

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**Position:** Autism Nova Scotia believes that early identification and diagnosis are imperative services that ease early life transitions, help assure continuity of support, and reduce system expenditures by connecting young people with ASD and their families to appropriate service and support structures at the earliest possible time. AutismNS is a vital resource for families that have received and are working their way through the diagnosis process.

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### ISSUES

Several issues outlined in a provincial survey of professionals and families conducted by AutismNS in 2010<sup>42</sup> remain serious and costly barriers for individuals and the system. First, while improvements are being made in educating experts and professionals in the field, there is still a definite lack of understanding of ASD among many in the medical community; the AMAT report found that family doctors, psychologists, psychiatrists, and occupational therapists exhibit a limited knowledge of ASD. As a result, identification and diagnosis are often not taking place in a timely manner. Moreover, health and community service professionals, from physicians to daycare workers, who work with people receiving or have received a diagnosis are



often unaware of the services, supports and navigation assistance that AutismNS can offer in their communities. This is particularly problematic because while they wait for diagnosis (which vary by community), families often reach out to community and health resources such as libraries, internet support groups, other community groups, and additional health services in an effort to identify, locate and expedite any services or resources that may be available to them should they receive a diagnosis.<sup>43</sup> Finally, wait times are increasing in some regions to as much as two years, which puts these children past the age of pre-school diagnosis.

## SCHOOL AGE DIAGNOSES

Although many children with ASD come to school with their diagnosis already in place, there are children who enter school undiagnosed. These are typically what has been referred to as “higher functioning” children who may or may not have already been on a wait list for diagnosis, or whose differences have not yet been identified. Some are identified in the Primary grade enrollment process where students are screened for hearing by a speech-language pathologist. This is then frequently the first person to suspect an assessment may be appropriate. Once a child is in school, sometimes indicators may be observed by the child’s teachers. If concerns are identified, parents, administrators, and the school program planning team are consulted. The program planning team may decide to ask board-level student services staff to undertake further observation and to recommend strategies to the school and family to support the student. This all takes time and follows a lengthy process.

All school boards in Nova Scotia have identified specific staff members who have expertise in the area of autism. Some boards have autism consultants or specialists, while others have autism lead teachers. In some cases, the school psychologist will also observe and make recommendations. If evidence that the child may be demonstrating characteristics of ASD persists, the child will be referred on to the area autism team or a mental health clinic for further assessment. If the child is subsequently diagnosed with ASD, the mental health team will meet with the parents to discuss the survey and interview findings of the assessment.

## ISSUES

In some areas of the province, the psychologist or another member of the diagnostic team will also meet with the student’s program planning team at the school to discuss the diagnosis and the child’s learning profile. This process to identify and seek a screening for an Autism Spectrum Disorder remains the same for children throughout all grade levels in public schools across Nova Scotia. Wait times for public services remain a challenge. For school-aged children in the Central Region, for example, there is currently a two-year wait time for a publicly-funded assessment.

It should be noted that some families make the decision to seek out costly private diagnostic services for which they must pay in order to minimize wait time and the delay in interventions that could improve outcomes for their child. Also, it is important to note that children diagnosed at school age will not have access to the provincially-funded EIBI program, and there is currently no publicly supported intervention program after six years of age.

Apart from the sometimes dramatic inconsistency in wait times for assessment across regions of the province, there are several additional issues and gaps in diagnosing school age children (ages 5 to 21). As with medical professionals, knowledge and expertise about autism at the school level varies widely across the province. This lack of knowledge and consistency leads to children not being properly identified, and can often result in an incorrect assumption about their behaviours and how their challenges manifest, resulting in ineffective program planning that impact the child’s overall learning and school experience. Frequently, children who are so often presumed to be on the “higher functioning” end of the spectrum, having apparent use of language and no visible physical limitations, are thought of as having behavioural issues and/or attention difficulties, or as being willful and non-compliant. This results in a delay in effective interventions, and unnecessary stress being placed on the families and the individuals being misdiagnosed.

## ADULT DIAGNOSES

### ISSUES

As the prevalence of ASD in the population increases, so too does the incidence of adult diagnoses. Increased awareness about autism means that many people with Asperger's Syndrome or other "high-functioning" forms of autism (which are largely invisible disabilities), were previously misdiagnosed with another condition, and those who were not identified as children, may now be seeking and receiving diagnosis as adults.<sup>44</sup>

In this province, the search for a diagnosis as an adult is a difficult one, especially for individuals who have likely already struggled with barriers and challenges throughout their lives.<sup>45</sup> This search most often starts when an individual seeks help from a physician or mental health practitioner for related problems at work or in their social lives. Once initiated, the assess-

ment process itself can be accomplished relatively quickly and often brings considerable relief to the person finally receiving their correct diagnosis, as well as a clearer sense of the tools and tactics available to support ongoing success. However, the cost of a private diagnosis, which can be as much as \$3,500, is often prohibitive for this population, and adult assessment is not typically publicly funded in Nova Scotia. And because adults with previously undiagnosed ASD commonly look for a diagnosis because of struggles in employment, they often lack the financial means to afford a diagnosis. This can create additional mental health pressures, and cultivate a reliance on public/community services or the health system, for example, where an initial investment in the diagnosis would have given them the opportunity to connect to appropriate interventionist support from the ASD community. The system for adults acquiring an ASD diagnosis, as well as support for the period immediately after, remains costly and unclear.

## Early Intervention and Early Intensive Behavioural Intervention (EIBI)

Once a diagnosis is received for a child, however, the system becomes slightly more coherent. In Nova Scotia, preschool-aged children who have received an ASD diagnosis are referred to early intervention services professionals who, along with parents, ideally work with other related professionals to develop an individualized family support plan (IFSP). Early intervention programs help families with children from 0-6 years old.

In Nova Scotia, families with pre-school children diagnosed with autism are specifically entitled to receive Early Intensive Behavioural Intervention (EIBI), which is delivered for a maximum of one year, and is typically delivered the year before the child begins school. This leaves a significant gap between the time of diagnosis and treatment, which may be problematic.

Separate from EIBI treatment, there are currently 18 early intervention programs throughout Nova Scotia, delivering services to preschool children with special needs. AutismNS has well-developed relationships with many of the program providers involved in early intervention, though these connections remain largely through personal rather than through formal relation-

ships. There are currently no formal evaluation systems in place for early intervention programs in Nova Scotia, nor specialized ASD programs that look at optimal intervention during the early years. This makes for uneven service delivery across the province, puts pressure on the costly EIBI system, and is a lost opportunity for the province to use other ASD-specific early intervention models to optimize outcomes in the early years, and potential cost savings for children for whom EIBI may not be an optimal "fit".

In addition to these early intervention programs across the province, the Early Intensive Behavioural Intervention program is specifically tailored to autism intervention. EIBI started delivering service to families in 2005 when Nova Scotia introduced the program, using best practices behavioural techniques and a team-based approach to improve preschooler's communication and social abilities. EIBI is a one-year intensive program led by a therapist trained in Pivotal Response Treatment (PRT), supported by a team that includes speech-language pathologists. The therapist works one-on-one with the child in a naturalistic setting, typically their home or day care. Therapy occurs on a graduated timeline, beginning with approximately 15

hours a week and gradually reducing to 2–3 hours a week by the end of the year. Parents are also taught techniques to support their child's learning when the therapist is not present.

## ISSUES

Once a child is assessed and receives an Autism Spectrum Disorder diagnosis, their name is placed on the list to receive EIBI. In the early years of EIBI, there were too few trained professionals to deliver the EIBI program to all preschool children diagnosed on the Autism Spectrum. As a result, a random selection model was utilized to determine which children would receive the program. If a child's name was not chosen, the name was returned to the pool and was eligible for the next selection time. This system resulted in some children never being selected and they eventually aged out of the EIBI program.

There was some change to the system in 2011 with the infusion of more funds. However, the numbers of diagnosed children vs. service providers still results in delays in service. Due to limitations in resources, and in order to ensure all preschool children diagnosed with ASD have access to EIBI before starting school, the EIBI program is taking children aged four or five first. Some families are faced with the decision of whether to withhold their child from school for an extra year so that they are able to access the program. And, in some situations families are not receiving a full year of EIBI services due to availability of spaces and start dates.

With children being diagnosed earlier (some as early as two years) there is a gap in service for many preschoolers who may have experienced better outcomes with other earlier intervention programming. Moreover, the current one year model of for EIBI has been determined by the availability of resources, and is not delivered based on the needs and outcomes of the individual child. In addition, there needs to be a seamless transition from the specific treatment model of EIBI to the supports they will receive in school.

In the fall of 2014 the Minister of Health convened an expert panel on EIBI to advise on the increased demand for treatment and evaluate the implementation of the EIBI program to date. The panel submitted a report to the Minister that resulted in a further \$1 million investment in the program to ensure that children on the waitlist did not miss the treatment window before going to school. In 2015, another panel was convened

and resulted in an additional \$3.6 million investment. This further speaks to the demand for services which applies to early intervention, but is symptomatic of demand across all aspects of the lifespan.

Although the new investment of funds addressed the immediate needs of the EIBI program, specifically the ever growing wait list, it did nothing to address the long-term demand for this program and the wave of children who will need access to this treatment in the coming years.

The province also needs to look at the role of EIBI as part of a continuum of services for preschool and school aged children. No one service should exist in isolation or without a continuum of support and intervention as a child ages and progresses through the school system, otherwise gains can turn into regression, and investments in optimizing long-term outcomes for Nova Scotians living with ASD are lost.

## IDEAL SYSTEM OUTCOMES

An ideal system for EIBI is one built through a collaborative delivery model that creates clear pathways at time of identification, diagnosis and early intervention. To facilitate the delivery of this outcome, AutismNS proposes the development of Autism Resource Centres that would, among other things, help coordinate the connection between families and early interventionists and other experts, thus easing the burden for families during the identification process and after diagnosis. Other provinces have models of service and supports in the pre-school years that we can learn from a part of a continuum of care model.

AutismNS believes there should be an evaluation of the effectiveness of the system around accessing EIBI and additional funding made available to mitigate the gap between needs and available services.

AutismNS will continue to work with school boards across the province; identifying schools that need additional support in autism awareness and education, and working to connect teachers to appropriate resources that will help them gain a familiarity with and ability to recognize the signs, strengths, and challenges associated with ASD.

## RECOMMENDATIONS

1. Improve access to timely and high-quality diagnostic services for pre-school and school aged children in Nova Scotia. This maximizes opportunity for these children to access the EIBI program and other ASD specific services that can impact outcomes in the early years.
2. Develop and implement high-quality and affordable diagnostic services for adults in Nova Scotia.
3. Re-convene the Minister's panel on EIBI, including participation by AutismNS, to advise on a long-term early intervention and EIBI strategy for the province. Exploration of parent-implemented training initiatives as intervention options should also be explored by this panel, as well as a cost analysis to increase treatment capacity to include complimentary therapies (e.g. speech language, physical and occupational therapy, other behavioural therapies) as part of a comprehensive, publically funded ASD support system in Nova Scotia.
4. Increased and enhanced access to training or coaching in ASD intervention for parents/ caregivers with children with ASD of all ages.
5. Include autism screening, diagnosis, treatment and support in the early years centres' model that is currently under development by the province.

## Family Support: System Navigation and Community Collaboration

Autism impacts not only the individual but all family members. Families need help to find the best supports for everyone in the household. These include access to support groups, information about professionals and therapies not offered under provincial medical plans, and finding advice for future planning for the health and well-being of the person with ASD. Many families are overwhelmed at the time of diagnosis, and it takes a great deal of energy and effort to uncover and understand what services might be accessible to them.<sup>46</sup> Furthermore, each transition over the course of their loved one's lifespan requires families to access new networks of supports. Families need a navigator to help them find the options in the system and the portals to access. They also need a navigator to help them understand the impact of services and the importance of determining a plan and course of action at each stage.

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**Position:** AutismNS believes that support for families and assistance in navigating the complex range of services and programs available to them across the life span is a crucial component of a supporting people with ASD.

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### SYSTEM NAVIGATION SUPPORT FOR FAMILIES

The Autism support and service landscape in Nova Scotia is multi-sectoral and diverse, and an individual or family's experience navigating it can be dramatically different depending on their geographic location, types of need, and financial resources. Because of the complexity and dynamic nature of their situations and needs, it is important that an experienced point of access for navigating the system is available, and clearly visible, to people seeking support and services.

Already experienced and connected to resources and communities across the province, AutismNS is a valuable navigation support that benefits the entire system on this front. Between April 2014 and March 2015, AutismNS's single Outreach Coordinator handled over 800 calls from families and individuals looking for support, or an average of four calls a day, and is on track this year to exceed that number by as much 15-20 per cent. These, of course, are only the calls that come to AutismNS's single outreach staff person in its central office in Halifax—hundreds of other calls are handled by Chapters or by additional program and service staff over the course of the year. AutismNS is already uniquely positioned as the visible, experienced interventionist in navigation support, acting as a referral point or first stop for many families and people looking for support. But important issues remain to be addressed in order for this to be sufficient and sustainable.

## ISSUES

### ***Building Capacity and Formal Evaluation across the Province***

It has been shown that navigation support that is trusted and knowledgeable is among the most important resources for reducing stress among families raising a child on the Autism spectrum. Recent reports from Ontario, where that province's Autism Society has been funded to routinely evaluate the qualitative impact of navigation support, show a marked reduction in anxiety and stress among those families who access their autism centres and Chapters for help in navigating the multi-sector care and support system. AutismNS knows the work that it is doing to support families across the province is impactful, and it is devoting substantial resources to it. Currently, AutismNS has one full-time outreach and navigation support staff person, whose week is divided into duties that include community education, outreach, community collaboration, and Chapter support—leaving about fiveeight hours per week for navigation and intervention support for Autistic individuals and their families. An additional part-time staff person has recently been hired to help add capacity, logging as many as 20 hours per week in additional family supports. System navigation—directing people to appropriate services and connecting them to community supports—is a major component of their efforts. Despite the recent increase in staff, however, demand is consistently exceeding available resources. AutismNS has the ability to track and record the impact of its family and system navigation support but is limited by resources. Additionally, because only the central Halifax office has a devoted staff Outreach Coordinator, which mean that person takes calls from regions all across the province.

While AutismNS is already best situated to help families, the current system faces several issues that we feel could be easily addressed with stronger collaboration and support from government. Autism Nova Scotia:

1. Relies heavily on a very few staff members for knowledge of all services, programs and supports across multiple sectors and multiple geographies;
3. Has important information being shared on phone calls and office visits that needs to be better tracked in order to ensure energies and efforts are directed effectively;

4. Is under-resourced and demand is consistently high, so that efforts at evaluation and formalization of a system that records impact and maps services are superseded by the day-to-day needs of families for basic navigation support.

Nova Scotia needs to continue to track and report on how it is helping people navigate the Autism system, and monitor what supports and services people are seeking, the impact of navigation assistance itself, and direct development by identifying gaps and points of higher use across sectors.<sup>47</sup>

### ***Family Support through Community Collaboration***

A second, related issue around family navigation is the need for increased collaboration, coordination and education in the community. Last year alone, AutismNS's Outreach Coordinator conducted 24 presentations, five education series presentations, one Chapter Workshop, and four meetings for potential support group development, reaching over 650 people. These numbers do not include extensive employer and employment service provider outreach outlined in the Employment section, and training delivered to Security and First Responders outlined in the *Safety in Communities* Chapter of this report. In addition, with the help of the new part-time staff person, AutismNS's outreach has built connections to:

1. School Boards and Autism Specialists, as well as the Student Services Facilitators across the province;
2. Preschool Transition Specialists who, along with Autism Specialists across the province, are promoting our classroom presentations with their school communities, and connecting with families who need help navigating supports;
3. Department of Education (Student Services Division—Special Needs Consultants, and the Provincial Autism Consultant);
4. Special Education Programs and the Services Advisory Committee;
5. Department of Community Services (Disability Support Program);
6. IWK Health Centre (Developmental Clinic, Preschool Autism Team, School-Aged Autism Team, Autism Research Centre, Maritime Psychiatry, Social Work Dept., Occupational



Therapy Dept., EIBI Team), which frequently uses AutismNS as a referral point for families looking for support;

7. Early Intervention Services (contacts with most of the 18 programs);
8. Daycares across the province; and
9. Private service providers (psychologists, speech language pathologists, behavioural specialists, private school options).

The efficiency of the entire support system depends on families' ability to know about and get to services, which itself depends on having system-literate navigators. This is to say nothing of the role that outreach plays in avoiding the duplication of services, identifying gaps in the continuity of services and supports, and spotting opportunities for collaboration. AutismNS has shown a remarkable ability to absorb demand from the community for navigation support, but its ability to accomplish extended outreach is limited by the amount of resources available.

## RESPITE SERVICES AND NAVIGATION

Respite is another important component of family support that requires navigation.<sup>48</sup> Hired by families and caregivers, respite workers give a short period of rest or relief from a the continuous responsibilities of care for persons with disabilities. AutismNS has also recently expanded the application of respite to include the use of respite workers to mentor Autistic Nova Scotians, assist them with socialization, and increase their participation in the community. The benefits of respite are well documented, and studies find that it “can encourage inclusion, dispel myths related to disability,...promote citizenship,” and relieves stress on a family unit.<sup>49</sup> However, families in Nova Scotia struggle with how to obtain respite workers. With the daunting task of finding suitable and qualified workers falling to families, as well as using energy and resources to train them in the needs of their family member, and find funding to pay them, receiving respite can be an overwhelming process.

Rather than directly delivering individualized respite support, AutismNS has organized once-disparate service providers into a centralized database that connects families across Nova Scotia with respite workers in the province's first comprehensive Respite Database. In partnership with the Department of Community

Services, [respiteservices.com](http://respiteservices.com) and the Geneva Centre for Autism in Toronto, AutismNS's Respite Database serves the greater Halifax area for a relatively low annual operating cost. Costs of this initiative include an annual platform fee, and the annual salary of a part-time Respite Database Coordinator who tracks respite workers, recruits new workers, processes and runs intakes and certification and background checks, ensures workers have completed specialized online training and respite orientation sessions, and connects families to appropriate respite providers.

The Respite Database has provided an accessible service that is building formal connections between respite workers and families caring for people with ASD across Nova Scotia. By the second year of operating the Respite Database, AutismNS recognized that it has the potential to connect the growing numbers of families needing respite support for their family members with other disabilities to qualified workers. Groups from across the disability service sector have reached out to collaborate with AutismNS, including the Halifax Association for Community Living and Easter Seals Nova Scotia. Initially launched to support families with a loved one on the Autism Spectrum, the Respite Database program has been expanded to support all disabilities.

## ISSUES

### *Uneven Access to Respite Services and Difficulty Navigating to Supports*

Among the most significant issues that confront people looking for respite care across the province is the uneven access to qualified respite workers across regions. While respite service providers in the Western, Northern and Eastern Region of the province still operate, increasing demand for services has steadily outpaced funding, and the geographic scope of the service providers' mandated areas of coverage poses tremendous challenges—especially in rural Nova Scotia. This is most acute for those caring for persons with complex and challenging respite needs, which have commonly gone unmet in the province.

Families are often reaching crisis points in part because of inadequate respite support, and the effect of deferred investment in upfront respite support increases costs down the line. Many families are therefore frequently turning to the emergency care system and residential care options, both of which bear significant

costs to the province compared to the relatively small cost of an investment in respite. And, unable to access any other kind of relief from the strains of being caregiver to a family member with complex and significant support needs, still others are being forced to rely on police and others when crises erupt.

An additional barrier to respite support is the access to the Direct Family Support funding, which remains accessible to people with an IQ of less than 70. Evidence shows that many of the families of people with ASD who test above IQ70 still require support. This leaves many families with children who do not qualify as intellectually disabled but are nonetheless unable to be left alone or safely function independently with little recourse.

The database is already showing its potential to track and report on several important areas of service that relate to respite. Using the database, the Respite Coordinator is able to map system resources and services, track the ratios of respite workers in different regions across Halifax, identify peak times that families

*“Many families with children on the spectrum are too busy attending to their day-to-day needs to have the energy for seeking out, interviewing and hiring a respite worker...having access to the database and all the helpful information Autism Nova Scotia provided streamlines the process enormously.”*

—Family member relying on the Respite Database

are in need of hiring a respite worker, when workers are most commonly available, and the types of support families require versus what workers are able to provide. However, instability in long-term funding of the Respite Database limits the time able to be spent on developing these reporting functions.

## CROSS JURISDICTIONAL COMPARISON

While AutismNS already represents a strong resource and support for navigating the ASD support and service system, there are several innovations across the country that would help build navigation support capacity, and improve the evidence base for constructing and delivering programs, services and supports in Nova Scotia.

### *Regional Autism Resource Centres*

While Nova Scotia already has the benefit of AutismNS and their extensive and remarkably well-organized

series of Chapters, a number of provinces provide funding for local autism resource centres through the autism societies in their province. Examples of these can be seen in areas such as Saskatchewan and Alberta. However, the Autism Resource Centre (ARC) model that has achieved particular success in New Brunswick represents perhaps the most promising system innovation that could strengthen Nova Scotia’s already well-organized Chapter system. In New Brunswick, ARCs are funded by the Department of Health, through its Mental Health Division, via a purchase of service agreement. The Centres are tasked with providing social supports to people with ASD, their families, and anyone else connected to an Autistic individual looking for support (regardless of age). Typically, ARCs have books, videos, educational material, appropriate toys, and equipment for projects like laminating, printing, binding and other services.<sup>50</sup>

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**Snap Shot:** AutismNS is currently helping support a family with two sons on the Autism Spectrum. The family was denied respite funding because their sons’ IQ levels tested above 70. However, the parents were recently pushed to the brink of crisis, and ended up calling both the Mental Health Mobile Crisis Team and the police because of their son’s challenging behaviors. The system paid thousands in reactive services that do little to address the support needs of the individual, where a fraction of that money invested in respite care could have prevented the crisis altogether.

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Centres in New Brunswick are tasked with achieving the following objectives:

- Provide a place where people can meet to exchange ideas and information and develop a sense of belonging;
- Provide families, children and youth with opportunities to participate in meaningful activities, which contribute to increasing their well-being, self-esteem and social functioning;
- Foster community integration and inclusion;
- Assist families to gain access to community-based resources; and
- Educate the public and the formal service delivery system about Autism Spectrum Disorder.

ARCs in the New Brunswick model share a similar series of objectives and values to those of AutismNS and their Chapters. ARCs build partnerships and a broad array of stakeholder involvement and experience, develop existing community resources, enhance community capacity for integrated resource availability, act as a key component of a support network, and complement and enhance the formal service delivery system in their regions.<sup>51</sup>

There are two major differences between the Nova Scotia and the New Brunswick models. First, each New Brunswick ARC is provincially funded for approximately \$30,000 annually, which pays the salary of a part-time coordinator and some overhead costs. This government funding has made it possible for New Brunswick to have multiple, locally attuned ARCs across the province (see Appendices for locations). However, in New Brunswick the ARCs grew out of a government effort to fund local initiatives, rather than building on the strengths of an existing pan-provincial, grassroots movement like AutismNS and their Chapters. As a result, the lines of communication between New Brunswick ARCs are limited, and they lack a shared navigation platform and evaluative structure that could consolidate information about interventions, referrals, service needs and gaps.

This underscores the importance of the 2010 AMAT recommendation that:

Regional autism centres should be located and coordinate services in key areas of the province. These would be built upon already existing infrastructure and would enhance services already available. They would include a lending library and resources for families and parents. A navigator or case manager, who can offer the information and access to required services, would be available. This will offer seamless and “wrap-around” services from childhood into adulthood within an inclusive system.<sup>52</sup>

By linking into and supplementing the Chapter system of AutismNS, the autism community across Nova Scotia could be instrumental in meeting the growing demand for ASD navigation support; connecting local knowledge and initiatives to a coordinated network in a way that addresses some of the inequity in service delivery while avoiding the pitfall of developing silos and duplicating efforts.

### ***Developing a Potential Programme in Nova Scotia for Programming, Services and Support***

While also addressing how to meet the growing demand for support, many autism organizations are moving towards impact and evaluation platforms that increase their ability to engage the community, while building a means to report on and track the work of system navigators. Perhaps the strongest model of this kind of tracking and evaluative platform is the Potential Programme (PP) now used by Autism Ontario and its Chapters.

The Potential Programme was developed to directly support parents of children with ASD through:

- Greater access to information;
- Direct contact between parents and Autism Ontario chapters;
- Improved access to experts in local communities; and
- Increased community-based learning opportunities for children with ASD.

The program is primarily funded by the Ontario Ministry of Children and Youth Services, which has invested \$2.3 million in program delivery of which four per cent is earmarked for evaluation.

PP includes several tools to track and evaluate Chapter activities and capacity in reaching objectives outlined by families and people with ASD on intake. These evaluation tools found, among other things, a substantial increase in the number of chapter events offered since the inception of the PP, and a substantial increase in the average number of calls to PP Chapters over the last nine years, since the program started. The most common reasons callers gave for contacting Chapters were: knowledge of Autism Ontario activities and resources; school-related issues; and community services. The evaluations of the program also revealed that access to navigation support, and proper tracking of cases by navigators, actually yielded a significant decrease in family stress levels and improvements in well-being.<sup>53</sup> While these benefits are difficult to monetize, that they are saving the system money and resources is undeniable.



## IDEAL SYSTEM OUTCOMES

AutismNS strives to build the means to help families and people with ASD navigate the Autism support system with clear windows of service entry, constructing a spoke-and-hub model of service navigation support; one built around key shared and predictably-funded infrastructure, and consistent evaluation.

Taking into account Nova Scotia's population (around 1/13th the size of Ontario), as well as its comparatively rural distribution, AutismNS would like to see an investment made into a Potential Program (PP) in Nova Scotia, with a commitment that AutismNS Chapters will provide in-kind volunteer hours to augment part-time staff resources that would come as a result of this investment. Funding would be for deployment of the PP in the existing ANS Chapter regions of NS, with additional money reserved to ensure Cape Breton's participation.

As the findings from Autism Ontario's deployment of the PP showed, funding for program evaluation provides critical data to inform decisions to identify, maintain or expand effective program components. Therefore four per cent of the funds would be held for evaluation and development of the program.

The same need for critical funding for program evaluation also applies to the Respite Database and its deployment. After initial evaluation, and when coupled with a roll-out of the Potential Programme, a core-funded Respite Database would help equalize access to family relief through respite support across the province, and act as a tool for existing respite coordinators in regions across the province.

With extended funding for the Respite Database, AutismNS will work with other disability groups to explore how the database can serve the cross-disability community.

With the requested provincial funding, AutismNS will be able to explore how to extend or scale up the Respite Database model. AutismNS would also work to develop tools within the Respite Database to track, report, and help clients to navigate support tools in areas such as self-managed care, workplace attendant programs, job coaching, academic support during post-secondary education, etc. The cost savings of data-basing and creating connection between families and these services at a systems level, rather than relying on individuals to acquire support on a case-by-case basis, are difficult to measure but are nonetheless powerful indicators.

AutismNS, with a fully deployed and funded PP program and Respite Care Database program, would work with evaluators to report findings on program needs and service gaps to Chapters, as well as to the relevant government departments and community sector stakeholders, to help direct development of supports and services.

The impact of this work, and the reach of both navigation and respite functions would be greatly increased were the province to agree to an investment in funding for Autism Resource Centres (ARCs) in Nova Scotia. These ARCs would be an amalgam of the New Brunswick model outlined above and the existing chapter system that the grassroots ASD community has built. AutismNS would provide space and its Chapters would absorb any related overhead expenses through fundraising or by adjusting the hours—with commensurate salary adjustments—of the coordinator.

AutismNS would coordinate the ARCs, adjusting its Outreach Coordinator's responsibilities to take on a directing role in order to ensure all ARCs provide consistent, standardized navigation support. This would provide the foundation for increased programming and service development among the Chapters, and regular accounts of the impact and results of their local family and individual support.

If stable funding were invested in an ARC system that supplemented the existing AutismNS Chapter system in Nova Scotia, AutismNS would re-allocate the energies of its current Chapters and Outreach Coordinator to direct and coordinate, in all regions, increased:

1. Outreach
2. Education
3. Navigation
4. Surveillance and program impacts (using the Potential Programme model)

## RECOMMENDATIONS

1. Implement Regional Autism Resource Centres (ARCs) by utilizing the Chapter system developed by AutismNS, and working with AutismNS to set up a seamless “wraparound” service system for families navigating the system from the time of identification, through diagnosis and support throughout the lifespan. The existing system, currently supported mostly by volunteers, cannot absorb the current demand in rural Nova Scotia without an investment by government. For the province, the proposed model represents a cost effective approach and fulfills the outstanding AMAT recommendation that was identified as a top priority need by families across Nova Scotia. In addition, like the models in Ontario and New Brunswick, implementing this model provides the opportunity to enhance community capacity, promote integrated services, and standardize sharing of information and best practices.
2. Continue investment in respite support in partnership with AutismNS which would ensure the continuation of the respite database program, training of respite workers in ASD across the province, as well as, further explore structured respite programs for families (March Break and after school options).
3. Ensure that community recreation programming across the province is accessible to children, youth and adults with ASD. This includes an investment in ASD training and access to appropriate accommodation support for Autistic participants.
4. Remove the IQ criteria as a qualifier to access services for families living with ASD in the province, or add Autism Spectrum Disorder as its own category based on a level of need system that is individualized to the family and individual with ASD.

## Healthcare

Children diagnosed with ASD have unique health care needs that require complex care from multiple health and clinical specialists that typically continue throughout their lifetimes. Children and adults with ASD often require multi-disciplinary care from a range of service providers including medical professionals (e.g., family physicians, pediatricians, psychiatrists, nurses), psychologists, behaviour analysts and interventionists, speech-language pathologists, occupational therapists, educators, and social workers.

**Position:** AutismNS believes that all people with ASD, of all ages and regardless of the complexity of their health needs, have a right to access health care in a timely manner, that does not impede their development, health outcomes, or potential.

The complexity and heterogeneity of ASD requires a broad approach to addressing the health needs of this population that includes quality basic health care, disability-specific services, and evidence-based autism-specific interventions (including ongoing

comprehensive assessments). Continuity of care for individuals with ASD and their families can be effectively managed in multidisciplinary Primary Care settings, and AutismNS is encouraged by moves in this direction being undertaken by the Department of Health and Wellness.

### ISSUES

Currently, most medical supports targeting individuals with ASD are focused on diagnosis and early intervention in children, but the service needs of children and adults with ASD are much broader, and encompass the entire lifespan.

#### *ASD Training for Health Professionals and Paraprofessionals*

The AMAT Report identified a surprising lack of understanding about ASD within Nova Scotia’s community of health care professions—family doctors, psychologists, psychiatrists, and speech language pathologists. This lack of knowledge has real impacts on the timeliness of ASD diagnoses.<sup>54</sup>

Further to this, in the post-diagnosis period, many families go unsupported as they wait for early intervention services (EIBI). In the intervening period, parents of children with ASD often seek help from professionals to find resources for their child (e.g. early childhood educators, social workers), but many of these professionals are similarly unequipped to assist families to find appropriate services. With the proposed funding, AutismNS Chapters are positioned to provide much-needed assistance to families seeking help and service providers seeking information.

### ***Mental Health Services***

Co-occurring mental health concerns are common among persons with ASD, including high incidence of anxiety and depression in adolescence and early adulthood, conditions such as Conduct Disorders and ADHD, and learning disabilities. Accurate mental health diagnoses can sometimes also be confounded by the communication difficulties common to individuals with ASD, which can delay the provision of appropriate treatment. Not surprisingly, people with both ASD and co-occurring mental health conditions are more likely to interact with crisis-associated social service systems (i.e. Mobile Mental Health Crisis Unit, child welfare, alcohol/drug treatment, justice), so more effective mental health care for individuals with ASD would result in significant cost savings to these resources as well.<sup>55</sup>

In addition to this, it is also important to acknowledge that the mental health care needs of family and caregivers are also commonly unmet. A full continuum of care for individuals with ASD would include preventative and acute mental health care for the key members of the family or personal support team.

### ***Homecare***

As part of the Department of Community Services' (DCS) ongoing transformation process, disability service provisions are transitioning to a "direct care funding" model, which puts the onus on families to administer care teams and supports for their loved ones. AutismNS supports DCS's intention to move from a facility-based system to a more individualized support model that respects the agency and existing strengths of families affected by ASD. Given the growing burden of care associated with increased prevalence of ASD, the potential for significant cost savings under the new

system (compared with acute health care settings) is also attractive. It is important to strike the right balance, as further outlined below.

## **IDEAL SYSTEM OUTCOMES**

To ensure early diagnosis, timely intervention, and appropriate support into adulthood for persons with ASD, Nova Scotia must prioritize ASD awareness and professional development for health care professionals across the continuum of care, and across the lifespan.

Investments in mental health care and crisis intervention would help families to navigate the most challenging aspects of supporting a loved one with ASD, and help the overburdened health care system to avoid the long-term costs of leaving these families unsupported.

A well-supported homecare system for persons with disabilities will help persons with ASD in need of more complex health care to age with dignity in a supported care environment, will give families peace of mind, and will generate significant cost savings relative to expensive hospital care (up to \$35,000 per month) for individuals with ASD with high support needs.

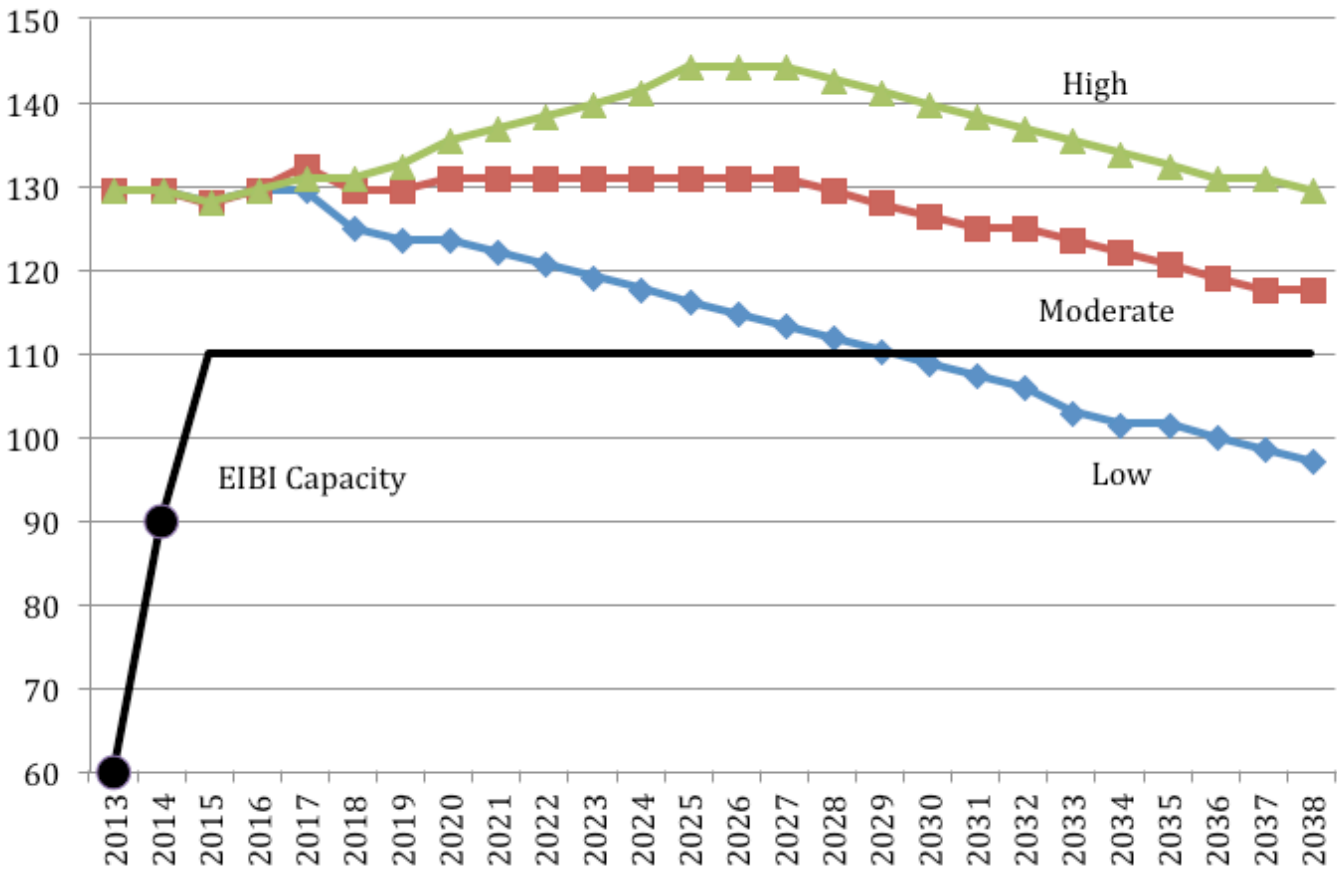
Any mental health strategy must understand the particular vulnerability of people with ASD, should address the mental well-being of caregivers, and ensure that it adopts a holistic idea of support as including access to respite and employment assistance as integral to the mental health of a person with ASD and their families.

## **RECOMMENDATIONS**

1. Develop autism-specific competency and capacity in the health care system to provide appropriate care, including crisis care, for children, youth and adults with ASD, with a particular focus on: mental health, first responders/emergency rooms, primary care and dental care.
2. Recruit and retain qualified clinical professionals with ASD expertise to support the complex and challenging needs of this population in order to ease waitlist times for service, and to ensure adequate staffing ratios are in place to avoid professional burnout and loss of service.
3. Create standards of care that include "autism friendly" spaces in all health and mental health settings across the province.

P-12 Education

Table 5: Projected Population of Nova Scotian 4 year olds with ASD to 2038



Projection assumes an overall population decline in Nova Scotia, built on 3 potential population growth scenarios (High, Moderate, and Low)<sup>56</sup>, with the incidence of ASD at the current level of 1:68. The EIBI Capacity line (black) indicates program capacity in 2013 & 2015, then held constant to 2038.

Nova Scotia's Primary and Secondary Education systems are critical sites in our efforts to improve the lives of Autistic Nova Scotians.

In 1996, Nova Scotia's Department of Education adopted a new school inclusion model ensuring that children with exceptional needs were integrated with their same-aged peer group in regular classrooms. At that time, our education system had little expertise or experience with appropriate teaching techniques for children with ASD. A Children and Youth Action Committee was formed to study best practices and this led to the Early Identification and Intervention Services (EIIIS) pilot project for children with ASD.

**Position:** Primary and Secondary Education for children with ASD should set a solid foundation for each child to become a more fully-realized healthy individual and, where possible, to achieve an appropriate degree of independence in adulthood.

Since that time, Nova Scotia's education system has made considerable progress toward serving the needs of children with ASD.

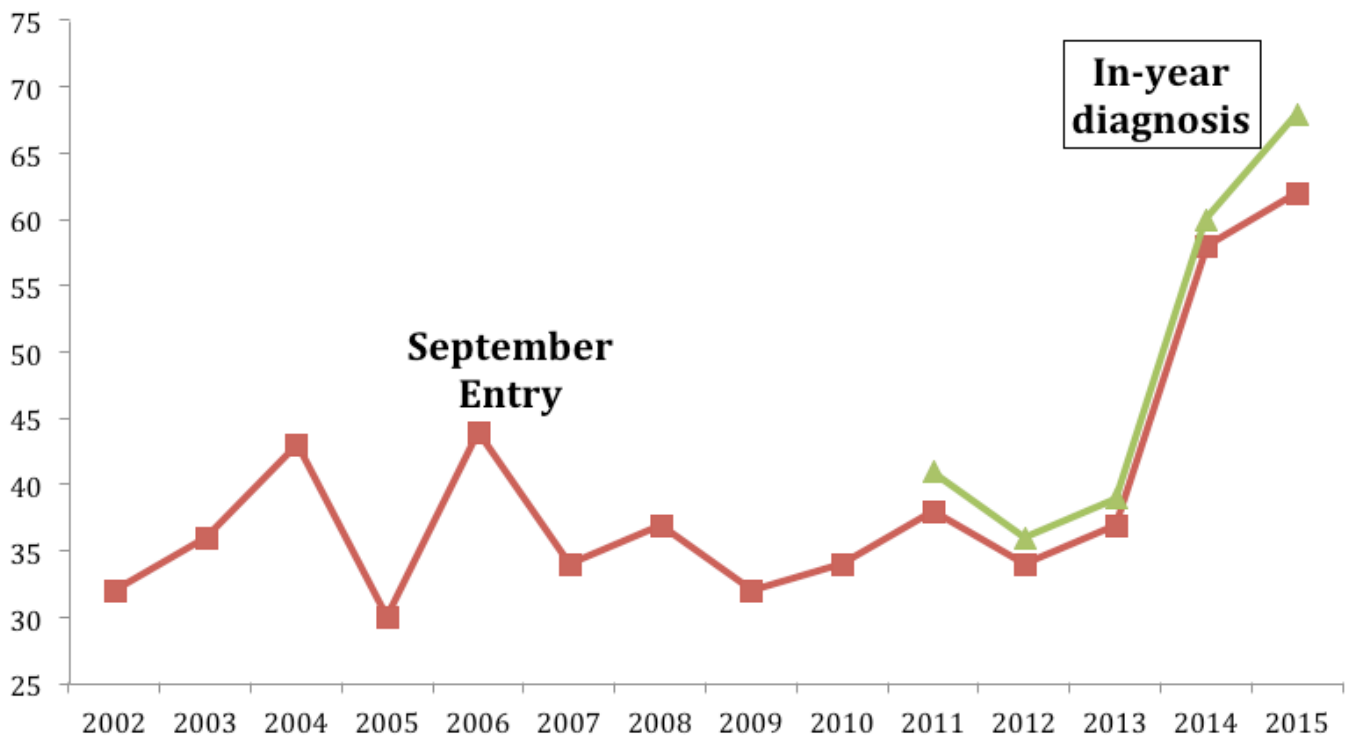
- The provincial Special Education Policy sets out clear expectations for the transition of children with ASD into primary school and for individualized special education program planning.<sup>57</sup>

- All school boards have staff resources to support the learning and development of children with ASD (i.e. autism consultants or specialists, school psychologists, speech-language pathologists, and special education consultants).
- Each school board receives targeted funding for professional and paraprofessional training on autism (e.g. total provincial budget of \$413,000 in 2012; see N.S. Education Action Plan).<sup>58</sup>
- School boards have Teaching Assistants to provide individualized support to students requiring medical care, personal care, and/or safety behaviour management.

## ISSUES

The number of children entering Grade Primary with an ASD diagnosis has risen precipitously in recent years, and recent provincial investments have increased the capacity of the EIBI program. The number of ASD diagnoses during the first year of school is also increasing. In one respect these are positive developments, because we know that early diagnosis and intervention can provide children with ASD much greater opportunities for healthy development and future success.

Table 6: Nova Scotians entering Grade Primary with an ASD Diagnosis (2002-2015) or Receiving a Diagnosis during Their Primary School Year (2011-2015).<sup>59</sup>



At the same time, the increasing prevalence of Autism creates significant resource and capacity challenges for the education system, which can result in below-standard services and supports for some children with ASD. These issues include:

- Transition to school and program planning processes set out in the *Special Education Policy*, though extremely positive and effective when followed, are not always adhered to consistently throughout the province.
- School Boards already face critical human resource shortages with respect to speech language pathologists, skilled behavioural interventionists, occupational therapists, and school-based resource teachers.
- Overall knowledge of ASD within School Boards (and individual schools) is well below optimal, even among more highly trained support staff and new teachers entering the system.
- The number of Teaching Assistant positions typically does not match the number of children with ASD requiring individualized support.
- School-to-employment and school-to-post-secondary transitions are becoming increasingly complex but are inadequately supported in the school system.

Each of the above issues become even more challenging as the number of children with ASD grows. In fact, the most recent prevalence rate estimates from the CDC (1 in 68) suggests that the resource burden will grow even larger, but we know that this challenge must be met head-on. Failure to properly support children with ASD inevitably creates even greater resource needs later when these children become less-than-fully-independent adults.

## IDEAL SYSTEM OUTCOMES

AutismNS is well positioned to complement the core services of the education system by acting as a navigation and referral hub for individuals and families during the child's transition into and out of the school system. But this is only feasible if AutismNS is resourced appropriately.

Development and implementation of Autism Resource Centres (ARCs) would create the potential for a spoke and hub navigation and information sharing system that would facilitate broader, more efficient navigation

of transitions through the school years and thereafter (see Appendix 2: Proposed NS Autism Resource Centres). This would ease some of the existing resource burden on the education system and would more adequately set-up children and youth with ASD on a path to better outcomes.

Of course, several of the critical resource shortages identified can only be addressed through additional investments beyond the ARCs. There is a need for more skilled support professionals and more professional training to increase general awareness and overall knowledge among staff that interact with children with ASD both in and out of the classroom.

The findings in the Department of Education's report, *Disrupting the Status Quo: Nova Scotians Demand a Better Future for Every Student—Report to the Minister's Panel on Education*, October 2014, acknowledges the shortcomings of the current education system, including gaps in curriculum, too few supports for special needs students, the need for active use of technology to maximize communication and learning needs, the need for highly qualified specialist teachers trained to support students with identified complex learning needs, and improvement in providing parents with more information about services and how to effectively access them.<sup>60</sup> Collaborative work will be critical in addressing these gaps for students with ASD in the school system.

## RECOMMENDATIONS

1. Ensure that education professionals and support workers have strong autism-specific knowledge and skills that optimize learning for all students with ASD in the school system.
2. Maintain and review appropriate staffing levels in specialized positions (Autism Consultants, assistive technology positions, speech language pathologists, occupational therapists, behavioural specialists) in school boards, and the Department of Education and Early Childhood Development. These ratios have not been reviewed in five years, and have not considered the increase in diagnoses we are seeing in the school system.
3. Develop transition support programs for school-entry at the elementary and secondary levels, as well as transitions from high school towards community or post-secondary opportunities.



4. Ensure access to appropriate life skills and job training curriculum to support improved and enhanced transition success to adult life.
5. Develop autism education “centres of excellence” with highly-trained teachers and professional support staff who consider the unique and complex learning needs of students with ASD in each school board. This also represents an opportunity for ongoing training and professional development of education professionals who can then transfer knowledge and skills to all learning environments, further maximizing outcomes for all students with ASD and other special needs. This is also a cost-effective approach to educating and training skilled professionals.
6. Explore models of innovation in the school system for possible province-wide replication.
7. Partner with AutismNS to conduct an environmental scan of the school system that reviews the consistency of the program planning process and overall experience of families and students with ASD.

## Housing and Community Living

A unprecedentedly large cohort of Autistic Nova Scotians are reaching adulthood in the midst of a housing shortage. This is not just a general housing shortage, but specifically a shortage of *appropriate* housing options for adults with ASD.<sup>61</sup> A home is more than a roof over a person’s head; it is the nexus of their social life, a gateway to community living, a haven when the outside world is rough, a stable residence, and a source of dignity and pride. Without a home other sources of stability, such as employment and post-secondary education, would be impossible to sustain.

In short, housing is the foundation of community living and where efforts to ensure independence, enable contributions to society, and avoid social isolation start. In recent decades, community living—having one’s home, school and work integrated in a community as opposed to marginalized in an institution—has become a central goal of disability advocacy groups and the government. But meeting this goal has been an uphill battle. Community living requires specialized supports, and supported housing, its foundation, is in short supply.

Although AutismNS does not itself coordinate or provide community housing or accommodations for people with ASD, it often finds itself serving as a first stop for families trying to navigate the housing support options available to them, particularly when their children are nearing adulthood. Thus, AutismNS has heard first-hand from families about the challenges they face and the strong desire for attachments to community into adulthood, and it has seen the “domino effect” that shortages in appropriate housing have

on other areas of service provision, support, and family and community well-being.

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**Position:** AutismNS believes that any strategy to promote community living and address the housing needs of adults with ASD must focus on developing an adequate supply of a range of different housing options, located and distributed according to community need, so that people with ASD and their families across the province can truly and freely choose the living arrangement and level of support that works for them.

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### ISSUES

#### *The Importance of Community Living*

The push for community living—one component in a wider integrationist movement—has emphasized the importance of community attachment and integration for quality of life for people with disabilities and ASD. It has also underscored the financial and social savings that are likely to accrue when governments and communities invest in “the whole person”, assuring them the freedom to have a range of experiences and to build relationships with different people and places.

The community living movement has given rise to enhanced recreation and leisure programs and services for people living outside of 24/7 care facilities, programs geared toward building independence-skills, and social interaction programming that gives people access to environments where they learn to make and keep friends. Particularly important are adult services

and day programs that begin once the structure of compulsory K-12 schooling and extra-curricular activities are no longer available to them. Autistic individuals use these programs alongside people with intellectual disabilities and already benefit from them greatly, but there is additional work to do in providing appropriate programming for people with ASD (for more on the programs offered by AutismNS in this area please see the chapter on Adult Services). The effect that support programs, particularly those that are designed to facilitate social interaction, have on mental health and capacity for independence in people with ASD is difficult to overstate. Moreover, such programming benefits communities at large, particularly where they facilitate organic, locally-led initiatives that lighten the burden on formal provincial systems. While there have been countless positive developments in community living support structures in Nova Scotia, the key challenge is keeping people with ASD connected to these programs, and ensuring that they have a place to actually live their lives in the community from which to access the skill-building, network-sustaining and leisure-enhancing options available to them. In other words, a fundamental barrier to the effectiveness of community living programming is housing—not just in terms of the physical structure, but also the support of the community that surrounds the individual and their home. Whether a person with ASD lives independently, with their parents, or in a Licensed Home (see below), there are challenges in linking them to community living programming in a sustainable way.

### ***The Need for Appropriate, Suitable Housing***

The specific housing needs of adults with ASD vary depending on how the condition affects the person's ability to live independently. Currently, there are four main options for adults with ASD in Nova Scotia. Many adults with ASD *continue living with parents or guardians*, and have access to Direct Family Support (DFS), which allows them to purchase respite services on an ad hoc basis. Living with family is ideal in some, but certainly not all, cases. Although familial connections are important, we are hearing from individuals and families that living with family well into adulthood can have a detrimental impact on a person's cognitive and social development. As same-age peers move into adult life, people who continue to live at home with their parents can get left behind and excluded. More-

over, adults with ASD place additional pressures on families, who must take on more daily work to keep their adult children connected to social programs, activities and institutions—in short, to give some structure to their daily life—when the formal structure of compulsory schooling and all of its attendant extra-curricular activities are no longer available.

One alternative to living with parents is for people with ASD to *live with an “alternate family.”* That is, two or more non-related people who are qualified and approved to provide support, but in a private home in a “family-like setting.”<sup>62</sup> Although this solves the problem of a sudden increase in additional pressures, it does not solve the problem of social isolation on its own. Moreover, the availability of “alternate family” arrangements is limited. This is unfortunate because a recent survey of families with adult children with ASD in Alberta showed that the most preferred option for living arrangements is a single-family home.<sup>63</sup>

If the first two options are unsuitable or untenable, Autistic adults can live in one of the following **“Licensed Homes for Special Care”**:

- 1. Small Option Home (SOH):** three to four people with disabilities in community homes staffed by qualified caregivers.
- 2. Group Homes / Developmental Residences:** four-twelve people in a residential setting, staffed by qualified caregivers; usually younger people with disabilities. Group Homes and Developmental Residences offer more structured developmental support programs.
- 3. Residential Care Facilities:** four or more people with disabilities are given minimal support and supervision.
- 4. Adult Residential Centres:** long-term residences with structured supports and services; much like group homes and developmental residences but geared toward adults with disabilities. Staffed 24/7 by professional caregivers.
- 5. Regional Rehabilitation Centres:** larger facilities that offer intensive rehabilitation and developmental programs to adults with disabilities; residents often have complex behavioral challenges and skill development needs. Staffed 24/7 by professional caregivers.



The waitlists for all of these types of Licensed Homes are long and growing.

There is one other option for adults with ASD who need only limited support, and who wish to or have to move out of their parents' homes: they can live independently, in their own home or apartment, under the *Independent Living Support program*. This option is designed for individuals who need less than 21 hours of support per week.<sup>64</sup> Financial support from this program could be used to secure a service provider to help with activities of daily living, transportation, community participation, and meeting health and medical needs / connecting with health service providers. Eligibility for such supports is determined by financial and functional assessments. Access to Independent Living as an option is limited by the availability of affordable housing—which is further restricted given the employment and income challenges already faced by people with ASD—in areas that are well-served by public transit and other services conducive to community living. When asked what their preferred living arrangement would be in five years, respondents to an Alberta survey of individuals with ASD overwhelmingly chose living “in my own home,” either alone or with roommates.<sup>65</sup>

The suitability of each of these options, from Licensed Homes to Independent Living, obviously depends on the person with ASD's capacity for living independently. Although there are no province-wide statistics available for Nova Scotia on this matter, a recent survey conducted in Alberta showed that around 35% of adults with ASD needed 24/7 care, 25% needed slightly less than that (ad hoc assistance throughout the day), and the remaining 40% needed a few hours a day or less; it is safe to assume that need in Nova Scotia follows a similar distribution.<sup>66</sup> However, the suitability of each housing option also depends on the extent of family support available to the person seeking a residence. For some people who could otherwise live comfortably and securely in a family with minimal direct support, family matters unrelated to ASD itself could make family living inappropriate or untenable, no matter what level of supports are available. Aging parents, family separation, and other family dynamics can exacerbate the daily challenges that adults with ASD face.

Because of the complexity of needs—not only because of ASD but also because of family situations and capacities for care—it is crucial that a person with ASD

looking for residential options has a range of different support levels to choose from. Presently, people's decisions about where to live and with what kinds of support are largely dictated by external structural circumstances (what is available, where, and at what cost) rather than following personal need.

It follows that one of the biggest barriers to developing a comprehensive housing strategy for people with disabilities is the wide range of disabilities affecting people in need. Housing and specific residential supports that are appropriate for people with certain intellectual disabilities, or people with certain physical disabilities, might be inappropriate for people with ASD. The specific mix of people and disabilities living in one home or facility has to “work”, but the pressure to move people off of waitlists and set them up in residences means that there is no way to be “choosy” when placing residents. Moreover, like anyone, the residential needs of people with ASD change over time, with age, and with life circumstances; the Nova Scotia Department of Community Services has itself noted that people in supported living are outgrowing their homes because additional, often age-related, disabilities arise after they settle in.

Despite these challenges, addressing the shortage in appropriate housing is crucial. And it will have knock-on positive effects, because currently the strain in one area of support has the tendency to spill over into strain on other areas of support. For example, respite care programs are currently acting as a bulwark against waitlists for residential care, which was not their intended purpose. AutismNS's Respite Coordinator receives significant numbers of requests from the estimated 400 people on waiting lists for residential care options in the province. These people have often approached the Nova Scotia Department of Community Services, as well as the Nova Scotia Department of Health and Wellness, and they have been turned away because those departments do not have the resources or the physical capacity to effectively support this volume of people. While there is great need for effective home-based support options such as respite to assist caregivers in keeping their children at home, respite is not meant to be—nor is it sustainable as—a stopgap for those who are waiting for years on waitlists for residential care.<sup>67</sup>

The upshot of all this, for people with ASD, similar to people with intellectual or physical disabilities, is that basic human rights to security, well-being and partic-

ipation in community life can sometimes inadvertently be compromised in the effort to secure whatever housing or residential support is available, even if it is not ideal, and even if, in the long run, it leads to additional problems.

### ***Independence, Support, and the Shifting Costs, Risks and Responsibilities of Care***

The state of housing support for people with ASD, as well as for people with other kinds of disabilities, is strained by a central tension between several competing desires and objectives. On the one hand, many people with ASD want to live as independently as possible, and many stakeholders in the ASD community work to open that possibility up to anyone who desires it. Many others want to live in the family settings they are accustomed to, and many families want to keep their adult children close by and well cared for. On the other hand, there is pressure on families and individuals to assume responsibility for their very complex housing needs simply because there are not enough realistic supported living options available, and there is not enough funding allocated to increasing availability in all communities where there is need. Moreover, there are many families who cannot, or do not wish to, support their adult children with ASD at home.

On surface, it is in the provincial government's immediate financial interest to move away from reliance on hospital settings, as the cost of housing people with intensive or even moderate ASD-related needs in such settings, by the government's own estimate, is about \$420,000 per year. It is generally assumed that moving people back into their family homes, and providing more individualized support services, would result in significant cost savings because the cost of delivery is inherently cheaper. However, the mechanics of this cost savings are unclear, and, more importantly, it depends on families absorbing more costs and shouldering more responsibilities for care, and not every family can sustain these increased pressures. Families of adult children with ASD end up shouldering an immense burden: driving their children to social groups, recreation activities, jobs and school; accompanying them to health service appointments; arranging for therapy and other kinds of services. This burden increases as the families, and their children, get older. Many families would not have it any other way, except that they desire better funding to pay for respite services to help

them delegate some responsibilities (transportation, e.g.) to paid service providers.

The assumptions that underlie the push toward more individualized supports are also problematic for people with ASD whose families do not wish, or are unable, to care for them at home in the first place. The shortage of alternative housing options (small-options homes, e.g.) becomes, for these people, an acute barrier to living outside of a healthcare facility.

Thus, while AutismNS agrees with the Department of Community Services' stated intention to move away from a facilities-based model of care to a more individualized support system, AutismNS maintains that this shift must be informed by the families and individuals whose well-being depends on adequate and appropriate residential supports. It is more complex than simply closing down care facilities and waiting for communities and families to absorb the people who are displaced. This issue requires a deliberate strategy to meet the variable needs of adults with ASD and their families.

## **CROSS JURISDICTIONAL COMPARISON**

Nova Scotia does not face this shortage of appropriate housing for adults with ASD alone. Across Canada, and indeed the rest of the world, governments are trying to figure out how best to meet their goals of increased community living in ways that are sustainable and affordable, and all are confronting the same phenomenon of the first large cohort of people diagnosed with ASD reaching adulthood, at a time when the expectation and the hope is that most will be able to live as independently as possible in communities, and with arrangements that facilitate active social and vocational lives.

Most identifiable solutions to this challenge are currently "works in progress" rather than established and available as models for best practices. These works in progress point to the need, and the potential, for housing that is designed specifically for people with ASD. But they also underscore the potential problems for people with ASD who are placed in residential facilities that are not designed with their needs and "triggers"—for quiet spaces, activity-specific rooms, and even aversions to certain geometric patterns—in mind. The UK's Kingwood Trust, a charity supporting people with ASD, has come up with an instructive guide to developers and planners who are considering developments geared toward residents with ASD.<sup>68</sup>

However, any housing that takes someone's sensitivities into consideration, when connecting them to a community or housemates, would have to be developed with the utmost care to balancing individual needs with the importance of community and integrated living. While ASD sensitive living arrangements are a right, the construction of any sort of housing separated from the larger community needs to be done thoughtfully so as to minimize the risk of creating a new institutionalized environment.

## IDEAL SYSTEM OUTCOMES

AutismNS will continue to serve as a specialized resource for people with ASD, their families, community initiatives and government looking for information about best practices around housing options.

## Adult Services

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The services available to people with ASD, and tailored to their specific needs, greatly decreases once a person leaves the school system and transitions into adulthood.<sup>69</sup> In the ASD community, adult services are commonly focused on programs and services that support the transition into adulthood or which aid in the development, acquisition or maintenance of skills that are essential to community and/or independent living as an adult. Considering the increased complexity of maintaining healthy community involvement, as well as navigating the social challenges of professional and personal relationships that are common among autistic adults, programming and services that cultivate these skills and abilities are extremely important. Thus, while AutismNS has robust pre-employment service system, as well as navigation, respite, and employment supports, adult services at AutismNS is largely understood as those programs that complement the development or general well-being of people with ASD by helping with transitions into particular stages or areas of community and independent living. For example, while someone with ASD may be accessing employment support in the community, they may also be participating in social groups or life skills classes aimed at giving them the tools needed to make the transition to employment, independence, or to feel more confident in social situations.

Working with the Department of Community Services, and with families interested in exploring innovative housing solutions, AutismNS will provide information on successful community-based models.

## RECOMMENDATIONS

1. Government include or task AutismNS in the discussion on appropriate community-based housing options for adults with ASD as the Transformation Roadmap recommendations are explored.
2. An investment in ASD training for residential care workers and behavioural support professionals be funded and implemented in the current residential care system in Nova Scotia.

This presents a real challenge for adult services and programs in Nova Scotia because the vast majority are either still built and focused on serving people with intellectual disabilities, or may have similar goals and outcomes as autism focused programs but are unable to accommodate or fit the needs of many people with ASD. There are, therefore, a number of issues with adult services that deserve attention.

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**Position:** AutismNS believes that services designed to support adults with ASD should aid in the development, acquisition or maintenance of skills that are essential to community and/or independent living.

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## ISSUES

As this proposal has noted already, although autism and intellectual disabilities have some overlap in population, the unique needs and multitude of abilities of people with ASD means that, very often, existing programs are not intentionally designed to support people with autism.

All adult services that AutismNS has developed, therefore, focus on creating spaces that accommodate and help develop individuals in three fundamental areas: social, recreation, and life skills. Recognizing the

consistent barriers and the needs of people with ASD in these three areas is fundamental to developing any program or service or environment that is understanding, supportive, and nurturing for people across the Autism Spectrum. These reflect, not coincidentally, the areas of need that people with ASD, parents and professionals have identified, in Nova Scotia and across much of the world, as the most significant deficits in existing adult service infrastructure.<sup>70</sup>

### ***Adult Social Group Program***

The Adult Social Group Program aims to provide adults with autism (ages 20 and up) with a safe, inclusive and understanding place to socialize, build friendships, and find a sense of belonging. The group works to reflect social environments that are appropriate to the age and capacity of the participants, embedding them in recreation and leisure activities that anyone would enjoy: trivia night; foods of the world night; board games night; dinner at a local restaurant; community walks; skating at the Oval. Social skills development is the main focus, but with capable facilitation the group introduces more targeted teachable moments where participants learn to develop new skills that help with independence and interdependence (e.g., turn taking, washing dishes, appropriate conversation tactics and topics, healthy relationships, safety in the community, etc.).

In Halifax, this program runs twice a month for two hours each meet-up. Participants typically have a high level of independence, largely because the program is volunteer-led and does not have resources for more acute needs. The Adult Social Group Program uses peer volunteers from local universities to facilitate activities, enrich and support social interaction and skill building among the participants. The structure of each session is developed based on the needs of the participants, gleaned from an orientation process, as well as conversations with participants.

While this program is doing important work, demand is consistently outstripping AutismNS's capacity. In fact, the current Halifax group serves 14 individuals, but a second Adult Social Group will have to be created to meet community demand in this region. While the cost to participate in the group is nominal (\$150, which covers basic costs for activities and outings), it should be noted that AutismNS is committing dozens of hours of time from a staff whose salary is entirely privately fundraised.

At this time, both Autism NS' main office in Halifax and the Annapolis Valley Chapter offer the Adult Social Group program. It is not currently available in other rural communities due to a lack of resources.

### ***Teen and Adult Supported Social Group Program***

In addition to the Adult Social Group, AutismNS also offers a Teen and Adult Supported Social Group Program, which aims to create a social communication learning space for teens and adults (ages 14 and up) with autism whom have higher needs or require more support. The supported social group offers the same opportunities for social and recreational skill development as the participants registered in the Adult Social Group Program, but participants are each accompanied by a respite worker provided by the family/caregiver. With that, the Supported Social Group also focuses on helping support the development of participant's skills necessary for independence, with the goal of participants eventually participating in the program without a support person accompanying them.

### ***Social Skills (PEERS) Program***

While social group offers a semi-structured social environment for people with ASD, at different levels of independence, the Social Skills (PEERS) Program offers a more formal, class-room based and, in some ways, fundamental space for developing social communication skills. Social Skills (PEERS) follows an adapted version of UCLA's Program for the Education and Enrichment of Relational Skills (PEERS®), the Adolescents model.<sup>71</sup> The program at AutismNS aims to provide adults (ages 18 and up) with autism "ways to help them make and keep friends."<sup>72</sup> As an interactive classroom-based program, with a parent-assisted component, participants and their parents/caregivers meet weekly for two hours for 14 weeks to work towards a series of individualized development outcomes including introduction skills, electronic communications skills, choosing friends, handling disagreements, etc. Parents participate as support, learning to act as social coaches to support the participant with their learning and skill development during and after the program. This program is coordinated by AutismNS staff and has a \$175 fee to participate. This fee is kept dramatically lower than most similar programs across the country, which charge upwards of \$1000 per participant.

### ***Life Skills Program***

The Life Skills program was piloted in 2014 as a 10 week program, and focused on money management and cooking skills. It was designed for adults with ASD aged 18 years old and up who were living on their own or transitioning to living independently within the community. Participants were taught financial literacy, budgeting and taxes through interactive class lessons and activities. With their financial literacy skills, they also learned to grocery shop for the necessary ingredients to make basic recipes, and the kitchen safety and basic skills to prepare daily meals.

The program pilot was a success, but will be modified to reflect the findings of a Life Skills Needs Assessment Survey conducted in 2015 by AutismNS. This highest ranked learning needs identified by people with ASD, family and professionals in this survey were: learning learn at-home skills (vacuuming, laundry); community connections (identify community services for needs, take part in community activities); personal appearance and hygiene; health and wellness; time management.<sup>73</sup> AutismNS will be developing curriculum based on these results to deliver in their Life Skills Program launching in 2017.

### ***Autism Nova Scotia's Ben James Summer Camp Program***

The Ben James Summer Camp provides children and young adults with autism aged 6 to 21 with the opportunity to attend summer camp in an environment that is safe, inclusive and designed around their needs, supported by counsellors trained in autism. This camp is unique in that each camper is supported individually, with a 1:1 camp/counsellor ratio, and activities are designed specifically with participants' needs and interests in mind, including a unique array of sensory based activities. Campers participate in activities in their community, going on frequent swimming trips, to the Discovery Centre, urban farms, and more. The young adult camp session, which is offered for two weeks out of the eight weeks of summer, is specifically designed for campers aged 15 to 21. This session was established in 2013 because of an evident lack of adult based summer programs for individuals with autism who have extensive support needs. The adult camp offers additional activities to support the development of life skills, including grocery shopping and cooking.

### ***Autism Arts Program***

The Autism Arts program is a supported recreational and developmental program where children and young adults with autism aged six-25 explore art mediums and self-expression. Through a unique partnership with the Art Gallery of Nova Scotia, the program facilitates social interaction in the community and provides people with ASD a space that nurtures self-expression and confidence.

## **SUPPLEMENTING EXISTING CAPACITY IN THE COMMUNITY**

AutismNS has developed an effective model of adult service through a system of program development that follows, roughly, a three step process: 1) evidence of need; 2) demonstration; and 3) community collaboration. AutismNS carefully identifies gaps in services to adults through extensive needs assessments. Next, it bridges any identified gaps by constructing and implementing pilot programming that is designed to test the feasibility and uptake of programs, which are generally evaluated formally or informally. Finally, wherever possible and appropriate, AutismNS works to find collaborators with other service sector partners or levels of government that might help take up into the existing and formal service structure any programs that are filling a real need. However, AutismNS's current capacity to manage and deliver its adult service programs is limited by the dependence on privately raised or fee-for-service dollars for programs.

## **PROGRAM ACCESS FOR LOW INCOME AND VULNERABLE POPULATIONS**

AutismNS' dependence on private funding or fee for service programming also creates a real barrier for access for people to confront the additional vulnerability that comes with a low income and/or lack of family support. This is particularly problematic with adult services, where people who want to access services may not have family resources to draw from, have an increased likelihood of under-employment or unemployment, or have never been attached to the labour market, making participation in social groups, skills groups or other groups almost unattainable. While AutismNS makes every effort to mitigate them, there are still real barriers to accessing many of the adult services that AutismNS offers if a potential participant does not have the financial means.



## CROSS JURISDICTIONAL SURVEY

AutismNS adult services mirrors offerings from autism organizations across the country, which almost universally aim to fill gaps in social, recreation, and life skills that many programs not explicitly aimed at people with ASD are unable to address in an appropriate or effectual way.

There are, however, important innovations in adult services that deserve some note. First among these is the Toronto based Geneva Centre for Autism Services' more refined social skills programming. Unlike the general skills and social groups offered at AutismNS, the Geneva Centre is able to break participants into more particular groups focusing on targeted areas such as emotional regulation, personal choice in friendship building, and more. Geneva also offers Life Skills groups that focus on elements not covered by the AutismNS group such as transit use and community safety. And finally, Geneva has several programs that help develop the skills necessary to have a healthy recreation and leisure life, which aids in mental wellness, and correlated physical health, and relationship building.<sup>74</sup> Similar programs skills programs also exist through the Ability Hub in Alberta, all of which receive provincial government support.

Sexual education is a program less commonly offered by autism organizations, but it is a more common adult program offering in other segments of the disability community. For example, the Sexcess workshops, run by the New Brunswick Association for Community Living, offers a solid example of a holistic, adult targeted program.<sup>75</sup> Considering the complexity of everyday social settings and interactions for individuals with ASD, the challenges of understanding healthy sexual relationships, social norms and expectations has very real implications. And yet, this is an area that is very rarely addressed. Parents and professionals in health, employment, education and post-secondary education continually highlight to AutismNS the need for sexual education and supports to help address the problems such as the "lack of socio-sexual knowledge, in addition to sexual segregation, inconsistencies and intimacy issues [that] can lead people with ASD to express sexual desire/emotion in socially inappropriate ways."<sup>76</sup> Simply put, there is a widespread understanding of a need for adult programming for sexual education programming targeted at adults with disabilities and some programs already being deployed in other jurisdictions, but little is tailored to the ASD community, and there is nothing at all available in Nova Scotia.

## IDEAL SYSTEM OUTCOMES

AutismNS, as well as employment agencies, post-secondary education support service providers and other stakeholders who regularly serve people with ASD also recognize the need for adult anxiety programming in Nova Scotia. AutismNS proposes to coordinate the development of a program, similar to the Facing Your Fears program offered at the IWK Health Centre, which teaches children and teens to cope with their anxiety through a cognitive behavioural therapy approach.<sup>77</sup>

As social settings and social interactions vary across ages, AutismNS would like access to the resources necessary to follow best practice of social skills programming already in place in Alberta and Ontario, providing adults in different age groups with social skills programming.

AutismNS proposes to work closely with employment agencies and adult service providers across Nova Scotia to deploy a sexual education curriculum that can help with transitions and interventions in the lives of adults with ASD.

AutismNS will continue its work to demonstrate best practice programs and educational components, evaluating their efficacy and outcomes, revising them appropriately, and then uploading them to the appropriate stakeholders (such as agencies, service delivery agents, educational institutions, etc.) where they can be managed in a more sustainable and systemic way.

## RECOMMENDATIONS

1. Review policy development under the SPD transformation that supports flexibility of respite funds usage, by eligible families. This would support a person directed approach to service, and allow families to use funds to pay fees or purchase social, leisure and recreation programs for their children. This option should also be available and accessible to adults.
2. Work in partnership with AutismNS to support best practice program development and delivery, and evaluate opportunities to share this work to build community capacity for program and service delivery across the province.
3. Coordinate development of a program teaching children and teens how to manage anxiety.
4. Review of gaps identified in adult programming.

## Post-Secondary Education

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Persons with disabilities have historically been woefully underrepresented in Nova Scotia's post-secondary institutions. Over the past two decades, financial aid and support service improvements have helped to increase the participation of such students but they are still significantly underrepresented: among Nova Scotians 17 to 29 years old, 16% had a registered disability in 2011, compared with only 9% of university students and 12% of Nova Scotia Community College (NSCC) students.<sup>78</sup>

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**Position:** Nova Scotians with ASD, with the academic qualifications for post-secondary studies, should be welcomed, integrated, and fully supported to reach their educational and career goals.

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### ISSUES

Unfortunately, we have very little information about the participation of persons with ASD in Nova Scotia's postsecondary education system. We know such students exist because AutismNS works to support some of them through an Autism Post-Secondary Student Support Group funded through Ready, Willing and Able (RWA), and is currently providing support for 10 students. Though not a controlled sample, our jobseeker database currently contains 74 job seekers, of which 22 (30%) hold some form of PSE accreditation. Ready, Willing and Able has also found dozens of additional people on the Autism Spectrum who have achieved Post-Secondary Accreditation in areas as diverse as Human Services, Computer Sciences, Law, Baking, and Broadcasting, in its search for applicants to put forward to committed employers. RWA also has anecdotal reports of dozens of people with ASD throughout the NSCC system in the Halifax area alone. If the PSE system matches the wider population, we would expect as many as 1,000 students with ASD are enrolled in Nova Scotia's universities and colleges (to say nothing of private colleges), though we lack data to confirm this.

All of this suggests that, while we cannot be certain about their overall number, there is a substantial population of people with ASD currently accessing post-secondary education.

### System-Wide Issues

Despite the lack of reliable student data, we nevertheless know about some of the key challenges facing persons with ASD in post-secondary settings. The harsh reality is that most institutions have very little experience knowingly working with students on the Autism Spectrum and, as a result, they often fall far short of providing adequate supports to help these students succeed. There are multiple factors to consider:

- The primary and secondary education systems often fail to adequately prepare students with ASD for the transition to postsecondary institutions.
- There is a lack of basic knowledge in the PSE system about what ASD is and how it must be accommodated. According to Students Nova Scotia, disability policies at most Nova Scotia institutions fail to differentiate ASD from broader class of "learning disabilities," which might help to explain the shortcomings in their approach to students with ASD.
- Students with ASD can struggle with academics and the basic organization skills required to succeed at the post-secondary level.
- Most institutions are particularly poor at offering ASD-friendly orientation activities and other supports that could help students with ASD to adapt to new and different social environments.
- Specific supports to help students with ASD to transition from PSE to the job market are similarly lacking.
- NSCC's implementation of an admissions test to qualify students with an identified disability to determine their fit for post-secondary education has further created barriers for students with ASD, and is viewed by the autism community as a discriminatory practice.

With all of these factors in play, it is hardly surprising that students with ASD often struggle in the first year of post-secondary education and, like other students with disabilities, are much more likely to drop-out at this early stage.

In response to community need, AutismNS recently started a Post-Secondary Student Support Group (with support from Ready, Willing and Able) to help Halifax-based students to navigate many of these challenges and make connections to their peers in the ASD community.

## INSTITUTIONAL COMPARISON

A handful of Nova Scotia institutions have made some initial efforts toward improving conditions for students with ASD. For example:

- NSCC publishes online Autism Toolkits for students and staff through its Disability Services division.
- Dalhousie University, through its Counselling Centre, piloted its first Asperger's/Autism Spectrum Support and Intervention Group in 2014. This group has been refunded by a grant provided by AutismNS via Ready, Willing and Able.
- Mount Saint Vincent University, through Disability Services, offers one-to-one mentoring to students with ASD through its Learning Strategist.

## IDEAL SYSTEM OUTCOMES

Nova Scotia's postsecondary institutions face a steep learning curve in order to accommodate an increasing population of students with ASD. They require significant investments to add on-site expertise in

their student services divisions and must also provide appropriate training to develop a knowledge base on ASD across the full spectrum of services provided by the institution.

Post-secondary institutions must develop collaborative relationships with secondary schools and ASD community support organizations (including AutismNS) to ensure healthy transitions of students with ASD.

Post-secondary institutions must better assist students with ASD in the transition to the labour market. AutismNS will work with any university or college willing to develop a strategy for student supports, counselling, and disability services that could better accommodate students with ASD, and what those supports might look like.

## RECOMMENDATIONS

1. Further research and analysis of the needs and support of students with ASD in the post-secondary environment is required, as well as follow up with students, post-graduation, to better understand transition outcomes.
2. Enhanced knowledgeable professionals.
3. Increase in autism-friendly spaces and greater recognition of accommodation considerations in the post-secondary environment.
4. Enhanced transition support to the labour market.

## Employment, Entrepreneurship and Social Enterprise

Employment is consistently identified by individuals on the Autism Spectrum, their families, and professionals as one of the most significant and important issues in their lives.<sup>79</sup> The data on labour market attachment among people with autism suggests that this concern stems not from personal troubles but from a systemic failure to connect people with ASD to inclusive workplaces. The most recent data shows that, in Canada, less than 33% of people with ASD who are looking for work are employed in any capacity. Data from the UK and US, countries with similar employment and participation dynamics to Canada, parses this further to suggest that less than 15-25% of people with ASD who are ready and willing to work have attained some form

of employment. And this is not the product of certain people being "too disabled" for the competitive labour market. Rather, individuals who are considered to be "higher functioning" confront endemic underemployment, more frequent job switches than the general population (despite commonly experiencing difficulty adjusting to new job settings), and almost universally earn less than both their peers without ASD and individuals with learning disabilities.<sup>80</sup> Even the significant number of people with ASD who have postsecondary education, experience similar difficulties.<sup>81</sup>

This makes people with ASD perhaps *the* most underrepresented and vulnerable group in the labour



market. And with the growing number of people with ASD transitioning from school to the workplace, and post-school aged people now receiving much needed diagnosis and reaching out for employment support, this issue is emerging as a pressing one here in Nova Scotia and across the world. This is particularly prescient given the poor labour market participation rate of vulnerable and marginalized groups that the OneNS Commission<sup>82</sup> identified as a root source of lower productivity in Nova Scotia.

For these reasons, AutismNS has devoted a great deal of effort over the last two years to building capacity as an employment support interventionist, working closely with existing employment agencies and community programs, developing and offering programs and skills to fill gaps in employment support and preparation. For AutismNS, this has meant offering new programs and working to transfer functional knowledge about ASD into the existing service infrastructure, as well as raising awareness among employers about the benefits of hiring people with ASD.

AutismNS's goal in developing employment and pre-employment services is clear: increase labour market participation among people with ASD by building capacity in the employment support and preparation landscape. AutismNS pursues this goal via three avenues: 1) ASD tailored pre-employment and employment programs alongside targeted, collaborative capacity building for existing programs outside of AutismNS; 2) employer and agency education; and 3) collaborative system building in standard employment and self-employment or entrepreneurship.

But before turning to these three avenues of work that AutismNS has been conducting in the employment and pre-employment systems, we must highlight a few of the major issues that have motivated AutismNS and their collaborators to try and build more robust employment supports for people with ASD.

## ISSUES

### ***System Costs of not having ASD Appropriate Employment Supports***

Apart from the right to work, the need for better ASD tailored employment supports in policy and administration also emerges from the collective and social cost of low employment among people with ASD. Simply put, unemployment among people with ASD

is extremely high, and studies are showing that this marginalization is very costly. A recent Ontario-based study indicated almost 75% of the 480 participants with ASD had an annual income under \$30,000, and the Ontario Disability Support Program was the *primary source of income* for 58.2% of those surveyed. Full-time employment was the primary income source for only 13.9%, and part-time employment for 6.1%. The report highlighted that despite higher IQs and achievements in postsecondary education, outcomes for this group were consistently quite poor. A majority of participants struggled with employment, meaning they have little work experience or have worked mainly in short-term, low-paying jobs.<sup>83</sup>

This sort of unemployment creates a system reliance that costs more than it needs to. One study of people with autism found that poor employment results in lost work time and productivity for an entire community. Further, it found that employment has a significant cost impact because people who are not included in the productive economy must rely on publicly funded social supports. This study reported that with employment, the cost of community supports decreases, creating less reliance on day programs and activities, such as adult day care.<sup>84</sup> Waged work also provides the means to pay bills, decreasing the need for living support that pays for housing, transportation and basic amenities covered by community benefits. Extra health coverage, common with many employers, can also help cover medical costs for items such as medications. This extra coverage can sometimes assist in psychological services, which are a common need since the prevalence of comorbid disorders is very high among people with ASD.<sup>85</sup>

At the same time, well-supported and fitting employment has an indirect cost benefit on the mental and physical health system fronts. As mentioned in the opening of this report, there are particular areas of social interaction that people with ASD struggle with, especially when it comes to obtaining and maintaining paid employment, many of which stem from social communication deficits. Yet, very often, people with ASD have high expectations of themselves, as well as high intelligence and valuable skills, but no workplace to use them in. The result is frustrating, discouraging and alienating for people with ASD and their families. Studies have shown that employment can actually help people develop the routines and stability needed to manage the mental illnesses which are commonly

co-diagnosed in people with ASD (e.g., anxiety, depression, schizophrenia, or psychosis). The prevalence of anxiety, depression and other mental health conditions is particularly high for those struggling to get and keep employment.

Meanwhile, there is ample evidence of *benefits* to employers and companies when they hire individuals with ASD.<sup>86</sup> Employers often value the trustworthiness, reliability, and low absenteeism of these employees.<sup>87</sup> Once employed, individuals with ASD often demonstrate strengths that employers look for, such as attention to detail and intense focus, and which result in increased work output. Moreover, some people with ASD may enjoy performing the kinds of jobs shunned by others due to a variety of factors, such as the relative social isolation or the repetitive nature of the task (depending on the particular strengths of the employee)—meaning that a worker with ASD may excel in situations where others do not.<sup>88</sup>

### ***ASD Tailored Supports for Employment in the Nova Scotia Employment Support Infrastructure***

#### ***Transition and Preparation for Employment***

Evidence shows that the availability of adequate services for people with ASD “during their education, their transition from school to work, and to independent living might influence employment outcome considerably.”<sup>89</sup> Many youth with ASD leave secondary school without basic life and job skills, are ill prepared for adulthood, and regress during this time of isolation when there is no school, no work, no friends, a lack of community programs, and no ASD-specific adult services. Available research also confirms poor outcomes in independence and social inclusion for adults with ASD, regardless of where they fall on the spectrum, and higher rates of unemployment and underemployment compared to other disability groups.<sup>90</sup>

Education professionals refer to the transition period as a critical time for high school students with disabilities, not only because transition programs could offer work experience, but also because transition is a period of planning and preparation for adulthood where specific skills can be taught in the school system.<sup>91</sup> But the transition for people with ASD is often a rough one. Much of this stems from the fact that we are only beginning to understand that people with ASD have markedly different vocational needs than individuals with other developmental disabilities, and also be-

cause each person with ASD demonstrates such a wide a variety of characteristics across the diagnostic criteria—ASD truly is a spectrum. While the current approach to planning for transition out of school is already individualized, the spectrum of need and ability among people with ASD makes the potential options in transition very broad, and the actual process of transition to successful employment or post-secondary education a great challenge.<sup>92</sup>

A 2012 Autism Speaks Employment Think Tank in the United States reported that inadequate soft skills (e.g. office small talk, workplace politics, and team-oriented projects), lack of self-advocacy skills, and an inability to identify their strengths were among the biggest barriers that people with ASD confronted both getting into and once in the workplace. However, having held a paid, community-based job while still in high school is strongly correlated with post-school employment success for young people with intellectual disabilities, multiple disabilities, and autism, as is increased independence in self-care and higher social skills. Ontario stakeholders have similarly noted that vocational success in adulthood is predicted by having a paid job during high school.<sup>94</sup>

Getting people with ASD into the labour force is challenging, but it is not impossible; just managing the transition from school to work, and getting young people with ASD into paid employment early, can help them establish life-long careers.

With all of this in mind, AutismNS has developed several pre-employment or employment preparation programs that are tailored to the needs of people with ASD as they enter the labour market (and which function often in concert with ASD tailored outlined in the chapter on Adult Services).

#### ***TRAACE***

Perhaps AutismNS’ most far-reaching pre-employment program is the Transition Readiness And Autism Community Employment (TRAACE) program. TRAACE began in 2011 as a pre-vocation program supporting high school students with ASD in HRM, and in 2014 it was piloted in the Cape Breton Victoria Regional School Board where TRAACE also partnered with NSCC Marconi Campus to train students as job-coaches. Later in 2014, TRAACE expanded to the South Shore region, and in 2015 to the Chignecto region. AutismNS currently receives a renewable grant from Post-Secondary Disability Support Services to run TRAACE in Halifax,

and AutismNS recently received a federal government grant to scale up the program across the province and conduct a formal evaluation, under the Worktopia program.

TRAACE includes seven skill-building modules, and all participants take part in an eight week community-based learning opportunity to give them hands on job experience and an opportunity for career exploration. TRAACE modules are based on current research and best practices and run under the guidance of knowledgeable professionals, including a Board Certified Behavioural Analyst (BCBA). In 2016 the program will reach over 60 students, and is running out of eight schools across the Chignecto Central School Board district as well as schools in the Halifax, Cape Breton Victoria Regional, and South Shore School Boards. TRAACE is filling a gap for students who too consistently miss out on community-based learning and career exploration opportunities that are essential in preparing them for entry to the labour market.

### ***Worktopia Canada***

AutismNS is also currently participating in a national pilot of the Worktopia program. Initially piloted in Calgary, Worktopia is funded in its federal capacity as a four-year initiative co-sponsored by The Sinneave Family Foundation, Autism Speaks Canada, and the Government of Canada's Opportunities Fund for Persons with Disabilities. The initiative has two core programs outlined below, with Halifax acting as one of two jurisdictions in the country (the other being Calgary) where a third stream, School Works, is being tested by leveraging the TRAACE program.

### ***Community Works***

Community Works is a 12 week *pre-employment* program aimed at targeting soft skills, such as social interactions and understanding social rules in a workplace, for people with ASD in high school aged 15-21. It is a community embedded program where participants and peers volunteer each week with a different community partner. It uses peer mentors as role models and supports an inclusive learning environment that allows people to hone many of the skills that would be needed in employment and in community living. A Board Certified Behaviour Analyst oversees the project to develop and implement goals targeting social communication skills and pre-employment skills. The program is built on a model of incidental and natural teaching interventions, implemented in a systematic

way that gives participants a concrete measure of progress and outcomes, while also generating community awareness—particularly among community partners and peers—about the abilities of people with ASD.

### ***Employment Works***

Similar to Community Works, Employment Works is a 12 week employment program aimed at targeting soft skills, but this program is for individuals no longer in high school aged 15-29. This program is 12 weeks long, conducted for 2.5 hours a day, twice a week. It consists of one day focused on direct teaching through a peer-directed employment curriculum, and a second day focused on experiential learning through various job-shadowing experiences in the community. It is also overseen by a Board Certified Behaviour Analyst to develop individual goals for the participants within the program. As well, it aims to promote the effectiveness of individuals with ASD as skilled workers within the community while giving participants the opportunity to experience several careers that they would not have necessarily had the chance to explore. The major aim of this program is to develop participants' skill sets and knowledge of employment so they can obtain, sustain, and maintain a job within the community.

### ***Autism Works: Launch Pad***

AutismNS has also developed a prevocational education program called Launch Pad. This program is designed to help young adults aged 18 or older and no longer in school to secure meaningful employment, as well as connect to community employment infrastructure to ensure ongoing support. This three-month program is a mixture of classroom lessons, customer service experience, and career counselling. Classroom lessons are taught three days per week, and focus on career exploration, professionalism, social skills, customer service, financial literacy, job applications, requesting accommodations, and anxiety management. Participants also explore which industries and employers would be a good fit with their particular skills, interests, and experience. This individualized approach was successful in securing four part-time jobs for the pilot program of five participants in October 2015, six part-time jobs for the second cohort of eight participants in April 2016, and one full-time job and one part-time job for the third cohort of eight participants in August 2016.

Several community partnerships have been formed to deliver Launch Pad's program content, including col-

laborations with Job Junction, St. John's Ambulance and Junior Achievement. All participants also join the Autism Job Seekers Database, and when participants apply to job opportunities, they are supported throughout the application process and the interview. Should the participant be the successful applicant, job coaching supports can be provided through Ready, Willing and Able to help with training and meeting employer expectations.

Taken together, these pre-employment and employment readiness programs are already being recognized as a much needed intervention in the provincial pre-employment and supported employment services. Worktopia and Autism Works receive regular referrals from Work Activity members, Collaborative Partnership Network members, and Careers Nova Scotia centre members who have clients with complex needs but a real potential to work. The need for AutismNS to perform an expert interventionist role in preparing people with ASD for the labour market and helping them connect to employment is clear.

### ***Employer and Agency Education: AutismNS as an Interventionist***

When we move from considering vocational preparation to employment support—that is, when we focus on what happens once people with ASD are *actively engaged* with the labour market—AutismNS's role as an employment interventionist becomes even more critical.

There is currently a distinct lack of specialized employment supports to meet the unique challenges faced by individuals with ASD once they are in the labour force.<sup>95</sup> Nova Scotia is by no means unique on this front. The vast majority of community employment services, like pre-vocational programming, are tailored to serve people with intellectual disabilities or mental health conditions. For example, Nova Scotia has an extensive Adult Service Centre (“workshop”) infrastructure. These Centres employ people who are excluded from other employment opportunities in “sheltered” settings. Specifically, 87% of their program participants have a primary diagnosis of an intellectual disability. These Centres are a poor fit for the needs and abilities of most people with ASD, who have a relatively low transition to employment rate. And, they also run counter to AutismNS's commitment to having people with ASD work in the community, in mainstream workplaces, inte-

grated with colleagues who do not have ASD.<sup>96</sup>

### ***Supporting Autism in the Workplace, & Autism 101 Training***

AutismNS is leading the country in its efforts to develop programs tailored to the unique needs of jobseekers and workers with ASD who are seeking or taking up employment in their communities. One such initiative is AutismNS's “Supporting Autism in the Workplace” training. This program is aimed at job-coaches and case workers within inclusive and disability specialized employment agencies, to whom it offers a 1-2 day workshop to equip them with the tools, tactics and knowledge to deal with the additional barriers that people with ASD confront in securing and keeping employment. They are also delivering a sector-specific “Autism 101” workshop to employers, service providers and any other interested stakeholder.

AutismNS works with dozens of employers, employment agencies, and universities and colleges across the province, for example delivering training to Metro Works, Options, Teamwork-Workbridge, Career Nova Scotia Centres, Collaborative Partnership Network members and even the Tourism Industry Sector Council of Nova Scotia's hospitality training program. At the same time, the request for training from across the province is growing. With the help of Ready, Willing and Able (see below), AutismNS has become a trusted facilitator in accommodating and building autism inclusive pre-vocational programming and employment supports. This has been a mixed blessing: particularly in light of the system transformation that is underway in Community Services and the employment support system under the umbrella of Career Nova Scotia, requests for training are outstripping AutismNS's capacity, sapping human resources away from existing programming that are funded entirely by private dollars raised by the organization.

AutismNS would like to expand its tested and well-respected employment support and job-coaching workshops across the province, but it needs to address capacity issues in order to do this.

### ***Ready, Willing and Able***

#### ***Educating Employers and Building Demand***

AutismNS is also collaboratively building the supported employment infrastructure in Nova Scotia as a partner with Ready, Willing and Able (RWA), a national



program that connects employment opportunities to job-seekers working through community agencies, and educates employers on the business case demonstrating the benefits of inclusive employment. RWA is an initiative designed to help increase the labour force participation of people with ASD and intellectual disabilities by generating employer commitments to hire, and then connecting these employers to a collaborative network of partner agencies who identify suitable candidates for a position and deliver employment supports for those clients should they be hired for the job. RWA staff, in their work with employers and agencies, have helped strengthen links between AutismNS and employment agencies across the province, while also opening up new employers to the benefits of inclusive, competitive employment—successfully supporting dozens of people to come off of income support in Nova Scotia by helping them connect to suitable, meaningful employment.

***Autism Job Seekers Database—Pooling Job Seekers, and Connecting them to Supports***

The RWA program also recently launched a new Autism Job-Seekers Database, designed to connect Autistic job-seekers to an agency that can case-manage and assist in developing employment opportunities, as well as to any vocational preparation programs (whether ASD-specific or general). This is meant to help bridge the divide between the many people with ASD who are unconnected to, or have a difficult time navigating, employment supports. A devoted Autism Outreach Coordinator has been building bridges to the agencies and sites where ASD job seekers may be accessing services across the city, pooling these jobseekers into the database and then routing and referring them through appropriate pathways to support and success in the labour market. The Database now has over 122 registrants looking for employment, and RWA staff have created efficient referral processes with Career Nova Scotia Centres and other agencies and programs to ensure continuity of support, with staff working with these groups to identify any training or education needs that AutismNS can deliver to help better support clients with ASD. To be clear, this is larger than the caseload of the largest employment support agency in Halifax. The database has facilitated dozens of job connections over its first year and a half, and is picking up steam.

RWAs work, the database and the education sessions, which are all responses to obvious gaps in the system

of support, all highlight a collaborative system building in standard employment supports that is careful to not duplicate existing infrastructure. AutismNS believes, strongly, that it is possible to create an inclusive employment support system where the needs of people with ASD who wish to work, no matter what their needs, can be met so long as the agencies, service delivery stakeholders and AutismNS are given the proper tools, resources and education.

**SELF-EMPLOYMENT AND ENTREPRENEURSHIP:  
BUILDING STRONGER SUPPORTS FOR PEOPLE  
WITH ASD**

The same collaborative philosophy directs AutismNS's efforts in helping people with ASD explore self-employment and entrepreneurship as an employment option. Entrepreneurship offers a very viable path for individuals who are unable to find success through supported, competitive employment, and for the many—if not all—for whom a sheltered workshop is not appropriate. Supported self-employment and entrepreneurship, for those who have particular skills or services, provides a means to earn income, while controlling for the variables which often make it difficult for a person with ASD to become an employee, such as scheduling needs, sensory sensitivities, and social barriers. At the same time, self-employment is among the fastest growing forms of employment in this province, and AutismNS believes that people with ASD ought to have the same opportunities and be given appropriate supports to explore entrepreneurship as an option for themselves.

***RWA and building a system for Entrepreneurs and Self-Employment for people with ASD***

AutismNS has, therefore, been working closely with existing business development and entrepreneurial service providers for persons with disabilities, as well as building new collaborative relationships that create the necessary amalgam of support for business and disability needs. This work is progressing on two major fronts.

***Uniquely Gifted—A Partnership with EDN***

Ready, Willing and Able plays an active role in supporting entrepreneurs with autism. The individualized support funds that have been made available by the federal government through that program have been

used to connect a number of interested entrepreneurs with ASD to business development consultants who are administered by Autism Works: Entrepreneurship (see below) and in partnership with the Entrepreneurs with Disabilities Network (EDN).<sup>97</sup>

By supporting several people in their entrepreneurial pursuits, RWA began to recognize what the EDN had long known: a critical need for growing many businesses is *pre-market* and *go-to-market* support. These two areas of business development are particularly acute barriers for people with ASD, who commonly struggle with the executive functioning involved in complex planning and abstract thinking, and who often struggle with the highly dynamic social interactions and environments involved in sales, which, for all entrepreneurs, also saps time away from the actual production of the good or delivery of service.

Working with the EDN, RWA accessed federal funds to launch Uniquely Gifted: a cross-disability social enterprise aimed at bridging the gap faced by many entrepreneurs by providing pre-market and go-to-market services. It helps entrepreneurs across Nova Scotia launch or sustain their business, earn income currently inaccessible because of barriers, and connect to a more extensive system of business development and disability supports

Uniquely Gifted is currently working with about a dozen entrepreneurs who are at various stages of business development and acceleration, including five people with ASD—and it intends to expand.

Importantly, Uniquely Gifted represents an opportunity for those who wish to produce or focus on selling their passion to access support for business preparation, including going to markets and venues that can supplement their sales efforts, while accommodating many aspiring entrepreneurs' scheduling needs, sensory sensitivities, and social barriers. Entrepreneurs also maintain autonomy within the social enterprise, producing at a rate that is appropriate for the individual, and able to sell their good or service wherever they please—though a pricing agreement is reached to avoid competition.

#### ***Autism Works: Entrepreneurship—A Partnership with Sobey's Business Development and ENACTUS SMU***

While Uniquely Gifted acts as important support in preparation for market and a supplemental sales point, people with ASD commonly require support beyond what Uniquely Gifted can reasonably offer. This is par-

ticularly an issue for those who are only beginning to explore the possibility of entrepreneurship or self-employment.

To respond to this gap, Autism Works Entrepreneurship has constructed a partnership with Enactus Saint Mary's University (SMU) and the Sobey School of Business Development. This program helps entrepreneurs who have business ideas and/or products connect to supports that accommodate any barriers as they develop their business.

Enactus SMU students and senior consultants from the Sobey School of Business Development Centre provide entrepreneurs with 1:1 consulting based on the Growth-Wheel Consulting Format. Consultants conduct a needs assessment with each entrepreneur, create an individualized plan, and implement the necessary supports and business expertise. The level of support depends on what stage the participant is along in developing their enterprise. Support from Enactus SMU may include, but is not limited to: organizational structure, business operations, human resources, finances, and marketing. Currently, Ready Willing and Able provides individualized support funding for entrepreneurs with autism on a case-by-case basis, applying a ceiling of funding available to support each step of exploration and development.

Investment in individualized supports for entrepreneurs with ASD is relatively small to date. It averages about \$2,000 per business per year, and with average amounts decreasing quickly once a support system is established and the viability of a business is tried and tested.

## **CROSS JURISDICTIONAL COMPARISON**

AutismNS is in an interesting position when it comes to a Cross Jurisdictional comparison of employment supports. Since 2014 it has been a partner in the nationwide RWA program, giving it the opportunity to see first-hand how employment is supported across Canada. The provincial system of supports for people with ASD vary dramatically, and Nova Scotia—while a leader with its current federally funded suite of programs coordinated out of AutismNS—is at risk of falling behind in supporting the legion of people with ASD who are ready, willing and able to work.

Across North America, efforts are underway to develop ASD-appropriate employment supports and



pre-employment programming. Before RWA's establishment, studies in Ontario found that there was no consistent or specialized supports to help individuals with ASD succeed in employment. Similar studies have shown this to be the case throughout much of the United States of America as well, and the experiences of RWA reveal—but also mitigate—a similar lack of tailored support and knowledge about ASD across Canada.<sup>98</sup>

In fact, the funds provided to individual supports via the federal funding available to RWA, for this purpose, are already showing that the supported employment system in Nova Scotia, like much of Canada, is ill-equipped for truly supported employment. The system is particularly unprepared to support the diverse needs of people with ASD, who often require a flexibility that standard “employment maintenance worker contracts or “job coaches” cannot offer because of the vast differences in ability and skills.

On a positive note, research and experience are now aligning to demonstrate that with customized intervention and training, individuals with ASD *can* work in a variety of businesses and industries, and are not limited to lower paying entry-level jobs or workshops. The recent announcement that, following the lead of Vermont and Washington States, the provincial government of Ontario will incrementally phase out support and end admissions to “workshops” or Adult Service Centres is a harbinger of the reform direction that Nova Scotia will have to take.<sup>99</sup>

AutismNS, through the outreach done by its employment division to Careers Nova Scotia Centre members, Collaborative Partnership Network members and Adult Service Centres, has found that people with ASD in need of support in gaining and maintaining employment are ending up in each of these places. And, through RWAs provision of individualized supports where existing supports are unavailable, AutismNS has seen that the amount and types of employment supports vary because the abilities and needs of people with ASD vary so dramatically. Yet, no matter if they possess an advanced graduate degree or have not finished high school, there is still an almost consistent need for supports.

## IDEAL SYSTEM OUTCOMES

AutismNS is a national leader in employer and agency education on supporting autism in the workplace. Supplementing existing community employment supports to better serve people with ASD, our **organization** will continue to collaborate with employers, employment agencies, and universities and colleges across the province as an interventionist in employment support.

AutismNS will continue to work with employers to educate them on the benefits of hiring people with ASD, and encourage them to become more inclusive in their practices and culture.

The Government of Nova Scotia should commit to becoming an inclusive employer and work with Ready, Willing and Able to both connect to governments that have successfully built inclusive employment for people with ASD and intellectual disabilities across Canada, and to aid as a strategic recruiting partner.

The planning and delivery of employment services and supports is a collaborative effort and AutismNS will continue its role as an ASD interventionist, supporting transitions from secondary school to the labour market and those agencies looking for interventionists who can support those people with ASD wishing to engage or re-engage with the labour market.

## RECOMMENDATIONS

1. The Department of Education should adopt TRAACE as a course for credit and make it available to any students with ASD or other developmental disabilities that qualify.
2. Labour and Advanced Education and Community Services should earmark funding for all Careers Nova Scotia Centres, former CPN members (eg. Teamwork-Workbridge), and Adult Service Centres (with supported or pre-employment programming), to take the extensive Supporting Autism in the Workplace, as well as the preliminary Autism 101 courses that AutismNS has developed. Another option would be to provide an annual training grant to AutismNS to deliver an agreed upon number of training sessions annually across the province. The training could be delivered to case managers, job developers, career practitioners, and all front-line staff, either on-agency-site or within the soon to be established Centre for Employment Innovation and Excellence.

3. AutismNS should work with Careers Nova Scotia to identify if a database, modeled on the Respite Care Database, could be adapted for use to maintain a list of Workplace Attendant Support Workers who would be trained in “Supporting Autism in the Workplace” curriculum, and could act as attendant job coaches for employees with ASD.
4. The provincial government, in light of recent changes to the federal labour market agreements and resulting shifts in some funding away from federal funds used for job coach supports, should explore the practicality of an individualized funding model for on the job support that could relax limitations on the workplace attendant program for people with developmental disabilities such as ASD.
5. The provincial government should move away from any disability targeted wage subsidies, and reallocate portions of that funding to individualized supports for competitive employment, as well as refocusing some resources into employer education on inclusive employment.
6. The provincial government should work with AutismNS and the Entrepreneurs with Disabilities Network to evaluate and identify how a sustainable system of self-employment supports can be provided to people with ASD, as well as other disabilities—including an exploration of non-workshop based affirmative enterprise models.
7. AutismNS should be included in conversations related to the transformation of the employment infrastructure in this province to ensure that adults with ASD do not become further marginalized and detached from the labour market.
8. AutismNS should maintain the funding allocations from the province for the Launch Pad and TRAACE program with the option to explore cost effective scalability across the province.
9. The provincial government within the federal labour market agreements continue funding the Ready, Willing and Able pilot program. This is currently a successful partnership with AutismNS and the Nova Scotia Association of Community Living (NSACL) that leads the country in successful labour market outcomes for adults with ASD or intellectual disability.

## Safety in Communities

Safe communities are accommodating and supportive communities. For families of people with ASD, a common concern may be how their loved ones will be treated as they venture into the community, and, particularly for those caring for people with more significant support needs, if authorities and first responders will know how to react to them.

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**Position:** AutismNS believes that safe communities are accommodating and supportive communities; that the best way to assure the safety of people with ASD and their communities is a proactive approach that assures upfront investment in community, housing, program, employment and health supports. The justice system is a last point of intervention, but the education of those charged with first response or search and rescue services about ASD is key to assuring appropriate intervention

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## ISSUES

### *Wandering and Search and Rescue for people with ASD*

For families caring for persons with ASD who also have an intellectual disability, and/or who are non-verbal, a common concern is that their loved one may wander into the community and become lost or find themselves in dangerous situations.

To help give families piece of mind on this front, AutismNS has closely collaborated with Project Lifesaver. Project Lifesaver is a proactive life protection program for individuals with cognitive disorders that equips and trains law enforcement and search and rescue agencies in an active response system that helps them to locate wandering individuals before they become victims of the elements, accidents or predators. Project Lifesaver is a non-profit organization that has fast become the lead organization in Canada and the

United States to effectively train, equip, and deploy the appropriate agencies in these increasingly common situations. Project Lifesaver uses directional radio frequency receivers and each individual enrolled into the project has a water resistant transmitter affixed to their wrist or ankle that emits a unique frequency. It is funded in Nova Scotia by the Emergency Management Office in the Department of Justice, in the amount of \$278,000 per year.<sup>100</sup>

Since the inception of Project Lifesaver in this province, there have been several calls for service from families supporting people with ASD, all resulting in successful rescues. In one case, a young girl with autism was found 2kms from her home and close to water—a situation that could have become much more dangerous if she had not been located quickly. Project Lifesaver sees its service to the ASD community as an integral part of its work.

With the increased need and demand for this service, AutismNS has stepped in to collaborate as a volunteer maintenance partner for Project Lifesaver. Few organizations in Nova Scotia have been able to provide the staffing and set-up infrastructure to create the monthly check-lists, referral steps, and extensive training needed to take on the monthly battery maintenance and administration needs for each Project Lifesaver client. AutismNS has made Project Lifesaver a priority within its community collaboration and outreach mandate, allocating one staff person for 10-12 hours per week as a Lead Coordinator for the Project Lifesaver serving the autism community in Halifax. However, AutismNS receives no funding for this staff position, which limits the time and the number of clients that AutismNS can serve. As of February 2016, Project Life Saver had trained search and rescue teams in 24 regions across Nova Scotia, but in the absence of volunteer capacity like that offered by AutismNS, handling the maintenance of batteries and training, the program was only available in five regions of the province. Response coverage is now available across Nova Scotia, and Project Life Saver is able to accept clients in all areas except the Musquodoboit Valley and parts of Inverness County.

#### ***Proper training for First Responders and Police***

While Project Lifesaver does valuable work in addressing the issue of wandering, an additional and imperative component of creating accommodating and

inclusive communities remains in terms of ASD training for first responders. It is important that individuals with autism learn to interact with first responders, and that first responders learn about and understand ASD so that they are prepared to identify and respond safely to situations that involve this population.

The need for first responder training has been a key priority among autism organizations across much of the world—and Nova Scotia is no exception. Following on the recommendations of the 2010 AMAT report, the 2012 Autism Action Plan outlined that the Department of Justice would develop an online training in ASD and Law Enforcement in consultation with AutismNS.<sup>101</sup> While this recommendation was fulfilled, the number of trainees who have completed the curriculum is not available to the public, and the curriculum requires periodic updating and evaluation.<sup>102</sup>

#### ***Incarceration and Offence Rates***

In the United States research shows that people with developmental disabilities are seven times more likely to have a negative encounter with law enforcement, and research in the UK points out that people with autism are over-represented in their prison system.<sup>103</sup> Because of their marginalization, and the common comorbidity with mental health conditions and other disabilities, people with autism are much more likely than the general population to deal with some form of crisis that will likely involve law enforcement, the court systems, and perhaps even incarceration. Some jurisdictions in the UK and Ontario have already begun inquiries into autism and the criminal justice system, looking at frequency of events, their handling by police, and how to gather the basic data that can help ensure just treatment and outcomes. Nova Scotia has no real data on autism and its criminal justice system at this time.

### **IDEAL SYSTEM OUTCOMES**

Working with Project Lifesaver and with the increased outreach capacity of more stably funded Autism Resource Centres (ARCs) in regions across Nova Scotia, Project Lifesaver would be available to any families in the ASD community who need it, thus building the user base of the project and ensuring long-term sustainability.

Education programs like the Law Enforcement and Autism online training should be evaluated by a qualified third party, and results should be released to AutismNS annually to ensure appropriate delivery and usage. AutismNS will work with the appropriate parties to refine the course and tailor the content.

The Department of Justice, working with AutismNS, should develop some form of surveillance protocol that can document the incidence and handling of situations involving people with ASD and other developmental disabilities and the justice system.

AutismNS will continue to develop and offer ASD awareness training for first responders and search and rescue teams. It will present an annual summary of its presentations to this cohort in its annual report, and to the Department of Justice and to relevant municipalities—outlining the hours and scale of investment in educating provincial and municipal services.

## Senior Care and End of Life

With people living longer, healthier and more active lives, combined with a decline in birth rates, our population is aging; it is estimated that senior citizens comprise an increasingly significant and important demographic.<sup>104</sup> By 2026, projections suggest that approximately 25% of Nova Scotians will be over age 65.<sup>105</sup> Understanding the outlook for individuals with ASD in their senior years can help inform decisions for how to best meet their needs.

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**Position:** AutismNS believes that all people, regardless of ability or need, deserve the right to age with dignity for individuals with ASD, and that aging with dignity means being able to access supports, services and housing that meet their needs.

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### ISSUES

Senior citizens are typically frequent or increased users of the health care system as they navigate later life, existing or emerging conditions, residential or other long-term care options, and end-of life supports. In addition, many senior citizens experience changes in their needs in the areas of housekeeping, personal

## RECOMMENDATIONS

1. A formal third party evaluation and review of the online ASD and law enforcement curriculum that measures the reach and impact of the training since implementation, including recommendations.
2. Development of a “Safety in the Community” strategy that looks at greater awareness and understanding of ASD by law enforcement and first responders. This strategy would also consider educating families and individuals living with ASD to support positive interactions, and better understand the role of law enforcement and first responders in their community.
3. Look at feasibility of implementing an autism registry for interested Nova Scotians similar to the Ottawa registry.

care, and activities of daily living,<sup>107</sup> as well as in financial and estate management. Many Canadians continue to live healthy and active lives well after age 65, increasing the need and demand for opportunities for seniors to engage meaningfully in the community, and recreation and leisure programs.

Furthermore, the government of Canada has begun to invest significant resources into understanding and recognizing the needs of our aging population, and there are online tools to aid in accessing and navigating policies, programs, and opportunities for senior citizens:

Looking ahead, the proportion of seniors in Canada, as well as their average age, is projected to increase sharply over the next few decades. Issues of concern to seniors will evolve as a result and will require further policy action. The Government of Canada is committed to ensuring that it meets the diverse needs of older Canadians, now and in the future.<sup>108</sup>

The Province of Nova Scotia has made a commitment to “an inclusive society of caring communities that supports the well-being of seniors and values their contributions.”<sup>109</sup> Through the Department of Seniors

and community partners, senior citizens in this province are able to access a wide variety of services and supports, including a commitment made in 2015 enhance supports to allow seniors to live in their homes longer. Also in 2015, the Provincial Government published *Towards Understanding: A Dementia Strategy for Nova Scotia*, which provides a model by which the needs of older individuals with complex neurological conditions can be understood and supported.<sup>110</sup>

However, significant research must be conducted to understand the late life supports and basic needs and usage patterns of people with ASD, and the accessibility of these supports to this population—particularly given the increased diagnoses and prevalence rates that mean thousands of people will age while living with dramatically different needs.

## CROSS JURISDICTIONAL COMPARISON

Attention has begun to turn to this subject only recently, with mention in one of Europe's first national autism policies in Wales in 2008,<sup>111 112</sup> significant work done by the National Autistic Society (NAS) in the UK since 2010,<sup>113</sup> and increasing discussions published by policy makers, media, and the community.<sup>114</sup> In the 2013 policy report *"Getting on? Growing older with autism,"*<sup>115</sup> the NAS identifies a number of priority areas for older individuals with autism, including:

- Diagnosis of autism in older adults, and lengthy wait times for diagnosis;
- The lack of research on aging with autism

(including changes in cognitive function or physical/mental health concurrent conditions such as dementia or stress-related conditions, quality of life, etc.);

- Accessing health care and communicating changing or emerging health issues to healthcare professionals;
- Transitioning from family-based support to residential or long-term seniors' housing or care;
- Age-appropriate "autism-friendly" services, such as trained support staff/workers and sensory-friendly environments/homes.<sup>116</sup>

There has been, as yet, relatively little research on older individuals with autism in Canada.

## IDEAL SYSTEM OUTCOMES

It is crucial that AutismNS and the Nova Scotia Provincial Government take steps to begin and understand the needs of the aging ASD population, to ensure full and equal access to health care, appropriate housing, supports for daily living, community engagement and inclusion, and planning for end of life. Nova Scotia is positioned to be a leader in this area.

## RECOMMENDATIONS

1. The provincial government, in partnership with AutismNS, should begin further exploration and research on aging and autism, including the impact on aging caregivers.



# Summary of Recommendations

1. Improve access to timely and high-quality diagnostic services for pre-school and school aged children in Nova Scotia. This maximizes opportunity for these children to access the EIBI program and other ASD specific services that can impact outcomes in the early years.
2. Develop and implement high-quality and affordable diagnostic services for adults in Nova Scotia.
3. Re-convene the Minister's panel on EIBI, including participation by AutismNS, to advise on a long-term early intervention and EIBI strategy for the province. Exploration of parent-implemented training initiatives as intervention options should also be explored by this panel, as well as a cost analysis to increase treatment capacity to include complimentary therapies (e.g. speech language, physical and occupational therapy, other behavioural therapies) as part of a comprehensive, publically funded ASD support system in Nova Scotia.
4. Increased and enhanced access to training or coaching in ASD intervention for parents/caregivers with children with ASD of all ages.
5. Include autism screening, diagnosis, treatment and support in the early years centres' model that is currently under development by the province.
6. Implement Regional Autism Resource Centres (ARCs) by utilizing the Chapter system developed by AutismNS, and working with AutismNS to set up a seamless "wraparound" service system for families navigating the system from the time of identification, through diagnosis and support throughout the lifespan. The existing system, currently supported mostly by volunteers, cannot absorb the current demand in rural Nova Scotia without an investment by government. For the province, the proposed model represents a cost effective approach and fulfills the outstanding AMAT recommendation that was identified as a top priority need by families across Nova Scotia. In addition, like the models in Ontario and New Brunswick, implementing this model provides the opportunity to enhance community capacity, promote integrated services, and standardize sharing of information and best practices.
7. Continue investment in respite support in partnership with AutismNS which would ensure the continuation of the respite database program, training of respite workers in ASD across the province, as well as, further explore structured respite programs for families (March Break and after school options).
8. Ensure that community recreation programming across the province is accessible to children, youth and adults with ASD. This includes an investment in ASD training and access to appropriate accommodation support for Autistic participants.
9. Remove the IQ criteria as a qualifier to access services for families living with ASD in the province, or add Autism Spectrum Disorder as its own category based on a level of need system that is individualized to the family and individual with ASD.
10. Develop autism-specific competency and capacity in the health care system to provide appropriate care, including crisis care, for children, youth and adults with ASD, with a particular focus on: mental health, first responders/emergency rooms, primary care and dental care.
11. Recruit and retain qualified clinical professionals with ASD expertise to support the complex and challenging needs of this population in order to ease waitlist times for service, and to ensure adequate staffing ratios are in place to avoid professional burnout and loss of service.
12. Create standards of care that include "autism friendly" spaces in all health and mental health settings across the province.
13. Ensure that education professionals and support workers have strong autism-specific knowledge and skills that optimize learning for all students with ASD in the school system.
14. Maintain and review appropriate staffing levels in specialized positions (Autism Consultants, assistive technology positions, speech language pathologists, occupational therapists, behavioural specialists) in school boards, and the Department of Education and Early Childhood Development. These ratios have not been reviewed in five years, and have not considered the increase in diagnoses we are seeing in the school system.



15. Develop transition support programs for school-entry at the elementary and secondary levels, as well as transitions from high school towards community or post-secondary opportunities.
16. Ensure access to appropriate life skills and job training curriculum to support improved and enhanced transition success to adult life.
17. Develop autism education “centres of excellence” with highly-trained teachers and professional support staff who consider the unique and complex learning needs of students with ASD in each school board. This also represents an opportunity for ongoing training and professional development of education professionals who can then transfer knowledge and skills to all learning environments, further maximizing outcomes for all students with ASD and other special needs. This is also a cost-effective approach to educating and training skilled professionals.
18. Explore models of innovation in the school system for possible province-wide replication.
19. Partner with AutismNS to conduct an environmental scan of the school system that reviews the consistency of the program planning process and overall experience of families and students with ASD.
20. Government include or task AutismNS in the discussion on appropriate community-based housing options for adults with ASD as the Transformation Roadmap recommendations are explored.
21. An investment in ASD training for residential care workers and behavioural support professionals be funded and implemented in the current residential care system in Nova Scotia.
22. Review policy development under the SPD transformation that supports flexibility of respite funds usage, by eligible families. This would support a person directed approach to service, and allow families to use funds to pay fees or purchase social, leisure and recreation programs for their children. This option should also be available and accessible to adults.
23. Work in partnership with AutismNS to support best practice program development and delivery, and evaluate opportunities to share this work to build community capacity for program and service delivery across the province.
24. Coordinate development of a program teaching children and teens how to manage anxiety.
25. Review of gaps identified in adult programming.
26. Further research and analysis of the needs and support of students with ASD in the post-secondary environment is required, as well as follow up with students, post-graduation, to better understand transition outcomes.
27. Enhanced knowledgeable professionals.
28. Increase in autism-friendly spaces and greater recognition of accommodation considerations in the post-secondary environment.
29. Enhanced transition support to the labour market.
30. The Department of Education should adopt TRAACE as a course for credit and make it available to any students with ASD or other developmental disabilities that qualify.
31. Labour and Advanced Education and Community Services should earmark funding for all Careers Nova Scotia Centres, former CPN members (eg. Team-work-Workbridge), and Adult Service Centres (with supported or pre-employment programming), to take the extensive Supporting Autism in the Workplace, as well as the preliminary Autism 101 courses that AutismNS has developed. Another option would be to provide an annual training grant to AutismNS to deliver an agreed upon number of training sessions annually across the province. The training could be delivered to case managers, job developers, career practitioners, and all front-line staff, either on-agency-site or within the soon to be established Centre for Employment Innovation and Excellence.
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37. AutismNS should maintain the funding allocations from the province for the Launch Pad and TRAACE program with the option to explore cost effective scalability across the province.
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40. Development of a “Safety in the Community” strategy that looks at greater awareness and understanding of ASD by law enforcement and first responders. This strategy would also consider educating families and individuals living with ASD to support positive interactions, and better understand the role of law enforcement and first responders in their community.
41. Look at feasibility of implementing an autism registry for interested Nova Scotians similar to the Ottawa registry.
42. The provincial government, in partnership with AutismNS, should begin further exploration and research on aging and autism, including the impact on aging caregivers.

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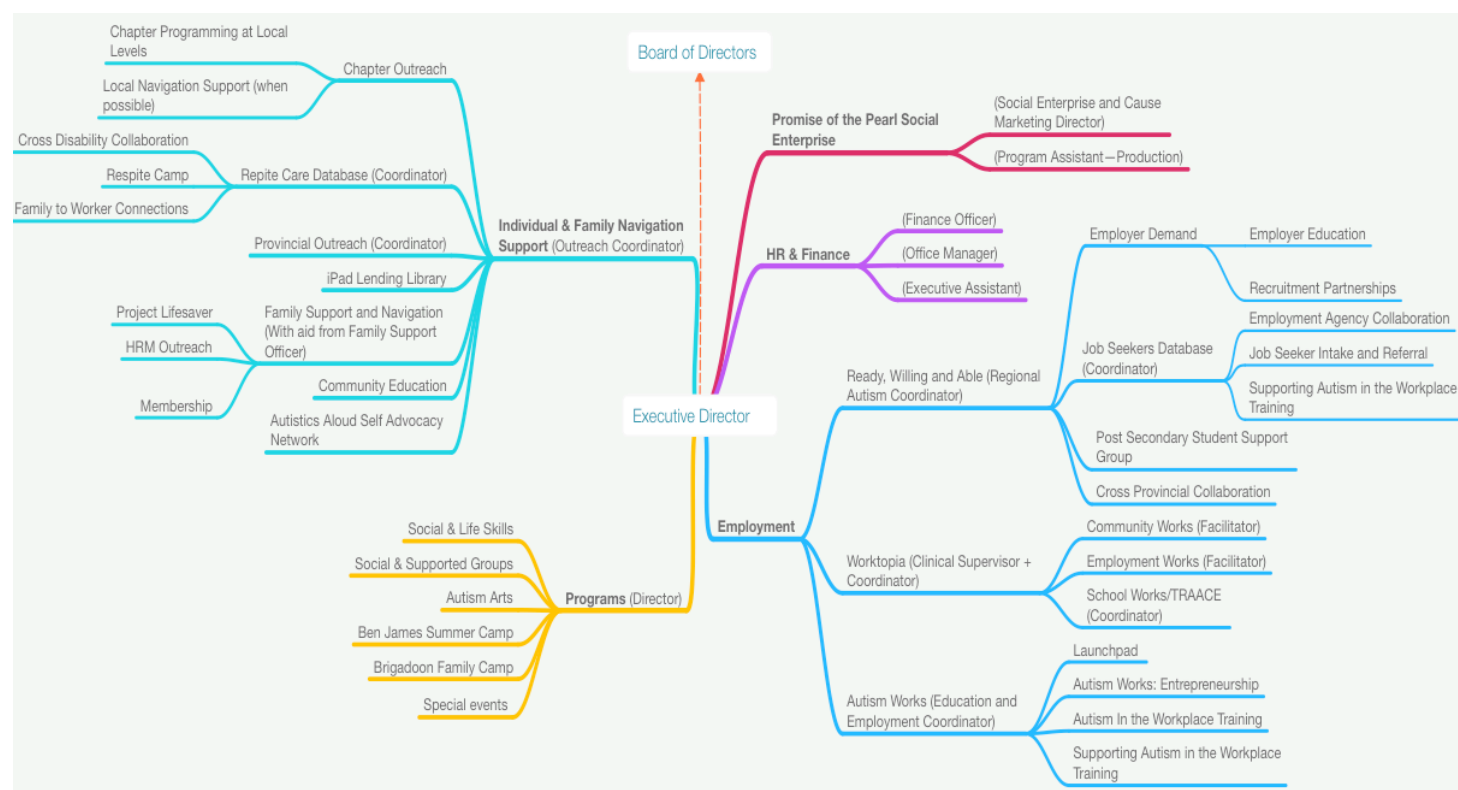


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# Appendices

## Appendix 1: Overview of Autism Nova Scotia Organizational Framework

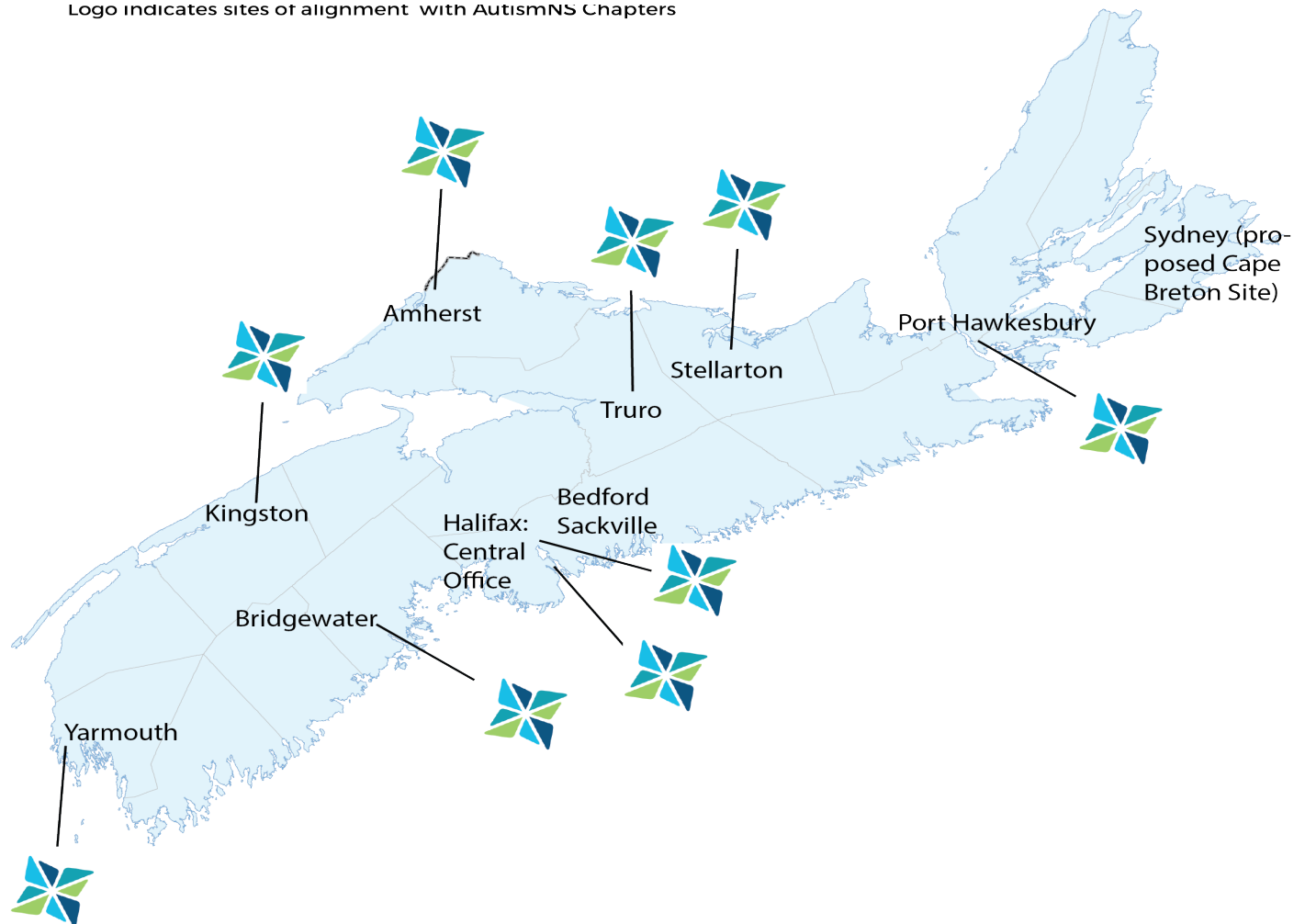


## Appendix 2: Proposed NS Autism Resource Centres

### PROPOSED AUTISM REGIONAL CENTRES

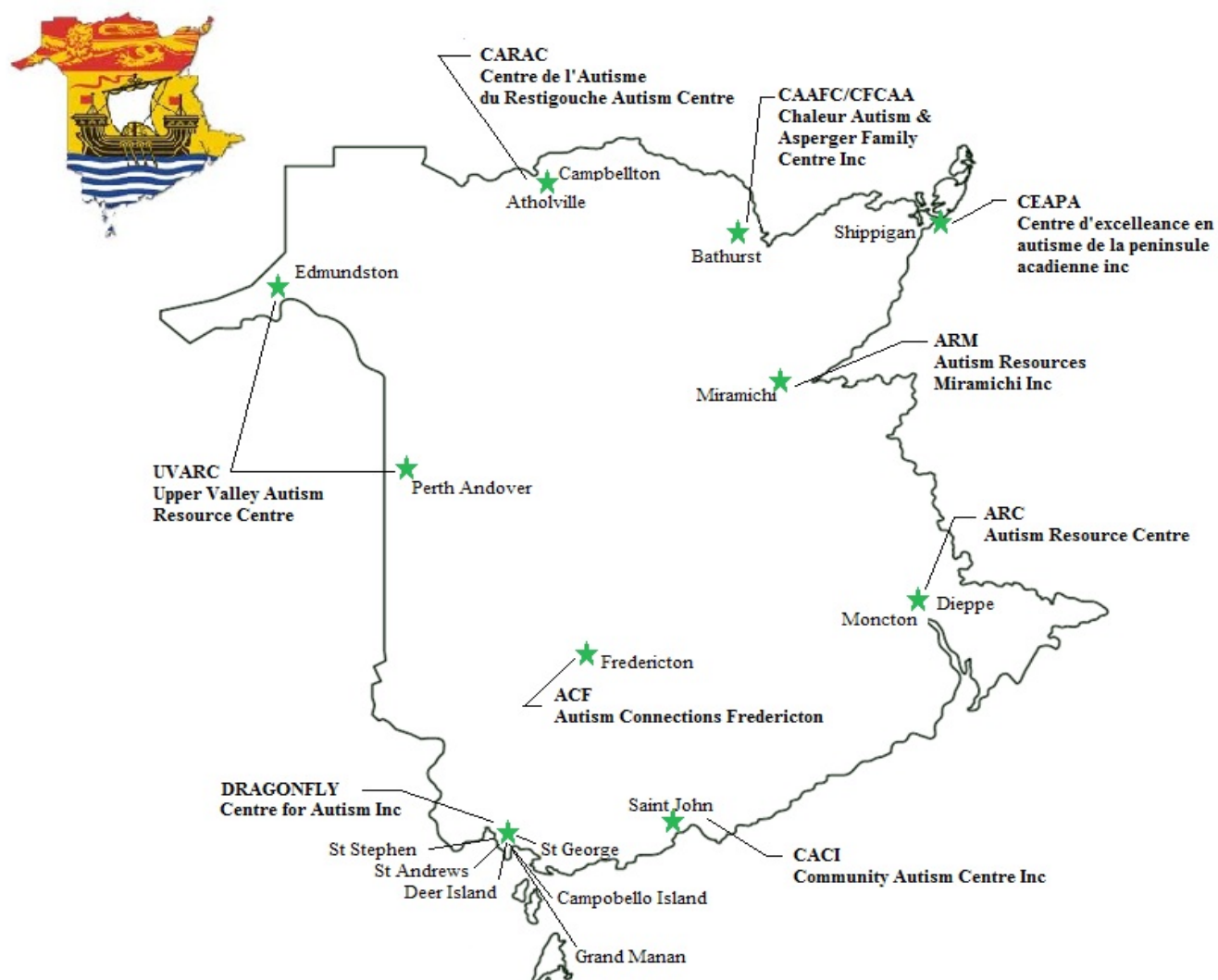
Logo indicates sites of alignment with AutismNS Chapters

Logo indicates sites of alignment with AutismNS Chapters



In order to build on existing infrastructure and community capacity, recommended sites for Autism Resource Centres correspond with the locations of existing Chapters of Autism Nova Scotia, as well as the headquarters of the Autism Society of Cape Breton.

## Appendix 3: Map of New Brunswick Autism Resource Centres



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