Autism Management Advisory Team Report on

Lifespan Needs for Persons with Autism Spectrum Disorder

NOVA SCOTIA

Cover artwork by Conlin Harvey

Conlin is a person with autism who lives in Eastern Passage, Nova Scotia. He loves to draw and to work on the computer. Conlin is in Grade 12 at Cole Harbour DIstrict High School. He would like to be a graphic novelist someday.

In this piece of art, which looks at the different values of good and evil, Conlin incorporates his keen interest in mythology and his concentrated attention to detail. On the left, good is represented by an angel's wing, a tree of hope, the sun, and a grassy landscape. In contrast, the right side represents evil with a demon's wing, a desolate landscape, and a sun in eclipse. For both sides, he lists attributes of good and evil, and centers the piece with the Chinese symbol of Yin and Yang.

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This report is dedicated to James Delorey and his family.

"Between the great things we cannot do, and the small things we will not do, the danger is we shall do nothing."

—Adolf Monod, French Protestant Churchman from the 1800s

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Autism Management Advisory Team Report on Lifespan Needs for Persons with Autism Spectrum Disorder

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Preface

Dear Readers,

In the late 1980s, based on research conducted in Nova Scotia and elsewhere, autism was reported to occur with a frequency of about 1.2 in every 1,000 people (Bryson, Clarke & Smith, 1988; for reviews, see Bryson, 1996; 1997). Only 20 years later, we have witnessed an astounding increase in prevalence: current estimates are that 1 person in every 100–150 has autism or a related condition (hereafter, 'autism'; CDC, 2009; Fombonne, 2009). The reasons for this increase are being actively debated. However, the more pressing issue is that Nova Scotia has as many as 9,000 children and adults affected by autism. Faced with these unprecedented numbers, how are we, as a province, going to meet the service needs of this diverse and challenging population?

This report, requested by the Nova Scotia Government, documents the results of a broad-based survey conducted over the past year. Respondents were surveyed about services needed to enhance the quality of life of children and adults with autism, and their families. Over 700 people residing throughout rural and urban Nova Scotia responded—an exceptionally high response rate by any standard. The respondents included families and individuals affected by autism, as well as community, social service, education, and health care providers working on their behalf. The survey is supplemented by more in depth discussions with stakeholders. The results serve as an eye-opener—a window into the lives and struggles of those most directly affected by autism.

But this is only the first step; now we need to move forward. Despite progress on a number of fronts, much remains to be done before we will even approach some semblance of fairness or justice. No one should be isolated, excluded from basic opportunities and services available to others, with little or no hope for the future. We need to ensure timely and equitable access to existing health, education and social services, as well as inclusion in all aspects of community life. We also need concerted and informed efforts focused on realistic, innovative, and person-oriented solutions for the large number of individuals living with autism.

A dedicated team of individuals have brought us to this point. To them, we extend our sincere thanks. Now it is up to all of us—policy makers, legislators, service providers, and citizens of Nova Scotia.

With deep appreciation to those who care to make a difference in the lives of individuals and families affected by autism,

Susan E. Bryson, PhD
Joan and Jack Craig Chair in Autism Research
Dalhousie University and IWK Health Centre

Executive Summary

The current prevalence rate of autism is 1 in 110, or 1 percent (Centers for Disease Control and Prevention 2009). This fact urges us to prepare for the increasing numbers of individuals diagnosed with autism in Nova Scotia. The increase in the prevalence rate of autism has made the call for enhanced services for people with autism of critical importance for the Government of Nova Scotia. This unparalleled rise in needs requires us to carefully develop and carry out a comprehensive plan to support this population. With this new prevalence rate, it is estimated that currently Nova Scotia has approximately 9,500 people with an autism spectrum disorder. These numbers are affecting all services and will continue to do so in the upcoming years. The unique and complex nature of autism compels us to think differently when we plan for support throughout the lifespan.

In the fall of 2008, the Government of Nova Scotia recognized the need to examine the needs of people and families living with an autism spectrum disorder. It developed a mandate to strike a committee to investigate this issue. The Department of Education took the lead and established a committee of eight people made up of representatives from the departments of Education, Health, and Community Services, as well as five members representing the autism community of Nova Scotia. This committee became known as AMAT, the Autism Management Advisory Team. It began meeting in November 2008 to start gathering information from Nova Scotians about present levels of service and identified gaps in services throughout the lifespan for persons with autism spectrum disorder.

The committee met with experts, and interviewed individuals in the field and family members supporting a person with autism. The committee also distributed a province-wide survey to the public, families, and those providing service to people with autism. The survey was filled out by 732 individuals, either online or on paper. The information gathered through the survey and interviews forms the basis of the findings and recommendations of this report. Throughout this endeavour, the committee kept the following guiding principles in mind:

- Services should be equitable and available across the province; geography should not determine levels of service.
- Best practices should be chosen when making decisions on intervention and support services.

- Services must be provided throughout the lifespan and across settings.
- Family needs and values must be respected, and families must be consistently involved in decision making and the planning process.

This committee examined many issues surrounding the needs for this population. The report is divided into the following sections:

1. Introduction and Background
2. Survey on Lifespan Services for Children/Adults with Autism Spectrum Disorder (Lifespan Survey)
3. Understanding Autism
4. Health: Regional Autism Centres
5. Identification and Diagnosis
6. Early Intervention
7. Education
8. Respite, Housing, Social, and Recreational Programming
9. Families
10. Adults with Autism
11. Safety in the Community
12. Autism Organizations and Support Groups

Each section has a background followed by survey and interview findings and recommendations. A summary of all recommendations can be found on page 69.

The AMAT committee recognizes that there are numerous recommendations included in this report and that government cannot act on all of them at once. The committee suggests a phased-in approach. It is therefore recommended that the Government of Nova Scotia act on the following two recommendations immediately:

- An Implementation Committee should be established by September 1, 2010, and be made up of members of the autism community and representatives from the Nova Scotia departments of Health, Community Services, Education, Justice, and others when warranted. The Implementation Committee will develop and carry out action plans for the recommendations contained in this report.
- The Implementation Committee should start by establishing regional autism centres around the province.

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Introduction and Background

Autism spectrum disorder (ASD) is a complex neurologically based developmental disorder that affects a person's ability to communicate and interact, both with other people and with their environment. At one time autism was considered to be a rare condition, but it is now recognized as one of the most common developmental disorders affecting children. Prevalence rates have soared from 1 in 2,500 during the 1960s to 1 in 110 in 2009 (Centers for Disease Control and Prevention 2009). The ratio of individuals with a diagnosis of ASD has and will continue to affect all department and community services and programs.

> *"We always want what is best for our children. With continued research and treatment options, these children can successfully strive to reach their full potentials."*
>
> —Parent

The increase in numbers in Nova Scotia has mobilized parents, advocates, and educators to call for more supports and services for this population. Initially the focus in Nova Scotia was on early interventions, with the hope that the benefits of early intensive interventions would decrease the numbers of youth and adults needing significant supports. However, even with the successes achieved by programs such as the Early Intensive Behavioural Intervention (EIBI) program, many individuals still need supports and services throughout their lifespan. The question needs to be asked: How will Nova Scotia be able to support individuals with autism so as to protect their potential quality of life?

Throughout the 1990s and into the first decade of the 21st century, a growing awareness of the numbers and needs of persons with autism in Nova Scotia has resulted in increased services and supports. The inclusion model adopted by the Department of Education in 1996 made sure that children with exceptional needs were included in their community school with their same-aged peer group in regular classrooms. This fundamental principle made sure that children with ASD had exposure to peers and typical school programming. However, there was little expertise in appropriate teaching techniques for these children. Parents and educators were looking for best practices to help children with ASD to learn. As a result of a report developed by the Children and Youth Action Committee (CAYAC), a pilot project called Early Identification and Intervention Services (EIIS) was carried out to enhance current services and offer best practices services for children with ASD.

Key programs have been developed because of increased advocacy and awareness. In 2004, the province introduced the EIBI program using best practices behavioural techniques to improve preschooler's communication and social abilities. A committee made up of representatives from the Valley Autism Support Team, Autism Society of Nova Scotia, and Autism Society of Cape Breton made presentations to the Nova Scotia Legislature Standing Committee on Community Services in 2004 and 2007. A recommendation was made for government to create a working group to study and report on the lifespan needs of people with ASD in Nova Scotia. In July 2008, the Department of Education started an interdepartmental committee that included representatives from the departments of Education, Health, Community Services, as well as, representatives from provincial advocacy and autism organizations. The Autism Management Advisory Team was given the mandate to examine the lifespan needs of persons on the autism spectrum in Nova Scotia, to look at current supports and services and identify gaps, and to prepare a report with recommendations for presentation to the provincial government.

The committee is made up of the following representatives:

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

The working group began meeting in November 2008, and immediately began to explore services and supports for persons with ASD. The committee focused on what services currently exist and identified gaps. The information was gathered through jurisdictional research, literature review, interviews with pivotal persons, guest speakers who were experts on the subject matter, and a provincial survey circulated from May to July 2009. The survey information gathered from parents, family members, professionals, and persons with ASDs provided much valuable input. This information has been analyzed and forms the basis for this report. The analysis can be found in Section 2: Survey on Lifespan Services for Children/Adults with Autism Spectrum Disorder (Lifespan Survey).

Survey on Lifespan Services for Children/Adults with Autism Spectrum Disorder (Lifespan Survey)

Rationale/Introduction

In the spring of 2009, the Autism Management Advisory Team (AMAT) released a province-wide survey to parents of children with autism spectrum disorder (ASD), professionals and individuals, and, more specifically, adults aged 18 years and older with ASD. The main goal of the survey was to identify key or priority program and service needs across Nova Scotia.

The survey was approved at the department level to be distributed by the regional school boards throughout the province. The survey was also available online through the Provincial Autism Centre website and the government working group website. A press release informing Nova Scotians about the survey was released in August 2009. The Provincial Autism Centre, Valley Autism Support Team, Autism Society of Cape Breton, and the Autism Society of Nova Scotia sent out the survey to partnering autism organizations and membership lists throughout the province in an attempt to reach as many families, individuals with ASD, and related professionals as possible for the sample size.

The survey was filled out by 732 individuals, either online or on paper. Paper surveys were mailed to the Autism Research Centre at the IWK Health Centre in Halifax and transferred electronically into the system for data analysis. Please refer to Appendix I to view the Lifespan Services Survey.

This section contains a sample of the survey results as reported from parents/caregivers, professionals, and individuals with ASD. The full report is contained in Appendix II.

Survey on Lifespan Services for Children/Adults with Autistic Spectrum Disorder

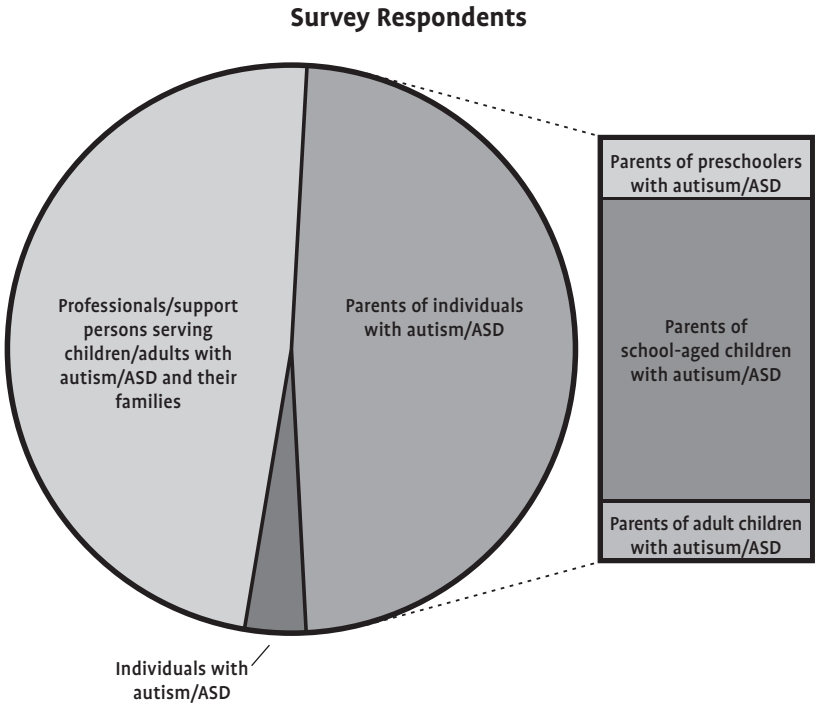
Survey Data Summary

Questions 1, 2, 3: *Demographics*

The survey was filled out by 732 individuals, either online or on paper.

- Individuals with autism/ASD: 26 (3.6 percent of respondents).
- Parents or caretakers of children with autism/ASD: 366 (50.0 percent of respondents).
  - Parents of preschoolers with autism/ASD: 55 respondents (7.5 percent of respondents, 15.0 percent of parents).
  - Parents of school-aged children with autism/ASD: 269 respondents (36.7 percent of respondents, 73.5 percent of parents).
  - Parents of adult children with autism/ASD: 54 respondents (7.4 percent of respondents, 14.8 percent of parents).
- Professionals or other support persons serving children and/or adults with autism/ASD and/or their families: 379 (51.8 percent).

(Note: These values total >100 percent as some respondents identified themselves as both a parent and a professional, for example, or as having children with autism/ASD in more than one category, or some parents did not identify the age group under which their child/children fell.)

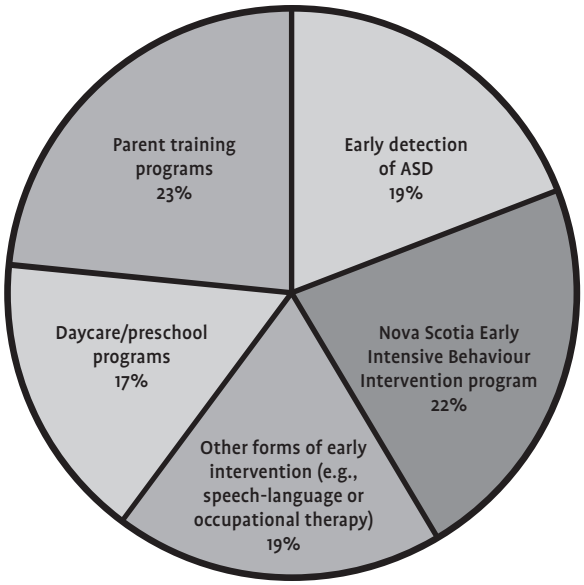


Question 4: R*espondents were asked to indicate from a list which of the following they need/would like but are unable to access, either for themselves (e.g., person with autism/ASD), their family member(s) or their clients, patients, or students with autism/ASD.*

Preschool-aged children category:

- Early detection of ASD: 180 (24.6 percent of respondents)
- Nova Scotia Early Intensive Behaviour Intervention program: 210 (28.7 percent of respondents)
- Other forms of early intervention (e.g., speech-language or occupational therapy): 176 (24.0 percent of respondents)
- Daycare/preschool programs: 155 (21.2 percent of respondents)
- Parent training programs: 220 (30.1 percent of respondents)

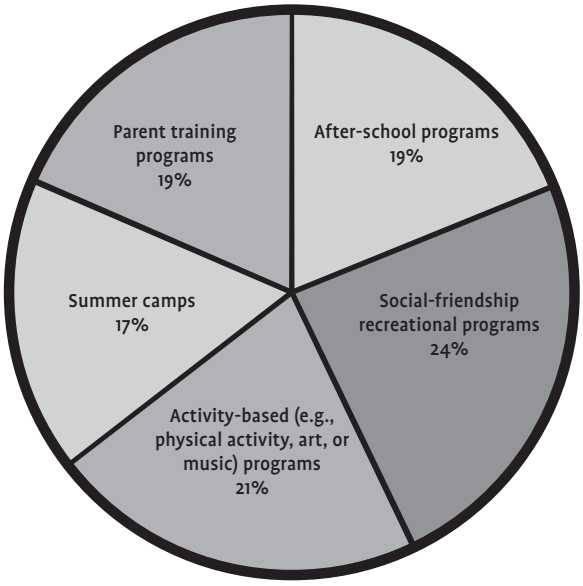
Areas Identified as Needs for Preschool-aged Individuals with Autism/ASD



School-aged children category:

- After-school programs: 354 (48.4 percent of respondents)
- Social-friendship recreational programs: 450 (61.5 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 403 (55.1 percent of respondents)
- Summer camps: 319 (43.6 percent of respondents)
- Parent training programs: 347 (47.4 percent of respondents)

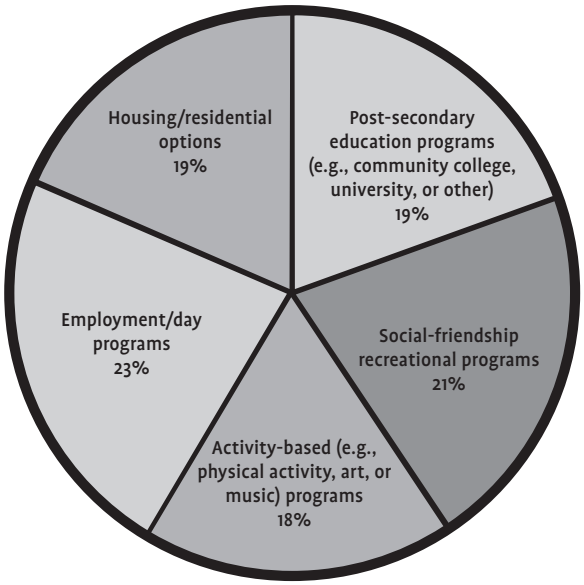
Areas Identified as Needs for School-aged Individuals with Autism/ASD



Adult category:

- Post-secondary education programs (e.g., community college, university, or other): 218 (29.8 percent of respondents)
- Social-friendship recreational programs: 237 (32.4 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 199 (27.2 percent of respondents)
- Employment/day programs: 255 (34.8 percent of respondents)
- Housing/residential options: 208 (28.4 percent of respondents)

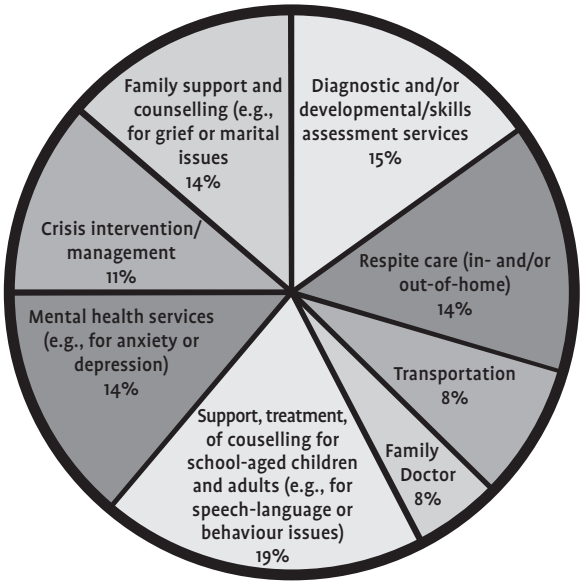
Areas Identified as Needs for Adult Individuals with Autism/ASD



General category:

- Diagnostic and/or developmental/skill assessment services: 329 (44.9 percent)
- Respite care (in- and/or out-of-home): 313 (42.8 percent)
- Transportation: 171 (23.4 percent)
- Family doctor: 108 (14.8 percent)
- Support, treatment, or counselling for school-aged children and adults (e.g., for speech-language or behaviour issues): 407 (55.6 percent)
- Mental health services (e.g., for anxiety or depression): 301 (41.1 percent)
- Crisis intervention/management: 245 (33.5 percent)
- Family support and counselling (e.g., for grief or marital issues): 298 (40.7 percent)

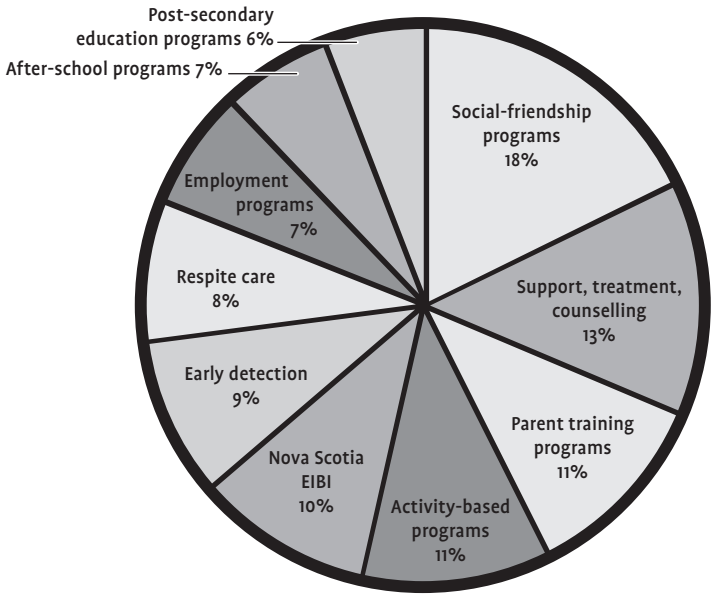
Areas Identified as General Needs for Individuals with Autism/ASD



Question 5: *Respondents were asked to indicate from the same options their top three priorities/most important needs.*

- Early detection of ASD: 133 (18.2 percent of respondents)
- Nova Scotia Early Intensive Behaviour Intervention program: 151 (20.6 percent of respondents)
- Other forms of early intervention (e.g., speech-language or occupational therapy): 76 (10.4 percent of respondents)
- Daycare/preschool programs: 35 (4.8 percent of respondents)
- Parent training programs: 161 (22.0 percent of respondents)
- After-school programs: 95 (13 percent of respondents)
- Social-friendship recreational programs: 260 (35.5 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 157 (21.4 percent of respondents)
- Summer camps: 70 (9.6 percent of respondents)
- Post-secondary education programs (e.g., community college, university, or other): 82 (11.2 percent of respondents)
- Employment/day programs: 100 (13.7 percent of respondents)
- Housing/residential options: 75 (10.2 percent of respondents)
- Diagnostic and/or developmental/skill assessment services: 76 (10.4 percent of respondents)
- Respite care (in- and/or out-of-home): 117 (16.0 percent of respondents)
- Transportation: 16 (2.2 percent of respondents)
- Family doctor: 13 (1.8 percent of respondents)
- Support, treatment, or counselling for school-aged children and adults (e.g., for speech-language or behaviour issues): 196 (26.8 percent of respondents)
- Mental health services (e.g., for anxiety or depression): 75 (10.2 percent of respondents)
- Crisis intervention/management: 39 (5.3 percent of respondents)
- Family support and counselling (e.g., for grief or marital issues): 56 (7.7 percent of respondents)

Top 10 Needs Identified by Respondents



Understanding Autism

Autism is a complex neurobiological disorder. It happens in all levels of society, knows no socio-economic boundaries, and affects all facets of a person's life. ASDs are housed under the umbrella of Pervasive Developmental Disorders (PDD). Autism spectrum disorders include Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS). It happens four times more often in boys than girls. Although there is no known cure for autism, significant and life-changing improvements can be achieved, if appropriate interventions and supports are put in place for the individual.

Autism is characterized by impairment in three areas of development:

1. **Communication (verbal and non-verbal):** People with autism will have challenges in using and understanding language. They may use words in odd ways, and not comprehend the complete meaning of statements or conversations. They struggle with social use of language. Some people never develop verbal language, while some become very proficient verbally. In addition, they will have difficulty understanding non-verbal body language such as facial expressions or gestures.
2. **Social interactions:** This is the ability to understand, respond, and interact effectively in social relationships.
3. **Behaviour:** People with autism may have unique patterns of behaviour. They may become preoccupied with specific objects or parts of objects, routines, and interests. A small, seemingly insignificant change to an environment, such as a piece of furniture in a different space, may cause great distress to someone with autism. Routines may be very important—so much so that a minor change in routine can be quite devastating for the individual and result in a negative and inappropriate reaction.

> *"I will never forget how Kyle began to speak after five long years of silence and how Brandon's challenging behaviour improved with continued support."*
>
> —Parent of two boys with autism

In addition to the impairments listed above, there can be additional features present. For example,

- Intellectual abilities can vary widely. The characteristics of autism range from individuals with limited cognitive ability to individuals who have high intelligence.
- There can be an uneven developmental profile, so an individual may be very skilled in one area (e.g., able to read at a much higher grade level than peers) but is unable to master a basic skill in another area (e.g., unable to manage buttons or tie shoes).
- People with autism may experience different perceptual responses to the environment. Many people with autism report that their sensory system is always hyper-aroused and that the environment is overwhelming. This can lead to inappropriate behaviours as they attempt to avoid loud sounds, bright lights, strong smells, etc. Other individuals with autism will seek out sensory input, such as deep pressure to the body, which they find calming.
- There may be challenges with sleep patterns, food preferences, and toileting.
- Executive functioning abilities can be affected. Executive functioning is the ability to plan and organize events, such as preparing for the day by packing and organizing the necessary items. Challenges with executive functioning also leave individuals with an impaired ability to use critical thought or solve problems effectively. With impaired ability to solve problems, individuals with ASD become highly frustrated, which can lead to rigid or anxious behaviours. Starting a task and being able to follow the sequence of steps can be difficult without visual support.
- Most individuals with autism report issues with anxiety, which can be extreme at times. Managing their environment and trying to understand social interactions can be extremely difficult and can lead to apprehension and worry over what to expect in new or confusing situations.

The needs of the autism community have direct effects on Nova Scotia's society. People with ASD have significant challenges in their abilities to function with others. They struggle with communication, with interactions with others, and with behaviours that can appear inappropriate to

society. Employment opportunities are limited as there are few employers who understand the support needs of the disorder. Society bears the costs of maintaining individuals who, if proper supports were put in place, could contribute more fully to their community.

> *"Imagine living in a world where, no matter how hard you tried, you couldn't make a single person understand your needs."*
>
> —Excerpt from parent contribution, Life Without Words

It is not only the individuals who require support, it is also the families. Families report significant stress in living with and supporting persons with ASD. Although the challenges may change with age, they do not disappear. The following experiences, one from a family and one from an individual, will give readers an insight into the world of autism.

Life Without Words

Our son is eight years old. He can talk, but almost without exception it is purely echolalic (randomly repeating words or phrases he has heard before. He recites episodes of his favourite TV show). He cannot comment on his day at school, tell us if he is hurt or sick. While we don't hear the "gimmes" and "I wants" typical of his age group, neither do we hear "I'm scared" nor "I love you." He is very smart, loveable, and affectionate, but his lack of communication skills leaves him frustrated and volatile.

With no means to say what is on his mind, he often resorts to the only thing he can do: tantrums borne of pure frustration. Imagine living in a world where, no matter how hard you tried, you couldn't make a single person understand your needs. Perhaps you've just done something that has made you burst with pride, but you can't share that with anyone, because no one understands you. Maybe you see something dangerous and want to warn someone, but go unheard. You may simply want to know if someone is having a good day. You'll never know, because not a single soul understands you.

Without the ability to be understood, we can't be sure if the things setting him off are in his surroundings. We know he has trouble processing sensory input at times. Maybe the lights are too bright, the TV too loud, a scary commercial is on. Maybe he doesn't like the smell of whatever is cooking for supper. We are left with the guessing game plaguing our daily life. And with each wrong guess, his anxiety grows until it climaxes in meltdown. This is a typical day for him. Before you judge him, take a moment to consider what he is going through.

Susan's story: My Life with Asperger Syndrome (Excerpts)

Hated and still hate change; depended upon rigid routines and rituals; the nighttime especially … Then a ritual "goodnight," "NiNight," THEN I would read a bit to myself, and hopefully I would stay in bed until I fell asleep …

Adulthood

After the disaster of high school, college and university were my salvation; people, I learned, were weird all over. I made oddball friends and found I could write well and take interesting photographs.

However, I suffer from co-morbid anxiety and depression, and ADHD … And … I am a night owl to this day …

I must be honest: I was more adaptive in my twenties, but as I get older, I have found I have reached a plateau; I have begun to regress and become less adaptive. This may be due to stress, lack of early intervention, lack of mentors, or not fulfilling my dreams. But with new counselling and OT, I hope to get back on track.

I still struggle with social interaction; I misread lots of cues and have to accept this. I have also fought with myself regarding my chosen path. I love film, history, and human culture very much, but I also love animals and the natural sciences too. This was and still is an ongoing dichotomy that I fight within myself, and has been the source of some of my deepest problems. But I finally made up my mind this past year and will be pursuing an academic degree in Film History and Criticism … One day I want to be Dr. Susan!

I have been able to form some lasting relationships.

I use earplugs when necessary, and cope with smells using a facemask and a Vicks inhaler and cinnamon sticks boiled on the stove. But those two things are an ongoing struggle; I find human beings sometimes hard to live with! I deal with IBS and allergies, too.

Still clumsy … lousy dancer … one Latin dance lesson and that was enough for me!

—Still immature! Terminal nerdiness!

Was tested with inconclusive results as a baby; again in grade 6; and in grade 11. FINALLY diagnosed in 2004 at 34.

Health: Regional Autism Centres

Children with autism have special health care needs that need complex care from multiple medical and clinical specialists that typically continue throughout their lifetimes. Treatment across all ages should be individualized and multi-disciplinary, and should address: medical needs (metabolic/genetic conditions), seizures, sleep disorders, gastrointestinal problems, allergies, co-morbid psychiatric conditions, psychosocial needs, educational needs, speech and language services, and occupational therapy.[1] Multi-disciplinary care includes providers such as psychologists, educators, behaviour analysts and interventionists, speech-language pathologists, occupational therapists, nurses, and medical professionals (e.g., family physicians, pediatricians, psychiatrists).

> *"My child needs a team of professionals working together to create and then implement a program to assist her in learning and concentrating or focusing on tasks that are presently impossible to reach due to behaviours. My child needs an autism centre where all professionals are located."*
> —Parent comment from survey

ASD is a complex and multi-faceted condition. The appropriate management of health care needs is complicated by the impact of the symptoms of ASD itself. For example, communication difficulties limit the information given to the health care professional and the explanations, instructions, and advice given to them.[2]

Autism spectrum disorders are behaviourally defined. As a result of their social and communication problems, people with ASD are at risk of developing behavioural and emotional difficulties from childhood. Once established, they are not likely to decrease without intervention and may even worsen. Appropriate treatment of ASD encourages normal development and skills for independent living.[2]

There is a growing body of literature about the mental health concerns of people with ASD. Preliminary research suggests that those with ASD have a much higher chance of developing psychiatric problems. People with ASD are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life.[3] However, as previously mentioned, communication difficulties, both verbal and non-verbal, often make it very difficult to diagnose depressive or anxious states.[4, 5] This can mean that it is not until the mental illness is well developed that it is recognized. It should be noted that in the committee's survey results, mental health services and crisis intervention were rated a top priority by parents of adults with ASD.

"Mental health support is significantly missing in the area of managing anxiety, depression, and behavioural concerns in the family home. I hope there doesn't need to be a tragedy before we step up to the plate and see the real need that exists in this area."
—Comment from survey

The complexity and heterogeneity of ASD necessitates taking a broad approach to addressing the health needs of this population. Treatment of ASD and co-morbid conditions are most appropriate when derived from comprehensive diagnostic and ongoing assessments.[2] Comprehensive plans include those that address behavioural needs, educational interventions, psychosocial treatments, physical health needs, communication, etc.

A transparent and accessible health care system in Nova Scotia needs to be in place for all individuals with ASD and their families. Generic health care services and disability-specific services should be used; however, there also needs to be evidence-based autism-specific interventions available. A key area of the health care continuum is the primary health care setting, which is essential in making sure there is continuity of care and access to appropriate and specialized services for individuals with ASD and their families. This is supported by the Department of Health's strategic priority of developing a comprehensive primary health care system for all. People with ASD and their families need access to general practitioners and primary health care teams.

Survey and Interview Findings

- Many health professionals (psychologists, psychiatrists, doctors, nurses, dentists, etc.) do not have specialized training or courses in autism and have difficulty diagnosing, understanding, and treating patients with ASD.
- Most general practitioners do not know the early indicators of autism and do not refer patients for a screening for autism. This delays the diagnosis and the patient misses out on crucial early intervention.
- Individuals with higher functioning autism and Asperger syndrome are frequently misdiagnosed with other disorders (ADHD, OCD, ODD). This is generally due to lack of autism-specific training among health professionals, particularly around the characteristics of higher functioning autism.
- When a severe crisis erupts in the family home or in the school environment, there are few options for treatment. Health professionals in emergency rooms are ill equipped to manage a patient with autism who is in a crisis situation. The rural areas of the province, in particular, have very few supports for these incidents.

- With the severely affected persons with autism who have life-threatening behaviours, there are few professionals in health with the knowledge to offer appropriate treatment and medication.
- Families report that once a diagnosis is given they often do not receive resources to help them understand the nature of autism. In situations where no information is given, families/caregivers must begin the search themselves and often turn to the Internet or their local school for information. This process is overwhelming for families, who are often still in the grieving process after diagnosis. Families and caregivers need immediate access to quality and reliable information after diagnosis.
- Families also report that they do not know where to turn for services after the diagnosis. They do not know who to call and are unaware of what services their child needs. They are not given a navigator who can help them access the appropriate supports. As a result, parents become confused, isolated, and have feelings of helplessness.
- Parents report that they need help in their home to understand and manage the behaviours that their child with autism is exhibiting. This becomes a critical situation when the child (or children) has life-threatening safety issues, or has self-injurious or violent behaviours toward other family members. These families need the help of professionals who understand the complexities of autism and can offer solutions for inappropriate behaviours in the home. Families have said that this support must happen in the home, e.g., the interventionist works with the person with autism in the home.
- Families and professionals report that there is a lack of adequate services in the areas of psychology, speech-language therapy, and occupational therapy once their child has been diagnosed. Some families report that their child receives only minimal speech-language and occupational therapy, and can only see a psychologist if there is an emergency. If families have an adult child with ASD, services are almost non-existent. In times of crisis, the only option for support if a violent episode or "meltdown" takes place in the home is to call the local police. Families rarely access this resource because they are fearful of the interventions that may be used on their child, often resulting in family members being physically and emotionally abused in the home.

- Families and professionals report that there are very few private services to access, especially in rural areas of the province. Many parents are willing to pay for services but are unable to find them. Others are on fixed incomes and cannot afford them.
- The general public is unaware of the characteristics of autism and needs to understand the behaviours, especially when they erupt in a public place. Understanding autism is critical for families and individuals with ASD to find their place in their communities after diagnosis. This theme of autism awareness permeates throughout all areas of the report, further supporting the strong need for a widespread awareness campaign.

The unique and complex nature of the autism disorder is best served by a "total care centre" approach. It is proposed that *regional autism centres* be established throughout the province. The departments of Education, Health, and Community Services would work together to establish these centres. Using *existing infrastructure (programs, services, and sites where assessment and diagnosis presently take place)* the centres would be a place where all autism services would be housed.

> *"One thing that is desperately needed in this province is a total care centre for people with autism, and those who live with or work with them … This one-stop shopping approach would mean less travel for families, less stress for everyone, and would simply make life easier for people living with ASD."*
>
> —Parent comment from survey

These centres would offer a range of evidence-based services and supports to individuals with ASD, families, service providers, and the general public. The centres would include a variety of professional services such as psychology, speech and language, occupational therapy, behaviour therapists, counselling, etc. As well, each centre would have an autism navigator who would guide the family through the process and link them with other services and autism organizations available in the community. A critical part of each centre would be a lending library of autism resources for professionals, families, and other interested people to borrow. Diagnostic teams would refer the family to this library of resources so that they might become more knowledgeable about the disorder. Having all services housed in one location will allow families and members of the community to access autism services and credible resources in a single location.

The regional autism centres would be a welcoming place for all to visit. Social programming, specialized playgroups, and other activities could take place at the centre. As well, training workshops and information sessions could be offered to enhance autism knowledge for service

providers, families, and the general public. For additional information and to see a suggested model, please refer to Appendix III.

General Public

Because of the prevalence rate of 1 in 110, autism is now a common topic in the media. Documentaries, articles, letters to the editor, movies, novels, conferences, and workshops abound. Although the general public is becoming more knowledgable, misunderstandings are still common. There is a long way to go before an adequate understanding of the spectrum is widespread throughout general society. Employers and businesses typically do not understand autism and are missing out on a potential workforce that has special talents for many different kinds of jobs. Families who have a member with autism have reported that they fear poor public perception when they are trying to manage their child with autism who may be displaying autistic behaviours.

RECOMMENDATIONS

1. An Implementation Committee should be struck by September 1, 2010, made up of members from the autism community and representatives from the departments of Health, Community Services, Education, Justice, and others when warranted.
2. 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.
3. People with ASD should have regular health assessments that include gathering information on areas including but not limited to behavioural, emotional, and mental health issues; screening for medical conditions; nutritional issues; and motor, sensory, and perceptual difficulties. (These services would be offered through the regional autism centres.)
4. People with ASD and their families should have access to a wide range of health professionals/interdisciplinary health teams (e.g., psychiatrist, psychologist, social worker, occupational therapist, speech-language pathologist, behaviour analyst, behaviour interventionist, and related professionals based on family and individual needs.

5. The province should designate the positions of behavioural analysts and interventionists as job descriptions within the Department of Health and make these trained staff available across the province to support families and individuals.
6. All general practitioners should become knowledgable in recognizing the features of autism. The *Physician Toolkit* (see www.autismcentral.ca/research/index.php?option=com_content&task=view&id=67&Itemid=70 to download a copy), a manual for medical doctors, should be available to all general practitioners across Nova Scotia.
7. Treatment/support plans should be comprehensive and include behavioural needs, educational interventions, psychosocial treatments, physical health needs, communication needs, environment, functional development, and skills for independent living.
8. Further explorations of crisis services for families and individuals with ASD should be investigated to determine if supports are appropriate, timely, and accessible.
9. A course on autism should be included as a mandatory part of training for all student medical professionals, including physicians, nurses, dentists, speech-language pathologists, occupational therapists, psychiatrists, and psychologists.

10. An autism training module should be developed and offered as a Continuing Medical Education (CME) credit to practising medical professionals and for the Mental Health First Aid program.
11. An ASD Clinical Practice Guideline should be developed that addresses the needs across the lifespan. (A possible model to consider is the *New Zealand Autism Spectrum Disorder Guideline*; see www.moh.govt.nz/moh.nsf/indexmh/nz-asd-guideline-apr08?Open.)
12. An autism education and awareness campaign should be developed and carried out. It should target employers, the justice system, general practitioners, health care workers, educators, and the community at large. The Department of Health should take the lead.

Identification and Diagnosis

During the preschool stage, it is generally the parents or other family members who first recognize that their child is not developing in a typical way. Sometimes it is the babysitter, or the daycare worker, or the neighbour next door. Once a question is raised in the parents' mind, they will first go to their family doctor or pediatrician. As a result of that consultation, the child may be referred for an assessment. Each district health authority (DHA) in Nova Scotia has established an autism assessment team, and the child is placed on the waiting list for assessment. Waiting times for assessment can vary throughout the province, based on the number of professionals qualified to assess and diagnose, and the number of children needing assessment. As a result, a child usually waits between three months and one year to be assessed.

The assessment approach is multi-disciplinary. Assessment team members vary in the different DHAs, but generally they will be made up of a psychologist, a speech-language pathologist, a social worker or community support worker, and an occupational therapist. Families bring the child to an appointment at a designated site and go through the assessment process.

A diagnosis is based on a number of tests that offer a profile of the child's strengths and needs. These tests include standardized assessment procedures, observation, and parental report. In Nova Scotia, two particular standardized tests (Autism Diagnostic Observation Schedule, or ADOS, and the Autism Diagnostic Interview—Revised or ADI-R) are needed to determine a diagnosis of autism. If the child receives a diagnosis of autism, the family should be given information about the next steps.

Although many children with autism come to school with a diagnosis of autism spectrum disorder, there are children who enter school undiagnosed. These are typically the higher functioning children with autism or Asperger syndrome.

For school-aged children, the identification and assessment process is different.

Schools in Nova Scotia have scheduled primary registrations throughout the winter and spring, at which time parents enrol their child for the upcoming school year. At most of these registrations, parents bring their children to

the school where the child engages in a number of activities while being observed by the primary teachers. In some school boards, the new primaries are screened for hearing by speech-language pathologists who frequently are the first people to suspect a diagnosis of autism. When a child enters school, careful observations are made by the classroom teacher, the speech-language pathologist, and the resource/learning centre teacher. If there is a concern, the teacher should discuss this with the parents. It may then be brought to the administration of the school and the school program planning team. The team should meet to discuss the behaviours of concern and decide on a plan of action. The program planning team may decide to ask board-level student services staff to consult for further observation and to recommend strategies to support the student. 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.

> *"A one-year wait for diagnosis of ASD is absurd and torture to a family trying to help their child ..."*
> —Parent comment from survey

After further observation, if there is evidence that the child may be demonstrating characteristics of an autism spectrum disorder, the child will be referred on to the area DHA autism team or the mental health clinic for further assessment. If the child is subsequently diagnosed with an autism spectrum disorder, the mental health team will meet with the parents to discuss the survey and interview findings of the assessment. 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 the grade levels in public schools. It should be noted that some families make the decision to seek out private diagnostic services for which they must pay personally.

Survey and Interview Findings

- There is a significant lack of understanding of ASD within the medical professions; family doctors, psychologists, psychiatrists, speech-language pathologists, and occupational therapists exhibit a limited knowledge base. As a result, identification and diagnosis are not taking place in a timely fashion.

- Once the referral has been submitted for an assessment, the wait begins. The wait time varies by DHA. During this time the family is on its own, desperately seeking help. In an effort to find help and support/resources, families turn to the Internet, community groups, and libraries—anywhere they can think of to find help. Some families, for many reasons, do not reach out. The DHA autism team has very few resources on hand to offer as support to these parents.
- There are several issues and gaps in identifying and diagnosing children ages 5 to 21. Knowledge and expertise about autism at the school level varies widely within the province. New teachers do not have a knowledge base from which to draw upon, as autism and the implications for education are generally not covered in their preservice education training. Classroom teachers and resource/learning centre teachers may or may not understand autism, and may not be aware of the behaviours that may indicate an autism spectrum disorder. Furthermore, not all school board student services staff have experience with autism. This lack of knowledge leads to children not being properly identified and can often result in an incorrect assumption about behaviours and, subsequently, ineffective program planning. Frequently, children who are on the higher functioning end of the spectrum are thought of as having behavioural disorders and/or attention difficulties, and being willful and non-compliant. (See recommendations in Section 7.)
- Another gap in service is the lack of adequate staff within each DHA who have the knowledge and training to carry out a diagnostic assessment for autism. The wait list is long, and the time it takes for families and schools to find out if a child has an autism spectrum disorder or not is too long.
- Identification and diagnosis of school-aged children is not uniform across the province and needs to be standardized with equitable services for all families. The wait list for a diagnosis is too long, and families and schools need more timely diagnoses.

RECOMMENDATIONS

13. Initial screening of ASD for all infants should take place at the 12-month, 18-month, and 24-month medical examination. Surveillance for ASD characteristics should be ongoing past 24 months.
14. If an ASD is suspected by the health-care provider, the child should be referred immediately for ASD screening and comprehensive medical testing should take place within one month. Diagnostic reports should be shared with the family in a timely manner.

15. Following an ASD diagnosis, treatment/intervention should start within three months.
16. Additional clinical psychologists with the appropriate training should be hired to shorten the diagnostic wait lists for school-aged children.
17. Further investigation should take place on identifying and standardizing a best practice assessment tool to diagnose adults with ASD, as well as training of related professionals to administer it.

Early Intervention

Once a diagnosis is received, the child is referred to other early intervention services. These can include occupational therapy, speech-language pathology, psychology, and early intervention programs. The combination of the parents and the key professionals results in a planning team for the Individualized Family Support Plan (IFSP), the child's individualized program.

Professional services are key components of a child's treatment path. An occupational therapist looks at any fine or gross motor issues (e.g., paper and pencil grip) or suggests supports to help with sensory integration needs (e.g., deep pressure techniques). A speech-language pathologist looks at the communication deficit and designs a treatment plan around improving communication abilities. They focus on both expressive (the way we give information) and receptive (the way we understand information) areas of communication. A psychologist offers assessment and diagnosis, and may help with behavioural issues and social understanding.

> *"As a parent of two children with autism, I would definitely recommend the EIBI (Early Intensive Behavioural Intervention) program as a first step towards continued successes. This program has started my boys in a direction that has shaped the way that they learn in a school setting."*
>
> —Parent comment

Early Intervention programs help families with children from ages zero to six with developmental disabilities. Early interventionists are trained in child development and use a family-centred approach. The interventionist works as a resource/support person for the family to help navigate the system. There are 21 early intervention programs throughout Nova Scotia. A map and full listing of these sites is at www.earlyintervention.net.

Daycare is also a service that families can use and value. Daycares offer a place for the child to work on social and communication skills while in a safe, inclusive setting. Daycares focus on the needs and development of preschoolers and are community based.

The IFSP team establishes goals that reflect the family's needs and objectives for their child. The meetings involve all planning team members, and others identified by the family as involved in the child's intervention. Besides establishing goals, the team also develops responsibilities and specific strategies. This support continues until the child enters school.

The Early Intensive Behaviour Intervention (EIBI) Program

In December 2004, the Nova Scotia Department of Health committed to develop, carry out, and provide funds to DHAs and the IWK Health Centre for a province-wide Early Intensive Behaviour Intervention (EIBI) program for young children with ASD. Pivotal response treatment (Koegel and Koegel 2006) was selected as the model of treatment.

A coordinated, family-centred model was adopted. The treatment team consists of psychologists, occupational therapists, autism support workers, a clinical supervisor, and a speech-language pathologist from Nova Scotia hearing and speech clinics.

> *"... and then the EIBI lottery to boot makes life dealing with the uncertainties of the spectrum cruel."*
> —Parent comment from survey

The EIBI program has a graduated team service delivery model, in which a one-year period of direct service is followed by consultation and support. Direct EIBI is offered over the first six months for up to 15 hours per week, and is gradually reduced over the following six months (10 hours per week for the first three months and then 5–6 hours per week for the remaining three months). Training in pivotal response treatment (PRT) is offered to parents during the year, and parents are expected to practise PRT techniques with the child every chance they get. This allows the child to continue to benefit from PRT techniques beyond the limited service delivery. Following the one-year period of direct service, families have access to EIBI consultation services in which problem solving, support, and booster sessions are available to parents and others working with the children.

EIBI Eligibility Criteria and Selection Process

While it is recognized that early intensive intervention is a best practice in autism therapy, not all children diagnosed with ASD will take part in the EIBI program. The volume of preschoolers diagnosed, combined with the limited numbers of service providers, results in some children aging out of the program before they are selected. The selection process involves three stages. A child must have a confirmed or reserved (provisional) diagnosis of ASD (autism/autistic disorder, Asperger syndrome, or atypical autism/PDD-NOS). The diagnosis must have been made in accordance with the provincial established criteria used by the relevant district health authority for access to their ASD services, and must have been made by a

predetermined selection date (usually four to six months before enrolling in the program). The child must also be able to take part in the program for at least six months before entering school.

Next, from the pool of eligible children within each DHA, selection is made from two age groups: age five and above, and age four and below (at the time intervention is to begin). Equal numbers of children from each group will be randomly selected. The total number of children selected to enrol at a given time depends on the resources of individual DHAs.

Finally, parents of children who have been randomly selected will be approached to review what the EIBI program involves. Discussion with parents also focuses on the intensity and potential intrusiveness of EIBI (up to 15 hours per week in the family home), to allow parents to make an informed choice about taking part. Parents need to make a commitment to take part in the parent-training component of the program. The need for the family to forego concurrent forms of treatment (e.g., discrete trial-based intensive behavioural intervention) is discussed to better assess the effectiveness of the program.

> "The issue of limited access to EIBI has raised the question of how we can most fairly allocate existing treatment services. The common approach is to use a waiting list. However, in an attempt to be as fair as possible, and after consulting with a bioethicist, we have chosen to select children randomly for treatment. The advantage of random selection is that every child has an equal chance or opportunity to be selected. In contrast, waiting lists have been shown consistently to be biased against particular groups, particularly those who are disadvantaged from the outset (e.g., by limited access to diagnostic services). An additional advantage of random selection is that the problem of limited access to treatment is transparent. In contrast, waiting lists can mask the real problem, that is, they can give the impression that treatment will be available, when this is not necessarily the case (i.e., the child may reach school age before treatment is available)."[6]
>
> —*Excerpt from Nova Scotia's* Provincial Autism Centre Newsletter, *October 2009*
> *For the complete article, please see Appendix IV.*

Survey and Interview Findings

Chart 1
Numbers of Children Receiving EIBI Services and Number Waiting for Service as of October 2009

District Health Authority	EIBI	Waiting List
South Shore	4	9
South West	3	5
Annapolis Valley	11	3
Colchester	4	8
Cumberland	4	2
Pictou	6	7
Guysborough	4	6
Cape Breton	8	17
IWK	23	44
Totals	**67**	**101**

- The EIBI program started service to families in July 2005. The $4 million yearly allocation has not been increased since the program's inception. The current service is unable to guarantee EIBI programming to every preschool child in Nova Scotia due to lack of capacity and funding. A random selection process has been adopted to be as fair as possible to the children waiting for service; however, some children enter school without ever receiving EIBI programming.
- There are many daycares established in the province of Nova Scotia, in both rural and urban locations. Although daycares are encouraged to offer programming to all children, regardless of abilities, many daycares are unable to accept children with special needs because they do not have trained staff to effectively program for the child. This results in an uneven ability to support children with special needs in the community.

- Families in rural settings who do not get selected for the EIBI program may not have the option of a daycare placement or early intervention services. As a result, the child and family are limited in the treatment options they can access, leading to increased isolation and a lack of crucial early intervention opportunities for the child.
- Not all daycare staff and early intervention staff have a comprehensive knowledge of autism and best practices for support.

RECOMMENDATIONS

18. Funding to the EIBI program should be increased so it can be made available to all families with a preschool-aged child diagnosed with ASD in the province of Nova Scotia.
19. Increased appropriate training opportunities should be made available to staff at daycares and early interventionists throughout the province.
20. A treatment plan should be created by the IFSP planning team and should include appropriate intensive intervention at the rate of 25 hours per week by ASD professionals.[7] Services in French should be made available if needed.

Education

Many children are now entering the public school system with a diagnosis of autism spectrum disorder that they have generally obtained through their local Department of Health autism team or mental health clinic.

> *"... I am concerned by the lack of support, treatment, and assistance available to educators who want to effectively, efficiently, and competently provide a viable education for children on all levels of the spectrum."*
>
> —Comment from survey

School-aged children typically are enrolled in public school and can enter primary if they are five years old by December 31. With a public school population of 131,000 in the winter of 2010 (Department of Education statistics) and including a modest estimate of 500 students in private or home schools, the number of school-aged children in Nova Scotia is approximately 131,500. Statistics from Nova Scotia school boards in January 2009 indicated that there were approximately 1,106 children between the ages of 4 to 21 and in public schools who have a formal diagnosis of an autism spectrum disorder. Statistics from November 2009 show an increase of approximately 244 students with the diagnosis, bringing the total number of students to approximately 1,350. This number represents only those students who are officially diagnosed and does not capture the number of students on wait lists for an autism screening, or those who are suspected as having an autism spectrum disorder in public schools who are not diagnosed for any number of reasons. The actual number of children in public schools with autism across the province is believed to be higher than the number reported by school boards. If the increase in the fall of 2009 is 244 new students with the diagnosis, we can reasonably expect that our public school population of students on the spectrum will continue to grow at an alarming rate each year, placing an increased burden on an already overstretched educational system.

At the time of this report, it was not possible to get the numbers of students in the three Designated Special Education Private Schools (DSEPS) or in any of the other private schools in Nova Scotia. It is known, however, that children with autism are enrolled in these schools.

While it isn't possible to get the precise number of children who are school-aged and are home-schooled, the authors of this report have anecdotal reports that indicate there are children with ASD who are being home-schooled.

What is known is that the number of children diagnosed with autism spectrum disorder is growing every year. With the number of students in the Nova Scotia public school system approaching 1,350 and the knowledge that there are students who are home-schooled and in private schools with autism, we can reasonably estimate that the number of students with autism in Nova Scotia today is over 1,400.

The Center for Disease Control in Atlanta, Georgia, recently (December 2009) released their newest prevalence figures obtained through extensive survey methodology. The generally accepted prevalence rate is stated to now be 1 in 110 (or 1 percent of the population) with boys being four to five times more likely to be given the diagnosis. As well, a new study published October 5, 2009, in the *American Academy of Pediatrics' Journal* (Kogan, Michael D., et al 2009) states that autism spectrum disorder has a prevalence rate of 1 in every 91 American children, including 1 in 58 boys. The study used data gathered as part of the 2007 National Survey of Children's Health, which was directed and funded by the Health Resources and Services Administration and Centers for Disease Control and Prevention. This makes autism spectrum disorder the number one neurological disorder diagnosed in North American children today, more than Down syndrome, muscular dystrophy, cystic fibrosis, cerebral palsy, and diabetes combined. (See Chart 2 below.) It is also now accepted that autism spectrum disorder is the most inheritable disorder. (Reported by Dr. Peter Gerhardt, Advances in the Science and Treatment of Autism, Dalhousie University conference, November 6-7, 2009.)

Chart 2

Name of Disorder	Prevalence rate according to CDC
Down syndrome	1 in 800
Muscular dystrophy	1 in 769
Cystic fibrosis	1 in 2500
Cerebral palsy	1 in 278
Diabetes	1 in 400
Autism spectrum disorder	1 in 110

Transition to school is a critical element of the program planning process and has four essential components: policy and guiding principles, collaborative consultation, the individual transition planning process, and the

development and implementation of an individualized transition plan. It is based on policy and guiding principles embedded in the *Special Education Policy* (Nova Scotia Department of Education 2008). Transition is a required component of the individualized program planning (see *Special Education Policy*, Policy 2.7). The transition to school process varies from school board to school board but most boards begin the transition process in the winter and throughout the spring. In most school districts, the early interventionists, EIBI team, or child developmental organization will (with parent permission) inform the school system of students with exceptional needs who will be transitioning into school for the fall term. Parents also contact the school and inform the principal that their child with ASD will be enrolling in the fall. The school program planning team (autism consultant/specialist, classroom teacher, administrator, resource teacher, and school-based SLP), the parents, early interventionists, community services, and health staff (psychologists, SLP, OT) who have been working with the family should meet to plan the transition into school. The strengths and challenges that the child has demonstrated are discussed. Supports and effective strategies that the child will need to be successful are identified and an individual transition plan is developed.

Transition to school can include any or all of the following actions:

- A member of the program planning team may visit the daycare or early intervention program and observe the child in that environment.
- Visits to the school by the child and the parent or support worker are recommended to help the child get used to the new environment.
- Visits to the classroom and playground can take place throughout the winter and spring.
- The school team can create a booklet with visual images of the school and the adults they will encounter for the child to look at over the summer with their family members.
- If the child has been involved with the EIBI program, members of the team who have delivered this program will also support the child as they enter the school in the fall by coming to the school and offering suggestions for programming.

A program planning team meeting is held in the fall (as per special education policy) with the school, the parents, and outside agency staff taking part. The outcomes for the year are identified and the school team

will develop an individual program plan (IPP) to guide the school team. Additional program planning team meetings are held throughout the year to discuss the student's progress.

In each school district, there is an autism consultant or specialist trained in autism that collaborates and supports the school team to plan and carry out best practices for programming and behavioural support. In the event that a school has been informed of a child entering school with a diagnosis of ASD and the transition process outlined above has not taken place, the parent can request a program planning meeting early in the fall. The principal will invite members of the school team to meet with the parent and develop a program plan to support the student at that time.

When the transition process outlined in the *Special Education Policy* is followed, transition into the public school system becomes an example of a positive and collaborative team process involving all members of the team surrounding a child with ASD. Representatives from the departments of Education, Health, and Community Services, along with the child's parents, all contribute to developing a successful transition into the public school system.

Public schools in Nova Scotia are guided by the *Education Act* and Regulations, public school program, and various policies and guidelines designed to support and delineate specific programs for students in classrooms across this province. The *Special Education Policy* (Nova Scotia Department of Education 2008) states that all school boards within Nova Scotia are "responsible for establishing a process of identification, assessment, program planning, and evaluation for students with special needs" (Policy 2.2). Program planning teams at the school level are to meet regularly to discuss appropriate strategies and methodologies that best support students with autism. Most students with autism have an individual program plan that outlines the annual outcomes and specific strategies to attain those outcomes.

An identified gap in service within the school system is a greater need for knowledge about what are best practices and evidence-based strategies for students with autism. Where the knowledge level is high, the programming for these students is effective and program planning teams report increased learning for the student. All members of the program

planning team must understand autism to strategize for possible solutions to learning challenges that the child might display.

Each school board employs a number of student services staff such as autism consultants or specialists, school psychologists, speech-language pathologists, and special education consultants who can support school program planning teams with recommendations for best practices for students with autism.

Across the province, teacher assistants (TAs) offer support to students who are identified through the program planning process as needing support with medical and personal care and/or safety behaviour management. Each board assigns TAs to schools in a variety of ways and the newly revised Department of Education *Teacher Assistant Guidelines* (2009) describe the role and responsibilities of these personnel. Students with autism benefit from effective TA support. Under the guidance of the classroom teacher and/or the resource/learning centre teacher, the TA gives the student the support they need. With the increase in students with disabilities in the schools of Nova Scotia and tight financial times, it has become more and more challenging to offer adequate support in this area.

From 2003 to 2010, the Department of Education has dedicated funds to support students with autism in the public school system as detailed in the following chart.

Targeted Autism Funding
2003–04 to 2009–10

Year	STAR Demonstration Sites	Department of Education Professional Development	(EIIS) Transition to School	SEIR/Autism Targeted Funding to Boards for PD, Training, Resources
2003–04			$213,000	
2004–05			$213,000	
2005–06		Summer Institute (Joann Seip) $55,000	$213,000	$200,000
2006–07	$160,000	$144,900	$213,000	$200,000
2007–08	(55K + 55K) $110,000		$213,000	$200,000
2008–09		$250,000	$213,000	$200,000
2009–10			$213,000	$200,000
TOTALS	**$270,000**	**$449,000**	**$1,491,000**	**$1,000,000**

The Department of Education, in consultation with school board autism consultants/specialists who compose the Provincial Educational Autism Advisory Team, planned and delivered numerous training opportunities for autism consultants/specialists, classroom teachers, speech-language pathologists, school psychologists, and resource/learning centre teachers. Care was taken to make sure that only evidence-based approaches were the focus of the professional development. Nova Scotia schools have embraced the Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) philosophy for a number of years and have followed the practice of structured teaching while identifying the characteristics of autism. Training opportunities were

- Division TEACCH—TEACCH Transition Assessment Profile (TTAP)
- Strategies for Teaching Children with Autism based on Research (STAR program)

- Pivotal Response Training (PRT)
- Assessment of Basic Language and Learning Skills—Revised (ABLLS-R)
- Ziggurat
- Comprehensive Autism Planning System (CAPS)
- Functional Assessment Teaching Everyday Routines (FACTER)
- Sensory Integration (SI)

Outcomes of this training included

- enhanced knowledge and skills in each school board
- improved program planning processes and increased learning for students with autism, as reported by teachers and parents

The training initiative by the Department of Education was successful and should be continued to increase capacity. Although many teachers who received training have a better understanding of autism, there are still many staff in education who have not had chances for training. They are struggling with effective programming and behavioural strategies to support students with autism in their classrooms.

> *"After the disaster of high school, college and university were my salvation; people I learned were weird all over."*
> —From Susan's story, pg. 16

The transition process from school to community should start when a student with ASD enters middle level/junior high. The program planning team, which includes the parents, meets to discuss long-term outcomes for the student. When appropriate, the student also attends these meetings giving his or her input and ideas about future hopes and aspirations. The program planning team designs a transition plan that outlines the challenges and intended outcomes for each grade level up to graduation. Of critical importance is a careful plan to teach the student life, work, and community skills to allow him or her to navigate life after graduation from public/private school. Although the age of graduation is typically 18, many students and their families choose to stay in school until the student reaches the age of 21. Transition from public school has been problematic for many students and their families, who have found few or no options for employment, social, and recreational choices in their community. Opportunities within the community for students with ASD for transition upon graduation are limited across the province, which often leaves the young adult at home with nothing to do and nowhere to go.

> *"As an educator, I find the greatest challenge is to respond appropriately to the complicated academic, social, emotional, behavioural, and sensory needs of some of my students ..."*
>
> —Comment from survey

Post-secondary options are also limited for students leaving school. The Nova Scotia Community College, through Special Admissions, offers one seat per program per campus for students who have been on an individual program plan in public school. This significantly limits the number of students with ASD who qualify for a seat in a program of their choice, restricting their education and career options. There are many courses at NSCC that are well suited to the learning style of a student with ASD and that would enhance the possibilities of these individuals living a productive and rewarding life.

Some students with ASD enrol in university and are pleased to find others who share their interests and unique behavioural style. They still, generally, encounter difficulties with learning and organization, and social interactions remain problematic.

Survey and Interview Findings

- The Program Planning Process described in the *Special Education Policy* is not followed consistently across the province.
- Even with the level of professional development offered by the Department of Education and individual school boards, schools and parents report that there are still many school administrators, teachers, TAs, SLPs, school psychologists, and other board staff who lack an adequate understanding of ASD.
- One of the greatest gaps in service as identified by schools is lack of occupational therapy services for students with autism. It is well researched that people with autism have sensory integration difficulties and can find their environment overwhelming. Many behaviours associated with autism are a result of students not being able to manage the sounds, lights, noise, smells, and touches/textures in a school environment that assault them daily. They become confused, anxious, upset, fearful, and agitated. Some of the interventions that work effectively to support these students in this area are those that an occupational therapist would suggest. School boards do not employ occupational therapists and must try to research this area on their own or try to collaborate with local occupational therapists who are employed by the Department of Health.

- Among the 34 recommendations made by the Special Education Review Implementation Committee (June 2001) was a recommendation to increase staffing for school psychology and speech-language across the province. Action was taken on this recommendation and additional staff were hired using targeted funding from the Department of Education. In 2001, however, the incidence of autism in Nova Scotia was approximately 1 in 250. Today, as stated previously, the prevalence rate is accepted as 1 in 110 (CDC). The level of specialist staffing today is not adequate to serve the needs of the burgeoning population of students with ASD in our school system.
- School boards across the province have indicated an increasing need for both additional school-based staff and increased knowledge of autism spectrum disorder. Speech-language pathologists, in particular, are stretched beyond capacity as they attempt to service students with communication difficulties in public school. Because students with autism generally have significant communication needs, speech-language pathologists' services are thinly stretched in an attempt to give adequate service to these students. This causes children with autism to sometimes be placed on "hold" while other children without the diagnosis are placed in therapy sessions or vice versa.

> *"My son receives a three-month block of speech therapy, then is placed on a break for the remainder of the school year. He has only just started to talk at age 9. The benefit of a speech therapist is crucial at this point. How is it right to remove this from his programming?"*
>
> —Parent comment

- As well, resource and learning centre teachers are struggling to give adequate service and appropriate programming to students on their caseloads. With the escalating numbers of students with different exceptionalities, and especially students with autism, these teachers are not able to develop and carry out the programming that students with autism need. Although they are given best practices professional development, through the Department of Education and their own regional school board, teachers do not have time within their schedules to actually carry out the autism curriculum and its many faceted approaches.
- It has been reported that new teachers entering the education system have little or no knowledge of ASD and how to teach these children. Education programs in Nova Scotia rarely offer courses on ASD. Teachers should have comprehensive knowledge of ASD before entering their first classroom to teach or to substitute. Many provinces

in Canada already have universities and/or colleges that specialize in autism and offer diplomas, degrees, or certificates focusing on autism. With the growing number of children with ASD in Nova Scotia, this lack of available educational opportunities to specialize in ASD has been identified as a gap that needs to be addressed.

- Transition to the community or post-secondary opportunities has been identified as a problematic and difficult process. Schools report that with increasing caseloads to manage, they do not have enough time to adequately develop and carry out successful transition plans.
- The numbers of students with ASD who will be transitioning out of public school in the near future is significant. There is a high degree of concern from families and schools that there are very few supports and opportunities available around the province for these individuals. Without a clear transition plan that includes appropriate placements in the community, further strain will be placed on the limited services and programs within the Department of Community Services.
- The Department of Education and the regional school boards have invested millions of dollars in educating and preparing students with ASD for transition to the community. There appears to be a lack of coordination of agencies and opportunities to support these students once they leave public school.
- Parents frequently have reported that the reason they want their child to stay in school until they reach the age of 21 is due to lack of services, including housing, employment, and support services available.

RECOMMENDATIONS

21. The Department of Education should give all school boards targeted grants to support professional development and board-based initiatives in the area of autism. Grants should be increased and reviewed annually. Furthermore these grants should be increased to reflect the increased numbers of children in the public school system diagnosed with ASD.
22. The Department of Education should continue to fund the position of Autism Consultant for the province of Nova Scotia. This position would manage the autism strategy and provide the leadership in coordinating the professional development needs identified by school boards across the province.

23. All school boards in Nova Scotia should make sure that an autism specialist or consultant is a part of the staffing allocation to support the training needs and program planning teams in schools.
24. The staffing ratio for speech-language pathologists should be improved to offer additional staffing to all school boards. Occupational therapy should be available within regional school boards to help schools with the sensory needs of students with ASD.
25. The Department of Education should give targeted funding to each regional school board to support the position of Transition Facilitator. This position would work collaboratively with high schools, government departments, and community organizations to support successful transition out of public school.
26. An ongoing professional development focus on best practices in the area of autism education should be provided for all staff (including administrators, public school teachers and TAs, bus drivers, and staff at private schools) involved in the education of children with autism spectrum disorder.
27. School boards should be allotted targeted funding to be used for purchasing materials to support the programming needs of the children with autism spectrum disorder.
28. Nova Scotia's colleges and universities should commit to offer post-secondary programming for students graduating from public schools with credits designated as IPP. Creation of additional seats in programs for students with IPPs is also recommended.
29. The Department of Education should make sure that each university in Nova Scotia offering an education degree offers a mandatory course in autism spectrum disorders to all students enrolled in education.
30. One university in Nova Scotia should become a leader in autism education. It should offer diplomas or degrees with specialization in autism similar to those offered in other provinces across Canada.
31. Staff at universities and community colleges should have opportunities for training in the area of ASD.

Respite, Housing, Social, and Recreational Programming

Many families caring for individuals with autism experience significant stress while assuming the numerous extra responsibilities associated with caring for their family member. Most families experience heavy caregiving responsibilities and tend to burn out from working intensively on behalf of their children. Autism spectrum disorders bring a significant amount of stress to any family dealing with its complexities. ASD affects the ability to function in home, school, and community settings. A person's ability to communicate effectively, learn self-help daily skills, and form meaningful work/personal relationships are greatly compromised by the disorder.

Families have shared their difficulties/challenges in managing such demands, which include, but are not limited to, such things as

- frequent medical appointments for various professional help
- meetings and training/teaching sessions involving school staff, specialists, and care providers
- coordination of service care
- research
- applying for support services
- advocacy
- over and above caregiving, including personal care, constant supervision, and safety provision

Services that recognize and offer support and financial assistance are critical to families' ability to function.

> *"The parents of people with ASD have long borne the brunt of the difficulties associated with raising and caring for a family member with ASD. The immense strains on individuals, families, extended families, personal relationships and health have been recognized by many professionals and caregivers. But it has been predominantly the parents of children with ASD who have carried the heaviest loads and the weariness of the impacts on their own health, their families and the societies in which they live."*
>
> —From *New Zealand Autism Spectrum Disorder Guideline*, New Zealand

> *"Both my husband and I had to get personal and marriage counselling to get thru the reality and grief associated with having children with autism."*
>
> —Parent comment from survey

Direct Family Support Program (DFS)

The Department of Community Services' Services for Persons with Disabilities (SPD) program offers a variety of programs and funding to support families caring for a family member with a disability living at home.

The purpose of the DFS program is

- to help individuals with disabilities to live at home
- to maximize family supports and community participation
- to prevent and/or delay the need for an out-of-home placement
- to establish a smooth and seamless transition between children's and adults' supports and services

Eligibility for DFS for Children (DFSC)

To be eligible for the DFSC program, the application and/or assessment process must identify and determine that the child and/or their family meet the following criteria:

- The family and child are permanent residents of Nova Scotia.
- The child is under 19 years old.
- The child is living in the home of a family member or guardian.
- The child has been diagnosed by an approved clinician as having a mild or moderate intellectual disability with a significant behavioural challenge that has been documented within the last two years.
- The child has been diagnosed by an approved clinician as having a severe intellectual disability that has been documented within the last two years.
- The child has a significant physical disability with ongoing functional limitations that are a result of the disability and that seriously limits their capacity to perform age-appropriate activities of daily living as determined by an approved clinician.
- The family meets the DFSC program income guidelines.
- The family agrees to take part in the assessment process.

Eligibility for DFS Adults (DFSA)

To be eligible for the DFSA program, the application and/or assessment process must identify and determine that the applicant/individual and their family meet the following criteria:

- The applicant and their family are permanent residents of Nova Scotia.
- The applicant is 19 years old or over.
- The applicant is living in the home of a family member or guardian.
- The applicant has a medical diagnosis of one or more of the following: intellectual disability, long-term mental illness, or physical disability.
- The applicant and family have unmet needs as identified through the assessment process.
- The applicant meets the financial eligibility criteria as outlined in SPD policy and procedures.
- The applicant and their family agree to participate in the assessment process as outlined in SPD policy and procedures.

The care coordinator of the SPD program meets with families to assess the family situation and identify the support needs of the individual. This is a very individualized process. Approval for this program means that funding is given to families supporting a family member with a disability to help with extraordinary costs associated with the support needs. This includes such items as respite, transportation to medical-related appointments, and medical and/or personal care supplies and equipment. Families generally express that their greatest need is for planned and emergency respite services. Families have a choice to either secure their own respite workers or access a formal respite program.

> *"'Taking care of yourself' was the most difficult to do but considered the most critical for parents to continue to care."*
>
> —Hutchinson et al., *Creating Respite Solutions for Nova Scotia Families with Chronically High Needs Children and Adult Children*

Respite Services

Timely and easy access to respite services and supports are crucial for families to be able to function and enjoy a quality of life that all families should enjoy. Community-based respite support is the general care and supervision of an individual with special needs. This respite focuses on relationship development and self-help skills through leisure and recreational activities. These can take place in the family home or in various community settings. Respite offers a break for caregivers while offering a fun and positive experience for the individual.

The Regional Respite Program is funded through the Department of Community Services. There are four programs across the province that offer respite services for children with disabilities to give relief to the parents/families or primary caregivers, while facilitating a positive and rewarding experience for the individuals receiving respite care. Typically, care is provided on a one-to-one basis.

The Regional Respite Program has two main components. The first is to offer support to the families who are unable to find suitable respite providers. Through the program, potential respite providers are recruited, screened, and trained. Suitable candidates are then referred to families, who interview and select the best match for their family. The second component offers out-of-home respite to families. Families can access a respite apartment for their child, and a respite worker for a scheduled period of time.

The qualifications of the respite worker can vary greatly depending on the needs of the individual family and the availability of qualified/trained workers. The respite workers are often students involved in related fields of study, TAs/teachers, small option and group home staff, childcare providers, or recreation and camp counsellors. It can often be difficult for a family to access qualified workers. Some families are simply overwhelmed and for various reasons may struggle with managing the planning involved in hiring and training respite care workers. As a result, these families may receive funding for respite but may not have the chance to use the funding and, therefore, not have the much-needed breaks from caregiving.

Residential/Housing Services

The SPD program offers a continuum of residential services. In addition to the DFS program, there is the Alternative Family Support program (families who have been approved and trained to offer support in their home), the Independent Living Support program, a supported apartment program for individuals who need minimum support (less than 21 hours per week), community-based settings, and a range of licensed residential services. Placement services are offered depending on the assessed level of support. The SPD program is a voluntary program, with a mandate to offer timely and appropriate services and a program vision that allow individuals with disabilities to live to their fullest potential within their community.

The SPD program does not have statistical information that would identify the number of individuals with a diagnosis of ASD. The program has a waitlist, and placement options are offered based on the priority of need and the urgency of the situation. The SPD program has been undergoing a redesign of services with a plan to expand residential capacity and offer appropriate services in the right place at the right time.

Social and Recreational Programming

Social isolation has a profound effect on people with autism. It can often result in a lack of peer relationships outside of the school and family environment. The AMAT survey results indicated that social programming was one of the highest rated needs by families and individuals with ASD.

Some individuals with autism may never develop meaningful peer relationships. Some individuals actively try to interact, but because of the degree of their impairment, they become socially isolated. Often, social isolation begins in the pre-teen years. This behaviour is dependent on the degree of social and communication challenges of the individual.

With appropriate best practice interventions, individuals with autism can have greater success. These strategies tend to be offered intensively in the early years in well-established programs. However, as individuals mature, there is little or no coordinated programming to address the lack of ability in the social realm.

Currently in Nova Scotia there are few social and recreational programs designed to support individuals with autism. Some programs do operate in the province, but they are only available in certain communities. Programs such as these should be available everywhere. The current programs that have developed are through private and grassroots organizations. Sustaining programming can be challenging without targeted funding.

The unique needs of persons with autism require specialized social and recreation programming. Our survey results indicated that although there are some opportunities for social and recreational activities, the needs of individuals with autism are not met through current programming.

By incorporating more social and recreational programming that is inclusive to persons with autism, the possibilities of successful inclusion can be endless.

Survey and Interview Findings

- Children who have severe autism often have extreme behaviours that can be destructive and violent. Occasionally, families are unable to continue to care for their child and are also unable to get a respite worker to support them in the home. In some cases, parents have had to give their children up as a result of the level of care and supervision needed for their child. There are few appropriate options available for these children in the province. Often, families must drive hours to visit their child once they are in the care of Community Services.
- The Direct Family Support program gives much needed support and financial help to families; however, the eligibility criteria is limiting those who very much need the program. A definition of "intellectual abilities" is needed to access the Direct Family Support program. A significant number of professionals and parents feel that children and young people with Asperger syndrome or high-functioning autism and challenging behaviour are disadvantaged because they do not meet the intellectual criteria for support. It is generally agreed that this group of young people are vulnerable and that they and their families should be seen as needing direct family support. As a result, individuals with higher functioning autism or Asperger syndrome may not be eligible for the DFS program. The financial eligibility guidelines also limit families in need of respite services. These income guidelines can leave families with little option for much needed respite and can alter career decisions.
- Families receiving respite funds have a choice to either recruit, train and hire their own respite worker, or access one of the four regional respite programs. Families have reported that it is often difficult or impossible to find someone to offer respite in their homes. Some family members have also reported that they are not able to train a respite worker. For families with children with severe behaviours, parents are often unable to find and keep a respite worker. Families who have been successful at finding, training, and hiring a respite worker live in fear that they will lose this person to other employment and have to begin all over again.

- Families have reported that there are very few supported housing and employment options for their children after transition from school. As a result, many young adults live at home and do not have the chance to develop an independent life outside their family structure. Many report having limited chances to engage in social or leisure activities and, as a result, have few if any social friendships.
- Because of the lack of supported housing or residential options across the province for individuals with autism, parents and family members have reported that they are worried about what will happen to their children who live at home once they are gone. They often remain the only caretakers of individuals with autism because there are no supported housing options available in or near their communities.

> *"Camps, and more camps for every break in their academic year. Christmas, March, summer, etc.*
> *Day, week, month, etc.*
> *Depending on need of child.*
> *FUNDED."*
>
> —Parent

- Caregivers are a vital part of our society. By supporting them, we can all contribute to stronger and healthier communities. Families and caregivers are key people in the lives of the person with ASD, and they have additional needs for support that must be considered to make sure that they, too, enjoy social inclusion to the degree that other community members take for granted. Often they experience frustration, extreme fatigue, and burnout because of the level of care needed for their family member with autism.
- Families caring for an adult or a child or children with autism experience considerable stress. The behaviour of the person with ASD will affect the other members of the family. Balancing the needs of other family members requires extra consideration. Chances for families and children to take part in recreational programs are limited. So are chances for the individual with autism to have fun and join in physical activity with peers.
- Social and recreational programming is unavailable to most Nova Scotians with autism.
- No support funding is available for autism-specific social and recreational programming.
- Social and recreational programming for people with autism requires a best practice approach run by staff who have training in autism.

RECOMMENDATIONS

32. Criteria for the Department of Community Services' Direct Family Support program should be reconsidered. Specifically, the definition of "intellectual" disability and income testing as a basis for eligibility should be reviewed. Eligibility for this program should be based on the needs of the family and individual circumstances, making sure that families who could benefit the most from respite services are receiving funding.
33. A training toolkit for recruiting and retaining respite care workers in working with people with ASD should be developed. A list of required core competencies and experience for respite care workers to offer quality services to persons with ASD across the lifespan should be defined as part of the toolkit. Where regional respite programs exist, training should be given to respite workers specific to ASD.

34. Appropriate, community-based housing options should be available to all adults with ASD based on the needs and ability of the individual seeking support.
35. Appropriate, inclusive leisure/recreation programming specific to after-school and school breaks (Christmas break, March break, and summer vacation) for all age groups across the province should be developed and carried out.
36. Opportunities should be created for recreational/leisure programming for individuals with ASD 21 years and older.
37. A granting system should be created to meet the social and leisure programming needs of various autism organizations.
38. Targeted funding should be offered for recreation departments throughout the province to support recreation/leisure programs specifically designed for individuals with autism.

Families

The Dark Side of Autism

My head pounds, heart races, stomach churns. My body is shaking, skin sweating. I breathe deeply, exhale slowly, willing it to stop. Flu? I wish. I am merely living in the darkness of autism.

Life with autism is the most incredible roller coaster ride imaginable: the highest highs, the lowest lows, with loops and turns leaving you breathless. Today we are in the lows.

In our house, autism almost equals prison, our son the warden. He sets the rules, exacts the punishments. Rigid rituals in place, every day is the same. The radio plays 24 hours a day, as does the TV; the computer set to his favourite website. Heaven help us if anything is altered.

We are directed in the car: where to turn, stop, what songs to play.

The countless rules are reverently followed. Punishment? Meltdowns and tantrums beyond the imagination of any sane person. Screeching to burst eardrums. Thrashing like a rodeo cowboy on an enraged bull. Crying to break the hardest of hearts. We've been left, literally, bloody, bruised, bawling.

Nothing has worked. No form of discipline, therapy, medication. We simply remind ourselves to breathe and somehow, miraculously, survive. However, as the tantrums increase, worsen; as our precious boy grows bigger, stronger, we are sobered by the realization that if things don't improve dramatically, quickly, we may no longer be able to keep him. We'll be forced to give his day-to-day care over to strangers. How will we find the strength to do that? What kind of parent does that?

Tonight, crying ourselves to sleep, we hope and pray to find answers. Find a cure. Find the key to the cell we are living in … the hell our child lives in.

> *"My son is 14 and having a hard time in school. I hate to think of what will come as he gets older. I constantly wonder what will become of him."*
> —Parent

The realities for Canadian families raising a child with autism are harsh. Research suggests that families with autistic children are at a higher risk of experiencing marital breakdowns, social isolation, and underemployment, leading many families to live at poverty levels while attempting to support the unique needs of their child's disability. With prevalence statistics on the rise, government systems and community-based organizations need to adapt quickly to support the needs of this growing global health crisis.

Compounding the stress on families is the limited resources within the autism community in Nova Scotia. There are currently eight

community-based autism organizations/groups throughout Nova Scotia. Except for the Provincial Autism Centre (PAC), these groups are volunteer-driven by parents with children on the autism spectrum. A system such as this lacks collaboration and access to consistent, accurate autism information. The challenge of navigating it can leave families without the support they need, leaving them feeling adrift and hopeless, and further taxing social systems that the non-profit sector was designed to reach.

In addition, Nova Scotia families affected by autism face the following reality:

- Up to 80 percent of marriages where parents have a child with autism end in divorce (Bromley et al, 2004).
- Many families living with autism live in poverty as it costs on average three times more to raise a child with a severe impairment than it does to raise a non-disabled child (Sharma 2003).
- Only 11 percent of caregivers who have autistic children work full time, and 70 percent say that the lack of appropriate care facilities and support prevents them from working (Broach et al, 2003).
- Only 18 percent of individuals with autism become independent as adults.
- Over 40 percent of autistic adults continue to live with their parents.

Parents reported in the *AMAT Survey on Lifespan Services for Children/Adults with Autism* that they lack knowledge of the disorder. They acknowledge that they know their own child and their specific behaviours but they do not understand autism and therefore have difficulty carrying out effective strategies at home. This can create situations where parents are dealing with severe, aggressive, and violent behaviours. These families need the support of behaviour interventionists at home.

For many families supporting a family member living with autism, the stress associated with the disorder alone is more than enough. Compound this stress with additional burdens, and the family unit can be at serious risk to disintegrate. Families need access to counselling services to help cope with the impact of a diagnosis of ASD on them. Counselling services such as marital, financial, and grief counselling can help families to start to support themselves and each other, building a stronger family unit rather than dismantling a weak one.

After diagnosis, finding access to accurate, evidence-based autism information and support for families/caregivers is challenging and overwhelming. It is particularly difficult for families living in rural Nova Scotia who are further burdened with resource, geographical, financial, and accessibility barriers. With a system in place to navigate and create services, Nova Scotia could become a leader in the autism field.

I sit and watch my boys sleeping. They are almost 10 now. Where does the time go? For most parents, it is a whirlwind of activity including sports, children's groups, and play dates. For us, it has been psychologists, various therapy sessions (speech, behavioural), specialist appointments, school meetings, and government advocacy.

I have watched my boys grow in ways that would amaze most people. Each day brings new challenges for our boys, us as parents, and the community in which they strive to be a part of. Everything is a struggle from getting dressed in the morning, to attaining the services that they so desperately need and deserve.

I sometimes feel like a terrible parent and struggle with the choices that we make to keep our children safe. We lock them in their room at night. There are locks on every door and closet with keys hidden or hung at the top of the doors with Velcro. (God help us if there is ever a fire). One of the boys has started to undo the dead bolts and goes outside with no shoes and stands in the snow. We have incorporated a whole new meaning to 'babyproofing' for nine-year-old bodies with interests of two-to-four-year-olds. I never go anywhere without someone to help me since neither understands that running into traffic is dangerous. We cannot leave them unattended (even for short trips to the washroom) without something going wrong.

In our house, things are destroyed daily and no day is without incident. Family members and friends get pinched, kicked, and bitten. Non-food items get ingested (such as glue sticks, crayons, and plastic). Raw hamburger was discovered and eaten when our son was seven years old. Toilet training is a constant battle, which can be quite frustrating, overwhelming, and just plain disgusting when dealing with nine-year-olds. We are constantly plagued with episodes of screaming with no known cause, which can last from 10 minutes to 2 hours. Overstimulation, obsessions, and anxiety (for the children and us) rule our days. It is best to keep the routines as predictable as possible, but life is not always like that. It is a constant battle to keep things "somewhat" peaceful and get through each day without the feelings of guilt that we are not doing "enough" to help our children.

My husband and I have spent the better part of eight years advocating for our children and see no end in sight. To be honest, we are exhausted most days. It is financially, physically, and emotionally draining on families like ours. There is always something that they need and not enough money in our province allocated to provide services for families living with autism. As we get older, our boys get bigger, and the services get more and more sparse. We worry about what will happen to them when we can no longer fight these battles.

I watch them sleep and they look like any other nine-year-old boys, but they need help which is out of our reach. Tomorrow is a new day. Perhaps things will change and our government will begin to realize the gaps that exist for autism services in Nova Scotia. Families need to believe this for the sake of their children and their futures.

Survey and Interview Findings

- Families supporting a person with autism are at risk for significant life stresses, which can result in disintegration of the family unit.
- Access to counselling services can help families to manage the increased needs they face in their daily lives.
- Families lack effective education to understand autism. Such training and education would help families develop strategies for better family management.

RECOMMENDATIONS

39. Training for parents and families should be developed and made available to help families to understand autism and their child. Effective training can be offered through the regional autism centres by improving access for families. Qualified professionals in various fields will be available to consult with families about challenging issues as they occur. This can be in the form of home visits, centre visits, email, and workshops to develop parenting skills in key strategies such as visual schedules, behaviour modification (functional analysis), and daily living skills.

40. Parents should receive funding to attend learning opportunities when they are offered in the province. Funds would be available through an application process.
41. Counselling services should be available to families who may be at risk of stress as a result of a diagnosis of autism.

Adults with Autism

There are insufficient numbers of trained professionals in all areas of autism services to support the needs of Nova Scotians with ASD, their families, schools, and communities. As children with autism transition from child services to adult services, many families and adults are being left to fend for themselves. As a result, adults with autism often report that they are frequently misunderstood and discriminated against, especially when trying to get a diagnosis, a job, or access to affordable and safe housing options. Parents of adults with ASD learn when their child turns 18 they must shift their advocacy efforts from fighting for more treatment and therapy hours to finding any help for basic supports for their adult child.

ASD is a lifespan disorder. Currently in Nova Scotia, adults with ASD face the most severe service gaps of any age group on the spectrum.

> *"There are no mental health services available to young adults over 19. If we've been fortunate enough to have been monitored by the IWK throughout school, we are cut off, cut loose, with no resource available for dealing with anxiety, depression, etc. We feel completely isolated in this regard."*
>
> —Parent of adult child with ASD

The Centre for Excellence for Early Childhood Development (CEECD) and the Centre of Excellence for Children and Adolescents with Special Needs (CECASN) hosted an adult autism policy forum on February 5 to 6, 2009, in Montreal. It was recognized during that forum that untreated adults with ASD are at risk for serious mental health concerns (sometimes leading to suicide), isolation, addictions, unemployment, and ongoing dependence on aging families, social services, income support, and mental health programs (*Policy Forum*, 2009). This further stresses the importance of support and intervention across the lifespan for people living with ASD.

While children with ASD are supported through the education system, adults need a very different network of support. They will often need combined and individual support in health, social care, housing, education, and employment.

Further barriers arise as adults with ASD are often excluded from the decision-making process, which further marginalizes them in society. Stigma, isolation, and exclusion are all major concerns for adults with ASD. Adults with ASD want to be valued as participating members of society who are supported and fully engaged in community life.

Survey and Interview Findings

Many adults with ASD missed the "diagnostic wave" that is now taking place in younger generations. For adults looking for a diagnosis and/or treatment, the reality is that only a handful of professionals in Nova Scotia will diagnose and support adults with ASD, most of whom are private professionals. Even among private professionals there is a lack of clarity as to which diagnostic tool, if any, is used and the cost for service is a barrier for many who live on fixed incomes.

A second option for adults looking for a diagnosis or treatment support is a referral to district health authorities' mental health programs. This leads to lengthy waiting lists across the province and psychiatrists who have no formal training in and/or little understanding of ASD. In addition, many psychiatrists identify that they do not formally diagnose but will treat the current behavioural symptoms of the adult seeking support (depression, OCD, anxiety, etc.). Further investigation and research needs to take place to examine the implications of approaching a treatment plan from a behavioural approach without taking into consideration the underlying condition of ASD. A lack of diagnosis or misdiagnosis can lead to inappropriate and uncoordinated services, which contributes to poor long-term outcomes for anyone living with ASD.

Another noted gap in adult services is a lack of post-secondary, employment/vocational, and social programming options for high school graduates, which results in many students with ASD remaining in the school system until age 21. This creates a further strain on education resources and for other children with special needs requiring support in a system where funding and resources are already limited. Transition/vocational programs and increased post-secondary and employment options are needed to help young adults in the transition to independence and community life after school. Please refer to the Education section of this report for recommendations that address transition support for school-age children with ASD.

In summary, there are basic and practical needs that are not being met for adults with autism in Nova Scotia. More specifically, these include issues around housing, employment, transportation, self-help, overall mental health and well-being, sensory issues, sexuality, coping with stress and anxiety. Results from the Provincial Lifespan Survey further support these survey and interview findings.

Lifespan Survey Results–Adult category

The following data was taken from the Survey on Lifespan Services for Children/Adults with Autistic Spectrum Disorder that was distributed throughout the province from May 2009 until August 2009. The survey and interview findings below relate specifically to the Adult category. For a comprehensive overview of the survey results, please refer to Appendix II.

Areas Identified as Needs for Adults with ASD in Nova Scotia

(Includes responses from parents/caregivers, professionals, and adults with ASD)

Employment/Day programs: 255 (34.8 percent of respondents)

Social-friendship recreational programs: 237 (32.4 percent of respondents)

Post-secondary education programs: 218 (29.8 percent of respondents)

Housing/Residential options: 208 (28.4 percent of respondents)

Activity-based programs: 199 (27.2 percent of respondents)

> *"I would like to have a program in which autistic people can learn training skills and be able to be employed by people who understand the condition. I am trying to look for a job and I am getting nowhere."*
>
> —Adult with ASD

Adults with ASD were most likely to select employment/day programs (38.5 percent), post-secondary education programs (26.9 percent), and social-friendship recreational programs (26.9 percent) as their top three priority services.

Parents of adults with ASD selected employment/day programs (53.7 percent), housing/residential programs (33.3 percent) and social-friendship recreational programs (37.0 percent) most often as priority needs. Parent comments clearly identify a desire for their children with ASD to have homes, a job, and a community that accepts them where they find a sense of belonging and enjoy a high quality of life. These results could also reflect parent concerns about the long-term well-being of their adult child with ASD when they are no longer able to care for them, due to illness or death.

In the general category of the survey, mental health services were selected most by parents of adults with ASD.

Transportation and family doctor were not selected often as being in the top three services; however, individuals with ASD were most likely to

select these services. These results could suggest that transportation is linked to independence for this population and family doctors represent one of the limited resources accessible by this population. This finding further reinforces the need for autism education, training, and awareness at the professional and community level throughout the province. Many family doctors are not trained in supporting patients with ASD, yet are frequently frontline.

Another significant gap identified by the survey is the lack of data on the true number of adults needing support in Nova Scotia. Out of 732 respondents, only 26 were adults with ASD. Although the priority needs identified by adults are consistent with other surveys and studies of its kind, more research on prevalence rates needs to take place at both the provincial and national level.

As noted above, the top priority need identified by adults with ASD was employment/vocational support. Research from the University of Kansas suggests that only 2 percent of people with autism are employed, and only 1 percent of that 2 percent is employed in the field for which they were educated. Considering that individuals with ASD have many strengths such as an ability to work independently, an acute attention to detail, an ability to complete complex and clearly defined tasks, three-dimensional thinking, and logical decision-making processes, it would suggest that people with ASD notoriously slip through the cracks. This could be in part because traditional supports and services offered are designed for either people with physical disabilities or intellectual challenges, not taking into consideration the uniqueness of ASD. This is particularly true of many employability or supported employment programs currently being offered in Nova Scotia.

Division TEACCH in North Carolina has operated a diverse module-supported employment program for people with autism for almost 20 years. With an 89 percent employee retention rate, Division TEACCH has demonstrated that with the proper support and understanding of autism, people with autism spectrum disorders can find and sustain employment success. This best practice approach is well known and has already been introduced to Nova Scotia through the Department of Education and regional school boards. Developing and supporting an employment model based on the Division TEACCH approach builds on an existing best

practice model and makes sure there is consistency. It also makes sure there is a seamless service across the lifespan for individuals, specifically adults with ASD seeking support in this area.

RECOMMENDATIONS

42. A comprehensive employment model for people with ASD should be developed and carried out across the province. This model would include educating employers about issues and strengths of people with ASD in the workplace. This model could be delivered within cross-disability, established employment programs throughout the province, specifically in rural areas. Organizations and groups with ASD expertise, like the Provincial Autism Centre, could lead and develop the model.
43. Diversity training in the workplace should include ASD training.
44. Educational workshops and support groups, based on best practice approaches, should be developed for adults with ASD that focus on self-care, social skills, mental health, sexuality, and sensory issues.
45. Life skills training programs should be developed and carried out with a focus on budgeting, transportation, safety in the community, pre-employment skills, and wellness.
46. An increase in vocational and day program options should become available in rural and urban areas of the province.

Safety in the Community

The recent tragedy in Cape Breton where James Delorey, a seven-year-old child with autism, died because he wandered away from the family home has clearly highlighted the need for all law enforcement personnel, fire fighters, paramedics, search and rescue personnel, and any other first responders to understand the nature of autism and the correct steps to take in the event of another emergency situation involving a child or adult with ASD. Cape Breton agencies have taken the lead on this and are currently working on a protocol for a response when faced with another emergency involving a person with autism.

Research indicates that individuals with developmental disorders are seven times more likely than other people to come into contact with police and their responses to encounters with the law may not always be socially appropriate.[8] Typical manifestations of autism spectrum disorders, such as running away, unsteadiness, impulsive behaviour or failure to respond, may be misunderstood by law enforcement professionals, with serious consequences.

> *"Information/training provided to the frontline officers would help them when interacting with persons with autism."*
>
> —Senior police officer, from a Nova Scotia police department

In addition, law enforcement and first responders may unexpectedly encounter or be asked to find and/or intervene with a person with autism. Recognizing the behavioural symptoms and knowing effective intervention approaches can minimize situations of risk and victimization for the person with ASD, as well as the first responder.

Survey and Interview Findings

- Currently in Nova Scotia, autism education and training does not exist for first responders and must include 911 operators, Emergency Health Services, fire fighters, search and rescue, and police. For example, fire personnel need to understand that a child or adult with ASD in a burning house could have reinforced locks on doors and windows, may hide from strangers, and/or act out in a violent manner. It is also important for fire personnel and first responders to be trained in how to transport people with ASD once they are located. This information and training could save time and lives.
- In addition, the numbers and locations of persons with ASD who are at risk of harm are not known to police and other first responders.

- Families also find it difficult to ensure the safety of a family member who does not understand danger and who does not have a concept of safety.
- In New Brunswick, Autism Resources Miramichi Inc. is working with local law enforcement officials to create an autism registry for first responders. Having the ability to flag individuals in the 911 system allows first responders to have information about the person with autism. It would be an invaluable tool for all first responders.
- Nothing is more frightening for parents and caregivers than the moment a person with autism goes missing. Further consideration needs to be given to a monitoring system for people with ASD who are at risk of wandering off. A monitoring system would help local law enforcement and public safety agencies to easily locate the missing person.

RECOMMENDATIONS

47. The Department of Justice should strike a committee that will examine this safety need and develop a standard protocol for all first responders, police, fire fighters, paramedics, etc. to be used when involved with a person with autism.
48. First responders (911 operators, EHS personnel, fire fighter, search and rescue, and police) throughout Nova Scotia should receive autism education by trained professionals in dealing with emergencies and persons with autism.
49. An autism census should be conducted in the province to accurately account for all persons with autism spectrum disorder.
50. Nova Scotia should develop and carryout a voluntary autism registry directly fixed to the 911 system.
51. A provincial monitoring system for people with ASD who are at risk of wandering off should be explored.

Autism Organizations and Support Groups

Autism groups and organizations in Nova Scotia have been supporting the autism community since 1978. Like all community-based non-profits, these organizations were founded and traditionally led by parents of children with ASD in urban and rural areas of the province.

The Autism Society of Cape Breton (ASCB) was founded in 1978 and is a non-profit registered charity. With a long history in the Cape Breton community, this organization remains a parent-led organization, run solely by volunteers. Today the ASCB supports parents, and youth with ASD, while promoting autism education and awareness in Cape Breton.

The Autism Society of Nova Scotia (ASNS) was founded in 1995 as a non-profit registered charity. Its mission and mandate focused on parent support, advocacy, and autism education and awareness. The ASNS is well-known for its parent support, advocacy work, and autism summer camp.

The Provincial Autism Centre (PAC) was founded in 2002 and opened as an information resource centre for families, people with ASD, professionals, educators, researchers, and the community at large. After a province-wide needs assessment, the PAC expanded its mandate to include programming for individuals, specifically teens and adults living on the autism spectrum. Today the PAC offers

- a toll-free information line for Nova Scotia
- parent/individual support
- teen and adult social groups
- an arts program
- employment program
- community education and awareness sessions

In addition to registered non-profit organizations, support groups have also been developed throughout the province. Parent-led groups established themselves in the Annapolis valley (Valley Autism Support Team, or VAST), south shore (Autism Centre Society of the South Shore), Cumberland County (Piece By Piece), Truro, Yarmouth, and even within HRM (Bedford-Sackville Support Group and Just Parents Advocacy).

Wherever there was a need, a group formed. This model of support posed many benefits and challenges. Although parents were coming together and finding support within their own community, duplication of services and confusion began to take place, fragmenting the autism community and further diluting already limited programs and services.

In November 2009, members of the autism community came together for a "Day of Sharing and Celebration" at the Provincial Autism Centre in Halifax. Members at the table included the

- Provincial Autism Centre
- Autism Society of Nova Scotia
- Autism Society of Cape Breton
- Valley Autism Support Team
- Autism Centre Society of the South Shore
- Just Parents Advocacy
- Bedford-Sackville Support Group

The groups came together to share resources, information, best practice models, and program ideas while recognizing each group's autonomy. Since that time this group has become the Autism Council of Nova Scotia, and continues to grow its membership. The Council is not a non-profit organization. It is a conduit for autism organizations and groups to come together, share information and resources, speak in a unified voice on provincial issues to government and the community, and build capacity in the communities in which these groups operate.

The Autism Council continues to meet monthly at the Provincial Autism Centre, and operates with a terms of reference. In addition, the Autism Society of Nova Scotia recently pooled its resources with the Provincial Autism Centre and will no longer be a legal entity as of March 31, 2010. Their leadership and advocacy efforts in Nova Scotia over the last 14 years have paved the way for initiatives, including the EIBI program and the AMAT Working Group. By uniting with the Provincial Autism Centre and creating a stronger, unified provincial organization more families and people with ASD will be supported across the province.

Survey and Interview Findings

- Non-profit autism organizations in Nova Scotia do not receive any government funding. As a result, organizations and support groups rely solely on volunteers and community fundraising initiatives to operate the programs and services they offer. Currently, the Provincial Autism Centre is the only organization with a full-time executive director and paid employees. Remaining groups rely on volunteers, specifically parents of children with ASD, to support all aspects of community-based support in their region of the province.
- This support system is problematic, as many parents are exhausted and experience burnout in their family and community. A further implication of this structure is that some communities are resource-rich, while others have limited or no support.

RECOMMENDATIONS

52. The implementation team for the AMAT report should consider existing best practice models for programs and support currently being delivered by non-profit autism organizations throughout the province.
53. Autism organizations/groups should be included in the comprehensive service model proposed by the recommendation of the regional autism centres.

Recommendations Summary

1. An Implementation Committee should be struck by September 1, 2010, made up of members from the autism community and representatives from the departments of Health, Community Services, Education, Justice, and others when warranted.
2. 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.
3. People with ASD should have regular health assessments that include gathering information on areas including but not limited to behavioural, emotional, and mental health issues; screening for medical conditions; nutritional issues; and motor, sensory, and perceptual difficulties. (These services would be offered through the regional autism centres.)
4. People with ASD and their families should have access to a wide range of health professionals/ interdisciplinary health teams (e.g., psychiatrist, psychologist, social worker, occupational therapist, speech-language pathologist, behaviour analyst, behaviour interventionist, and related professionals based on family and individual needs.
5. The province should designate the positions of behavioural analysts and interventionists as job descriptions within the Department of Health and make these trained staff available across the province to support families and individuals.
6. All general practitioners should become knowledgable in recognizing the features of autism. The *Physician Toolkit* (see www.autismcentral.ca/research/index.php?option=com_content&task=view&id=67&Itemid=70 to download a copy), a manual for medical doctors, should be available to all general practitioners across Nova Scotia.
7. Treatment/support plans should be comprehensive and include behavioural needs, educational interventions, psychosocial treatments, physical health needs, communication needs, environment, functional development, and skills for independent living.
8. Further explorations of crisis services for families and individuals with ASD should be investigated to determine if supports are appropriate, timely, and accessible.
9. A course on autism should be included as a mandatory part of training for all student medical professionals, including physicians, nurses, dentists, speech-language pathologists, occupational therapists, psychiatrists, and psychologists.
10. An autism training module should be developed and offered as a Continuing Medical Education (CME) credit to practising medical professionals and for the Mental Health First Aid program.

11. An ASD Clinical Practice Guideline should be developed that addresses the needs across the lifespan. (A possible model to consider is the *New Zealand Autism Spectrum Disorder Guideline*; see www.moh.govt.nz/moh.nsf/indexmh/nz-asd-guideline-apr08?Open.)
12. An autism education and awareness campaign should be developed and carried out. It should target employers, the justice system, general practitioners, health care workers, educators, and the community at large. The Department of Health should take the lead.
13. Initial screening of ASD for all infants should take place at the 12-month, 18-month, and 24-month medical examination. Surveillance for ASD characteristics should be ongoing past 24 months.
14. If an ASD is suspected by the health-care provider, the child should be referred immediately for ASD screening and comprehensive medical testing should take place within one month. Diagnostic reports should be shared with the family in a timely manner.
15. Following an ASD diagnosis, treatment/intervention should start within three months.
16. Additional clinical psychologists with the appropriate training should be hired to shorten the diagnostic wait lists for school-aged children.
17. Further investigation should take place on identifying and standardizing a best practice assessment tool to diagnose adults with ASD, as well as training of related professionals to administer it.
18. Funding to the EIBI program should be increased so it can be made available to all families with a preschool-aged child diagnosed with ASD in the province of Nova Scotia.
19. Increased appropriate training opportunities should be made available to staff at daycares and early interventionists throughout the province.
20. A treatment plan should be created by the IFSP planning team and should include appropriate intensive intervention at the rate of 25 hours per week by ASD professionals.[7] Services in French should be made available if needed.
21. The Department of Education should give all school boards targeted grants to support professional development and board-based initiatives in the area of autism. Grants should be increased and reviewed annually. Furthermore these grants should be increased to reflect the increased numbers of children in the public school system diagnosed with ASD.
22. The Department of Education should continue to fund the position of Autism Consultant for the province of Nova Scotia. This position would manage the autism strategy and provide the leadership in coordinating the professional development needs identified by school boards across the province.
23. All school boards in Nova Scotia should make sure that an autism specialist or consultant is a part of the staffing allocation to support the training needs and program planning teams in schools.
24. The staffing ratio for speech-language pathologists should be improved to offer additional staffing to all school boards. Occupational therapy should be available within regional school boards to help schools with the sensory needs of students with ASD.

25. The Department of Education should give targeted funding to each regional school board to support the position of Transition Facilitator. This position would work collaboratively with high schools, government departments, and community organizations to support successful transition out of public school.
26. An ongoing professional development focus on best practices in the area of autism education should be provided for all staff (including administrators, public school teachers and TAs, bus drivers, and staff at private schools) involved in the education of children with autism spectrum disorder.
27. School boards should be allotted targeted funding to be used for purchasing materials to support the programming needs of the children with autism spectrum disorder.
28. Nova Scotia's colleges and universities should commit to offer post-secondary programming for students graduating from public schools with credits designated as IPP. Creation of additional seats in programs for students with IPPs is also recommended.
29. The Department of Education should make sure that each university in Nova Scotia offering an education degree offers a mandatory course in autism spectrum disorders to all students enrolled in education.
30. One university in Nova Scotia should become a leader in autism education. It should offer diplomas or degrees with specialization in autism similar to those offered in other provinces across Canada.
31. Staff at universities and community colleges should have opportunities for training in the area of ASD.
32. Criteria for the Department of Community Services' Direct Family Support program should be reconsidered. Specifically, the definition of "intellectual" disability and income testing as a basis for eligibility should be reviewed. Eligibility for this program should be based on the needs of the family and individual circumstances, making sure that families who could benefit the most from respite services are receiving funding.
33. A training toolkit for recruiting and retaining respite care workers in working with people with ASD should be developed. A list of required core competencies and experience for respite care workers to offer quality services to persons with ASD across the lifespan should be defined as part of the toolkit. Where regional respite programs exist, training should be given to respite workers specific to ASD.
34. Appropriate, community-based housing options should be available to all adults with ASD based on the needs and ability of the individual seeking support.
35. Appropriate, inclusive leisure/recreation programming specific to after-school and school breaks (Christmas break, March break, and summer vacation) for all age groups across the province should be developed and carried out.
36. Opportunities should be created for recreational/leisure programming for individuals with ASD 21 years and older.
37. A granting system should be created to meet the social and leisure programming needs of various autism organizations.
38. Targeted funding should be offered for recreation departments throughout the province to support recreation/leisure programs specifically designed for individuals with autism.

39. Training for parents and families should be developed and made available to help families to understand autism and their child. Effective training can be offered through the regional autism centres by improving access for families. Qualified professionals in various fields will be available to consult with families about challenging issues as they occur. This can be in the form of home visits, centre visits, email, and workshops to develop parenting skills in key strategies such as visual schedules, behaviour modification (functional analysis), and daily living skills.
40. Parents should receive funding to attend learning opportunities when they are offered in the province. Funds would be available through an application process.
41. Counselling services should be available to families who may be at risk of stress as a result of a diagnosis of autism.
42. A comprehensive employment model for people with ASD should be developed and carried out across the province. This model would include educating employers about issues and strengths of people with ASD in the workplace. This model could be delivered within cross-disability, established employment programs throughout the province, specifically in rural areas. Organizations and groups with ASD expertise, like the Provincial Autism Centre, could lead and develop the model.
43. Diversity training in the workplace should include ASD training.
44. Educational workshops and support groups, based on best practice approaches, should be developed for adults with ASD that focus on self-care, social skills, mental health, sexuality, and sensory issues.
45. Life skills training programs should be developed and carried out with a focus on budgeting, transportation, safety in the community, pre-employment skills, and wellness.
46. An increase in vocational and day program options should become available in rural and urban areas of the province.
47. The Department of Justice should strike a committee that will examine this safety need and develop a standard protocol for all first responders, police, fire fighters, paramedics, etc. to be used when involved with a person with autism.
48. First responders (911 operators, EHS personnel, fire fighter, search and rescue, and police) throughout Nova Scotia should receive autism education by trained professionals in dealing with emergencies and persons with autism.
49. An autism census should be conducted in the province to accurately account for all persons with autism spectrum disorder.
50. Nova Scotia should develop and carryout a voluntary autism registry directly fixed to the 911 system.
51. A provincial monitoring system for people with ASD who are at risk of wandering off should be explored.
52. The implementation team for the AMAT report should consider existing best practice models for programs and support currently being delivered by non-profit autism organizations throughout the province.
53. Autism organizations/groups should be included in the comprehensive service model proposed by the recommendation of the regional autism centres.

Appendix I

Survey on Lifespan Services for Children/Adults with Autistic Spectrum Disorder

Please use a checkmark to indicate which of the following you need/would like but are unable to access, either for yourself (person with autism/ASD), your family member(s) or your clients, patients, or students with autism/ASD.

Preschool-aged children

- ❑ Early detection of ASD
- ❑ Nova Scotia Early Intensive Behaviour Intervention program
- ❑ Other forms of early intervention (e.g., speech-language or occupational therapy)
- ❑ Daycare/preschool programs
- ❑ Parent training programs

School-aged children

- ❑ After-school programs
- ❑ Social-friendship recreational programs
- ❑ Activity-based (e.g., physical activity, art, or music) programs
- ❑ Summer camps
- ❑ Parent training programs

Adults

- ❑ Post-secondary education programs (e.g., community college, university, or other)
- ❑ Social-friendship recreational programs
- ❑ Activity-based (e.g., physical activity, art, or music) programs
- ❑ Employment/day programs
- ❑ Housing/residential options

General

- ❑ Diagnostic and/or developmental/skill assessment services
- ❑ Respite care (in- and/or out-of-home)
- ❑ Transportation
- ❑ Family doctor
- ❑ Support, treatment, or counselling for school-aged children and adults (e.g., for speech-language or behaviour issues)
- ❑ Mental health services (e.g., for anxiety or depression)
- ❑ Crisis intervention/management
- ❑ Family support and counselling (e.g., for grief or marital issues)

Of those that you have checked above, please indicate your top three priority/most important needs by placing a star/asterisk beside three of the checkmarks.

Additional comments:

_____

_____

_____

Thank you for your time. We are most appreciative of your assistance.

Appendix II

Survey on Lifespan Services for Children/Adults with Autistic Spectrum Disorder

Survey Data Summary

Rationale/Introduction

In the spring of 2009, the Autism Management Advisory Team (AMAT) released a province-wide survey to parents of children with autism spectrum disorder (ASD), professionals, and individuals, and, more specifically, adults aged 18 years and older with ASD. The main goal of the survey was to identify key or priority program and service needs across Nova Scotia.

The survey was approved at the department level to be distributed by the regional school boards throughout the province. The survey was also available online through the Provincial Autism Centre website and the government working group website. A press release informing Nova Scotians about the survey was released in August 2009. The Provincial Autism Centre, Valley Autism Support Team, Autism Society of Cape Breton, and the Autism Society of Nova Scotia sent out the survey to partnering autism organizations and membership lists throughout the province in an attempt to reach as many families, individuals with ASD, and related professionals as possible for the sample size.

The survey was filled out by 732 individuals, either online or on paper. Paper surveys were mailed to the Autism research Centre at the IWK Health Centre in Halifax and transferred electronically into the system for data analysis. Please refer to Appendix I to view a sample of the Lifespan Services Survey.

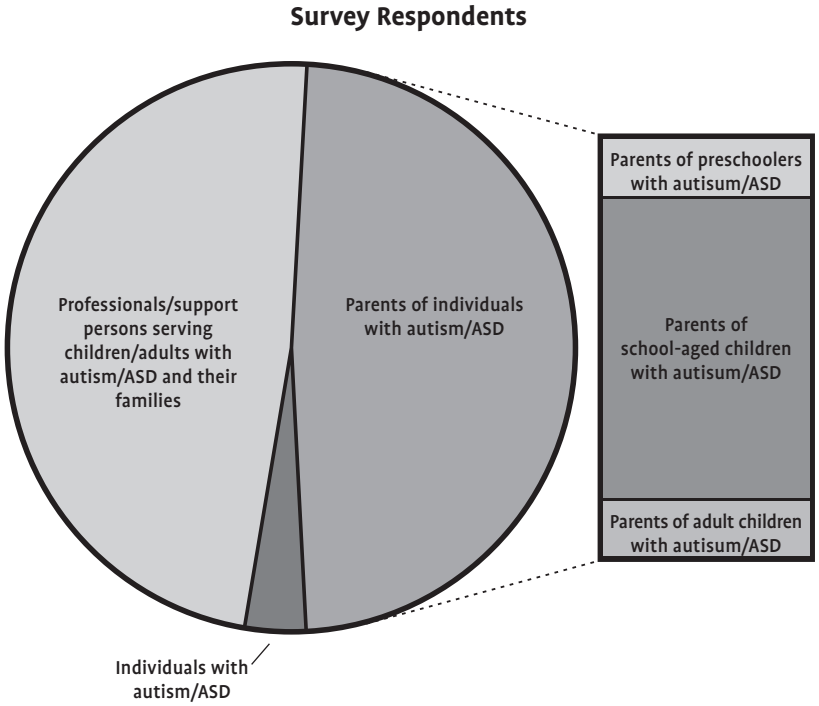
The following section contains the survey results as reported from parents/caregivers, professionals, and individuals with ASD.

Questions 1, 2, 3: *Demographics*

The survey was filled out by 732 individuals, either online or on paper.

- Individuals with autism/ASD: 26 (3.6 percent of respondents).
- Parents or caretakers of children with autism/ASD: 366 (50.0 percent of respondents).
- Parents of preschoolers with autism/ASD: 55 respondents (7.5 percent of respondents, 15.0 percent of parents).
- Parents of school-aged children with autism/ASD: 269 respondents (36.7 percent of respondents, 73.5 percent of parents).
- Parents of adult children with autism/ASD: 54 respondents (7.4 percent of respondents, 14.8 percent of parents).
- Professionals or other support persons serving children and/or adults with autism/ASD and/or their families: 379 (51.8 percent).

(Note: These values total >100 percent as some respondents identified themselves as both a parent and a professional, for example, or as having children with autism/ASD in more than one category, or some parents did not identify the age group under which their child/children fell.)

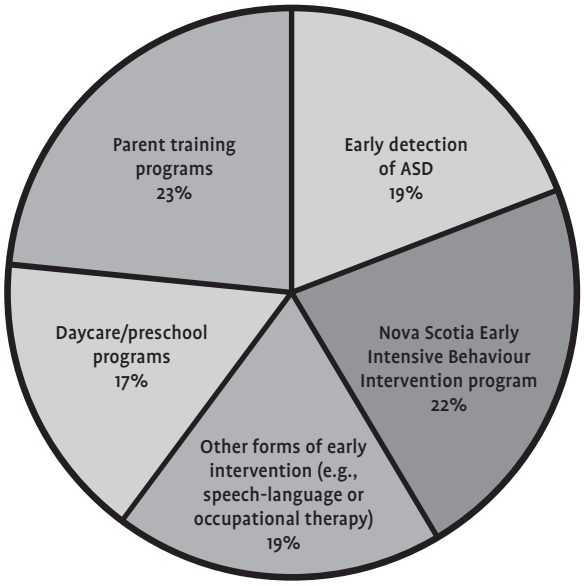


Question 4: *Respondents were asked to indicate from a list which of the following they need/would like but are unable to access, either for themselves (e.g., person with autism/ASD), their family member(s) or their clients, patients, or students with autism/ASD.*

Preschool-aged children category:

- Early detection of ASD: 180 (24.6 percent of respondents)
- Nova Scotia Early Intensive Behaviour Intervention program: 210 (28.7 percent of respondents)
- Other forms of early intervention (e.g., speech-language or occupational therapy): 176 (24.0 percent of respondents)
- Daycare/preschool programs: 155 (21.2 percent of respondents)
- Parent training programs: 220 (30.1 percent of respondents)

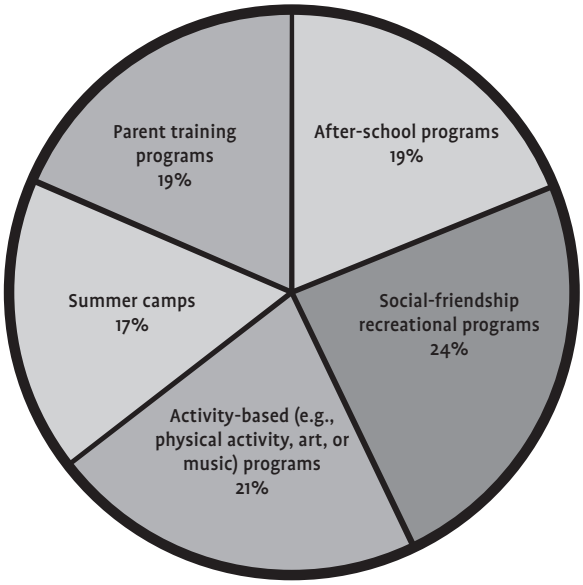
Areas Identified as Needs for Preschool-aged Individuals with Autism/ASD



School-aged children category:

- After-school programs: 354 (48.4 percent of respondents)
- Social-friendship recreational programs: 450 (61.5 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 403 (55.1 percent of respondents)
- Summer camps: 319 (43.6 percent of respondents)
- Parent training programs: 347 (47.4 percent of respondents)

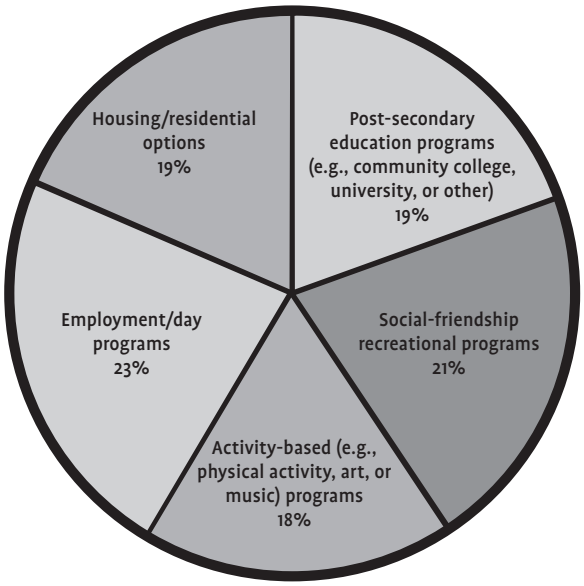
Areas Identified as Needs for School-aged Individuals with Autism/ASD



Adult category:

- Post-secondary education programs (e.g., community college, university, or other): 218 (29.8 percent of respondents)
- Social-friendship recreational programs: 237 (32.4 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 199 (27.2 percent of respondents)
- Employment/day programs: 255 (34.8 percent of respondents)
- Housing/residential options: 208 (28.4 percent of respondents)

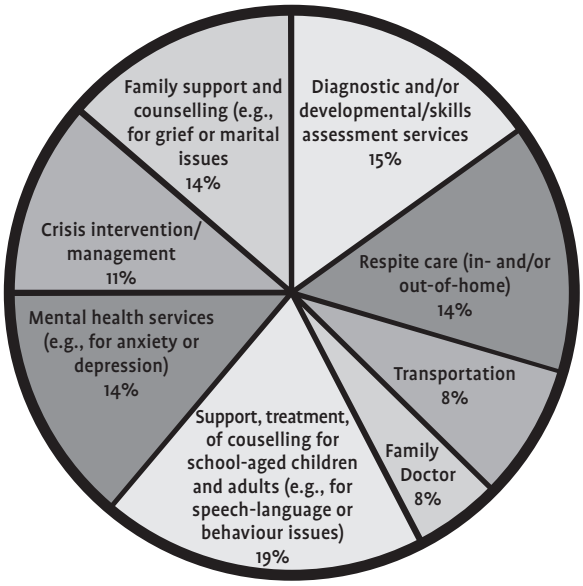
Areas Identified as Needs for Adult Individuals with Autism/ASD



General category:

- Diagnostic and/or developmental/skill assessment services: 329 (44.9 percent)
- Respite care (in- and/or out-of-home): 313 (42.8 percent)
- Transportation: 171 (23.4 percent)
- Family doctor: 108 (14.8 percent)
- Support, treatment, or counselling for school-aged children and adults (e.g., for speech-language or behaviour issues): 407 (55.6 percent)
- Mental health services (e.g., for anxiety or depression): 301 (41.1 percent)
- Crisis intervention/management: 245 (33.5 percent)
- Family support and counselling (e.g., for grief or marital issues): 298 (40.7 percent)

Areas Identified as General Needs for Individuals with Autism/ASD

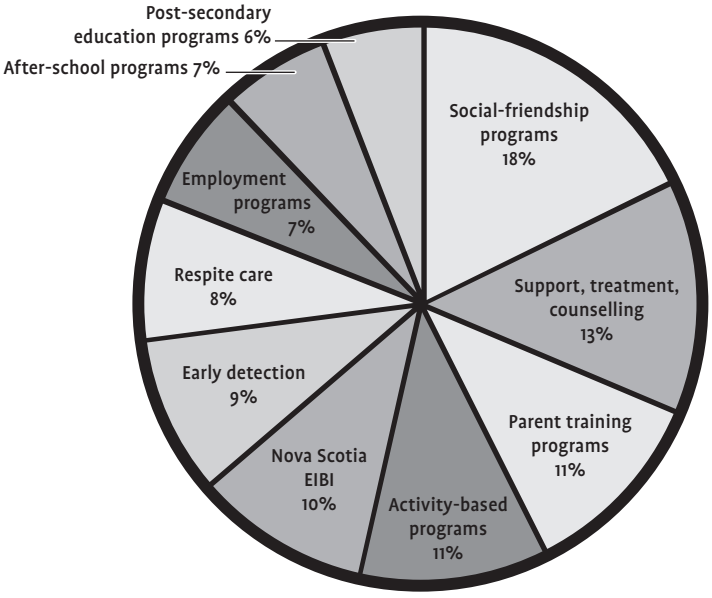


Question 5: *Respondents were asked to indicate from the same options which are their top three priority/most important needs.*

- Early detection of ASD: 133 (18.2 percent of respondents)
- Nova Scotia Early Intensive Behaviour Intervention program: 151 (20.6 percent of respondents)
- Other forms of early intervention (e.g., speech-language or occupational therapy): 76 (10.4 percent of respondents)
- Daycare/preschool programs: 35 (4.8 percent of respondents)
- Parent training programs: 161 (22.0 percent of respondents)

- After-school programs: 95 (13 percent of respondents)
- Social-friendship recreational programs: 260 (35.5 percent of respondents)
- Activity-based (e.g., physical activity, art, or music) programs: 157 (21.4 percent of respondents)
- Summer camps: 70 (9.6 percent of respondents)
- Post-secondary education programs (e.g., community college, university, or other): 82 (11.2 percent of respondents)
- Employment/day programs: 100 (13.7 percent of respondents)
- Housing/residential options: 75 (10.2 percent of respondents)
- Diagnostic and/or developmental/skill assessment services: 76 (10.4 percent of respondents)
- Respite care (in- and/or out-of-home): 117 (16.0 percent of respondents)
- Transportation: 16 (2.2 percent of respondents)
- Family doctor: 13 (1.8 percent of respondents)
- Support, treatment, or counselling for school-aged children and adults (e.g., for speech-language or behaviour issues): 196 (26.8 percent of respondents)
- Mental health services (e.g., for anxiety or depression): 75 (10.2 percent of respondents)
- Crisis intervention/management: 39 (5.3 percent of respondents)
- Family support and counselling (e.g., for grief or marital issues): 56 (7.7 percent of respondents)

Top 10 Needs Identified by Respondents



Selections filtered by type of respondent

Question 4: *Identifying the need for services*

(The top three services selected by each type of respondent and the most highly selected in each service type are in bold type.)

	ASD Individuals (*n*=26)	Professionals (*n*=379)	Parents of Preschoolers (*n*=55)	Parents of School-aged (*n*=269)	Parents of Adults (*n*=54)	Parents (all) (*n*=366)
Preschool-aged children category						
Early detection of ASD	23.1% (6)	29.3% (111)	**50.9% (28)**	19.0% (51)	14.8% (8)	21.9% (80)
Nova Scotia EIBI program	15.4% (4)	39.1% (148)	**56.4% (31)**	20.4% (55)	13.0% (7)	20.8% (76)
Other forms of early intervention	11.5% (3)	29.8% (113)	**45.5% (25)**	19.0% (51)	11.1% (6)	19.9% (73)
Daycare/preschool programs	11.5% (3)	26.6% 101	**50.9% (28)**	15.2% (41)	9.3% (5)	17.5% (64)
Parent training programs	11.5% (3)	37.7% (143)	**60.0% (33)**	22.3% (60)	18.5% (10)	24.3% (89)
School-aged children category						
After-school programs	15.4% (4)	48.5% (184)	50.9% (28)	**62.8% (169)**	18.5% (10)	52.5% (192)
Social-friendship recreational programs	34.6% (9)	**62.3% (236)**	52.7% (29)	**74.7% (201)**	27.8% (15)	**64.5% (236)**
Activity-based programs	19.2% (5)	**53.3% (202)**	50.9% (28)	**72.9% (196)**	31.5% (17)	**61.2% (224)**
Summer camps	19.2% (5)	39.3% (149)	41.8% (23)	**60.0% (163)**	24.1% (13)	50.8% (186)
Parent training programs	19.2% (5)	48.3% (183)	45.5% (25)	**59.1% (159)**	22.2% (12)	49.7% (182)

	ASD Individuals (*n*=26)	Professionals (*n*=379)	Parents of Preschoolers (*n*=55)	Parents of School-aged (*n*=269)	Parents of Adults (*n*=54)	Parents (all) (*n*=366)
Adults category						
Post-secondary education programs	46.2% (12)	36.7% (139)	18.2% (10)	20.8% (56)	**53.7% (29)**	23.2% (85)
Social-friendship recreational programs	**53.8% (14)**	39.3% (149)	20.0% (11)	21.9% (59)	**55.6% (30)**	25.1% (9)
Activity-based programs	34.6% (9)	34.0% (129)	20.0% (11)	18.2% (49)	**51.9% (28)**	21.6% (79)
Employment/day programs	50.0% (13)	42.0% (159)	16.4% (9)	22.3% (60)	**70.4% (38)**	27.6% (101)
Housing/ residential options	34.6% (9)	36.4% (138)	18.2% (10)	16.4% (44)	**63.0% (34)**	21.9% (80)
General category						
Diagnostic and/ or developmental/ skill assessment services	**53.8% (14)**	43.5% (165)	**58.2% (32)**	50.9% (137)	44.4% (24)	48.1% (176)
Respite care (in- and/or out-of-home)	23.1% (6)	42.2% (160)	**56.4% (31)**	46.5% (145)	40.7% (22)	45.9% (168)
Transportation	19.2% (5)	26.4% (100)	27.3% (15)	19.7% (53)	**35.2% (19)**	20.5% (75)
Family doctor	23.1% (6)	14.2% (54)	**25.5% (14)**	15.2% (41)	7.4% (4)	15.3% (56)
Support, treatment, or counselling for school-aged children and adults	**53.8% (14)**	**54.4% (206)**	54.5% (30)	**61.7% (166)**	53.7% (29)	**59.3% (217)**
Mental health services	50.0% (13)	42.2% (160)	32.7% (18)	39.8% (107)	**53.7% (29)**	40.4% (148)
Crisis intervention/ management	**46.2% (12)**	40.4% (153)	35.5% (14)	26.8% (72)	37.0% (20)	26.5% (97)
Family support and counselling	**46.2% (12)**	40.1% (152)	43.6% (24)	45.0% (121)	38.9% (21)	41.8% (153)

Summary of amount of support by type of respondent:

- Individuals with autism/ASD selected social-friendship recreational programs, diagnostic skill assessment services, and support/ treatment/counselling for school-aged children and adults most often.

- Professionals selected social-friendship recreational programs of school-aged children, support/treatment/counselling for school-aged children and adults, and activity-based programs for school-aged children most often.
- Parents of preschoolers most often selected parent-training programs for preschoolers and diagnostic skill assessment services. The Nova Scotia EIBI program and respite care were tied for third.
- Parents of school-aged children selected social-friendship recreational programs of school-aged children, after-school programs for school-aged children, and support/treatment/counselling for school-aged children and adults most often.
- Parents of adults selected employment/day programs, housing/residential programs, and social-friendship recreational programs most often.
- Parents (all) selected social-friendship recreational programs of school-aged children, activity-based programs for school-aged children, and support/treatment/counselling for school-aged children and adults most often.

  (Note: Data for all parents are skewed due to the high number of parents of school-aged children versus other parents, and thus may not be truly representative of all parents.)

Summary of amount of support by category:

- Services in the preschool-aged category were all most strongly identified as important by parents of preschoolers (every item was supported by over half of the parents of preschoolers), with parent training programs and the Nova Scotia EIBI program as their two biggest concerns.
- Services in the school-aged category were all most strongly identified as important by parents of school-aged children (every item was supported by more than half of the parents of adults), with social-friendship recreational programs and activity-based programs as their two biggest concerns.
- Services in the adult category were all most strongly identified as important by parents of adults (every item was supported by more than half of the parents of adult children), with employment and housing programs as their two biggest concerns.
- In the general category, crisis intervention and family counselling were most strongly selected by individuals with autism/ASD, diagnostic assessment services and respite care were most selected by parents of preschoolers, support and counselling for school-aged children and adults were selected by parents of school-aged children, and mental health services was most selected by parents of adults.

Question 5: *Respondents were asked to identify their* ***top thee priorities.***
(The top three services selected by each type of respondent are in bold type.)

	ASD Individuals (*n*=26)	Professionals (*n*=379)	Parents of Preschoolers (*n*=55)	Parents of School-aged (*n*=269)	Parents of Adults (*n*=54)	Parents (all) (*n*=366)
Early detection of ASD	3.8% (1)	24.8% (94)	**27.3% (15)**	1.2% (30)	7.4% (4)	13.4% (49)
Nova Scotia EIBI program	3.8% (1)	**28.5% (108)**	**41.8% (23)**	12.3% (33)	5.6% (3)	14.5% (53)
Other forms of early intervention	3.8% (1)	11.3% (43)	25.5% (14)	9.7% (26)	1.9% (1)	10.7% (39)
Daycare/preschool programs	3.8% (1)	5.3% (20)	20.0% (11)	3.0% (8)	1.9% (1)	4.1% (15)
Parent training programs	7.7% (2)	**25.3% (96)**	18.2% (10)	19.0% (51)	13.0% (7)	19.7% (72)
After-school programs	7.7% (2)	9.8% (37)	7.3% (4)	19.7% (53)	1.9% (1)	16.4% (60)
Social-friendship recreational programs	**26.9% (7)**	**31.7% (120)**	21.8% (12)	**41.6% (112)**	**37.0% (20)**	**38.8% (142)**
Activity-based programs	11.5% (3)	14.8% (56)	**30.9% (17)**	**31.6% (85)**	11.1% (6)	**28.1% (103)**
Summer camps	0% (0)	5.5% (21)	9.1% (5)	17.1% (46)	9.3% (5)	15.0% (55)
Post-secondary education programs	**26.9% (7)**	9.5% (36)	5.5% (3)	10.0% (27)	27.8% (15)	12.0% (44)
Employment/day programs	**38.5% (10)**	11.3% (43)	1.8% (1)	8.6% (23)	**53.7% (29)**	13.7% (50)
Housing/ residential options	23.1% (6)	9.2% (35)	1.8% (1)	5.6% (15)	**33.3% (18)**	9.6% (35)

	ASD Individuals (*n*=26)	Professionals (*n*=379)	Parents of Preschoolers (*n*=55)	Parents of School-aged (*n*=269)	Parents of Adults (*n*=54)	Parents (all) (*n*=366)
Diagnostic and/ or developmental/ skill assessment services	15.4% (4)	10.8% (41)	5.5% (3)	11.9% (32)	7.4% (4)	10.1% (37)
Respite care (in- and/or out-of-home)	0% (0)	13.2% (50)	23.6% (13)	21.2% (57)	18.5% (10)	20.5% (75)
Transportation	11.5% (3)	1.3% (5)	1.8% (1)	2.6% (7)	3.7% (2)	2.5% (9)
Family doctor	7.7% (2)	1.1% (4)	1.8% (1)	2.6% (7)	1.9% (1)	2.5% (9)
Support, treatment, or counselling for school-aged children and adults	19.2% (5)	25.1% (95)	2.8% (12)	**33.1% (89)**	14.8% (8)	**29.2% (107)**
Mental health services	7.7% (2)	11.1% (42)	5.5% (3)	9.7% (26)	20.4% (11)	10.4% (38)
Crisis intervention/ management	7.7% (2)	7.4% (28)	1.8% (1)	3.0% (8)	9.3% (5)	3.0% (11)
Family support and counselling	3.8% (1)	8.2% (31)	5.5% (3)	7.8% (21)	3.7% (2)	7.9% (29)

Summary of the top three services selected by type of respondent:

- Individuals with ASD were most likely to select employment/day programs, post-secondary education programs, and social-friendship recreational programs as their top three services.
- Professionals were most likely to select social-friendship recreational programs, the Nova Scotia EIBI program, and parent training programs as their top three services.
- Parents of preschoolers were most likely to select the Nova Scotia EIBI program, activity-based programs, and early detection of ASD as their top three services.
- Parents of school-aged children were most likely to select social-friendship recreational programs, support, treatment, or counselling for school-aged children and adults, and activity-based programs as their top three services.

- Parents of adults were most likely to select employment/day programs, social-friendship recreational programs, and housing/residential options as their top three services.
- Parents (all) were most likely to select social-friendship recreational programs, support, treatment or counselling for school-aged children and adults, and activity-based programs. *(Note: As previously mentioned, these numbers are skewed by the disproportionate number of parents of school-aged children.)*

Summary of the top three supports for each type of service:

- Early detection of ASD and the Nova Scotia EIBI program were most highly selected as a top three selection by parents of preschoolers, followed closely by professionals.
- Other forms of early intervention and daycare/preschool programs were most highly selected as one of their top three by parents of preschoolers.
- Parent training programs was most likely to be selected by professionals as being in their top three services, which was followed not too distantly by parents of preschoolers and school-aged children.
- After school programs was most likely to be selected by parents of school-aged children as a top three service.
- Social-friendship recreational programs was overwhelming selected by all groups, except for parents of preschoolers, as being a top three service.
- Activity-based programs was selected by parents of preschoolers and school-aged children as being a in their top three services.
- Summer camps received only some top three service selections by parents of school-aged children.
- Post-secondary education programs, employment/day programs, and housing/residential options were selected as being a top three important service by both individuals with ASD and parents of adult children with autism/ASD.
- Diagnostic and/or developmental/skill assessment services was selected most often by individuals with autism/ASD as being in their top three.

- Respite care (in- and/or out-of-home) was selected as one of the top three services by parents of preschoolers most often, but this was followed closely by parents of school-aged children and adults with autism/ASD.
- Transportation and family doctor were not selected often as being in the top three services; however, individuals with autism/ASD were most likely to select these services.
- Support, treatment, and counselling for school-aged children and adults was most often selected by parents of school-aged children as being a top three choice; however, this was followed not too distantly by professionals and individuals with autism/ASD.
- Mental health services and crisis intervention/management did not receive many top three selections but were most often selected by parents of adults with autism/ASD.
- Family support and counselling also did not receive as many top three selections but was most often selected by professionals followed by parents of school-aged children with autism/ASD.

Summary of the Additional Comments

Question 6: *Additional comments*
The survey was filled out by 732 individuals, either online or on paper.

- Respondents who *did not* include additional comments: 464 (63.4 percent)
- Respondents who *did* include additional comments: 268 (36.6 percent)

Of those respondents who included comments:

- 3.0 percent (8) were individuals with autism/ASD
- 66.0 percent (177) were parents of children with autism/ASD
  - 15.3 percent (27) were parents of preschoolers with autism/ASD
  - 71.2 percent (126) were parents of school-aged children with autism/ASD
  - 16.9 percent (30) were parents of adult children with autism/ASD
- 39.9 percent (107) were professionals

From the open-ended comments, 11 common themes were identified and extrapolated. These included

- support for an increase in the services already being offered and **additional services** that should be offered; there was evidence of frustration concerning long wait lists for current services and a need for increased availability of trained professionals, such as SLPs, OTs, EAs, etc.
- support for the **early detection** of autism/ASD in young children and immediate enrollment in **early intervention programs**, particularly EIBI; many were frustrated with the current lottery-type system for EIBI in the province
- a call for **additional training** to be provided for professionals who interact with individuals with autism/ASD, such as teachers, doctors, educational assistants, daycare teachers, etc. and an increased number of trained professionals available to work with individuals with autism/ASD
- requests for additional **social programs** to be offered for individuals with autism/ASD, including daycares/preschools, after-school programs, summer camps, and friendship groups; in particular, individuals commented that programs that included both individuals with autism/ASD alongside typically developing individuals and siblings of individuals with autism/ASD would be beneficial for teaching social skills
- a call for increased **services for adults with autism/ASD,** including post-high school education/training, residence programs/homes, and job placement services
- indications that the **financial costs** associated with private services were too high, that government funding for programs and services was inadequate, and that the income levels for families available to receive services was too high (particularly for respite care)
- a feeling of a lack of **family support**, including mental and emotional support for parents, siblings, and individuals with autism/ASD, and parental training programs/information for parents
- an indication that individuals felt that there was **a lack of services in rural areas** of Nova Scotia, that services/programs were not easily assessable (particularly outside the HRM), or, occasionally, that Nova Scotia itself was behind other parts of the country or behind other countries in terms of the services available

- request for **increased services for individuals identified as high functioning** as they are often left out of traditional services and have difficulty finding suitable programs
- interest in **alternative treatment(s)** for individuals with autism/ASD
- a feeling that there is a **lack of standard medical care** for individuals with autism/ASD, including access to family doctors and dentists, and difficulties waiting in the ER for care

Question 6: *Frequency of additional comments grouped by theme*

	ASD Individuals (*n*=8)	Professionals (*n*=107)	Parents of Preschoolers (*n*=27)	Parents of School-aged (*n*=126)	Parents of Adults (*n*=30)
Additional Services	12.5% (1)	29.0% (31)	40.7% (11)	33.3% (42)	20.0% (6)
Early Detection/ Intervention	12.5% (1)	22.4% (24)	48.1% (13)	21.4% (27)	6.7% (2)
Training for Professionals	12.5% (1)	30.8% (33)	37.0% (10)	15.1% (19)	13.3% (4)
Social Programs	12.5% (1)	15.9% (17)	25.9% (7)	25.4% (32)	20.0% (6)
Services for Adults	50.0% (4)	15.0% (16)	0.0% (0)	13.0% (16)	50.0% (15)
Financial Costs	12.5% (1)	7.5% (8)	22.2% (6)	24.6% (31)	20.0% (6)
Family Support	0.0% (0)	12.1% (13)	22.2% (6)	19.8% (25)	16.7% (5)
Rural Services	0.0% (0)	14.0% (15)	18.5% (5)	16.7% (21)	20.0% (6)
Services for HFA	0.0% (0)	3.7% (4)	0.0% (0)	9.5% (12)	13.3% (4)
Alternative Treatments	12.5% (1)	3.7% (4)	7.4% (2)	7.9% (10)	3.3% (1)
Medical Care	0.0% (0)	1.9% (2)	0.0% (0)	3.2% (4)	6.7% (2)

Examples of representative comments from each of the general themes
(Note: Comments are included below as they were written by respondents.)

Additional services

- "I would like to see regional centres where diagnosis, care and information could all be found in one stop. Perhaps by using the space available in vacated hospital wings and staffing them with SLPs, psychologists, doctors, dietitians, social workers, etc., and other specialists that are familiar with the needs of autistic people. Even if these centers were only open a few days each week, they would make things much easier. A data base there could connect families to social groups, respite worker list, available activities, etc. An all in one stop no more than an hour away."
- "We are in great need of having OT and SLP services in our schools. There is a long wait list and little chance for a follow up."
- "It seems that once children enter school, most services are withdrawn trusting that schools will take over all responsibility. Schools do not have the proper funding or supports to effectively program for students with autism, nor do they have the proper expertise, keeping in mind that teachers also have to give individual attention to all their students in very diverse classrooms. There has to be more cooperation/partnering between agencies!!"
- "Access includes whether or not there is enough of a service or any at all and the wait time for this service—in my field of SLP there is much attention on the fact that not all children diagnosed with ASD get EIBI and access to individual/specialized programs within daycares and preschools seems inconsistent."
- "The services available for autistic children and adults in Nova Scotia are simply appalling. Yes, there are scarce resources across the country, but Nova Scotia is one of the worst provinces in the country in terms of providing support for families with an autistic son or daughter. The need for diagnosis/early intervention/treatment in this province has reached a crisis level, with the children paying the price. Children who could be happily interacting with others, playing, making friends, and talking are silent and alone, simply because of a lack of funding for some very basic, proven therapies like ABA. There is also an appalling lack of daycare/after school options for autistic

kids, and virtually no support for autistic teenagers and adults. I really hope that this survey will lead to real and immediate change, and is not simply a public relations move on the part of a government that has left these children and their families behind."

- "One thing that is desperately needed in this province is a total care centre for people with autism, and those who live with or work with them. Such a centre would include service from psychology, occupational therapy, massage therapy, speech, early intervention, ABA, and other disciplines of treatment. A person with autism could go to this centre initially for diagnosis, then for treatment and therapy. Families could go there to get information and help. This one-stop shopping approach would mean less travel for families, less stress for everyone, and would simply make life easier for people living with ASD."

Early detection/intervention

- "We were very fortunate to have had our son selected for the EIBI Program. It has helped him/us so much. It's just too bad that he didn't get the full year of support because the program is not continued into the school system. I feel that the EIBI and school board should mesh their programs together. We have witnessed incredible success from the EIBI program. It is a shame that all ASD kids do not have access to it."
- "The EIBI program needs to be accessible to all parents in Nova Scotia. The program is currently a lottery system in which our family was lucky enough to be drawn. Unfortunately I know of another family who has pre-school children that has not been as lucky. Programs to help Autism need to be available to ALL Nova Scotia families and the draw system needs to be gotten rid of. This creates additional stress on a family not knowing whether they will be getting treatment for a newly diagnosed child. It is not fair that some families can get treatment and others do not. Accessible treatment for all autistic children is needed."
- "The difference that the EIBI program has made, not just in the gains children with ASD have made, but also empowering families to become advocates—I feel that the program should be gradually expanded across the lifespan. While budget restraints are always an issue, I strongly believe that services such as EIBI save dollars in the long run, by giving the children a good start through early intervention. We are at the point now where the gains made in the early years (0-6) through programs and support need to be maintained through the school years (6-12)."

- "It would be GREATLY beneficial for as many families as possible to receive services from the provincial Early Intensive Behaviour Intervention program. Unfortunately, with the funding available, only a limited number of families can receive services through the provincial program, given the intensity and length of the program for each child enrolled. Parents need to be trained in behavioural intervention in order to carry on treatment with their children for future years. Many parents are not able to help their children with autism because they do not know how to. It has to be a helpless feeling."
- "Knowing that EIBI is the only proven measure that could help these children become contributing members of society, versus being dependent on society for the rest of their adults lives, it makes no sense that the government is not investing in Early Behavioural Intervention. I omitted the word intensive, as 15 hours per week for 6 months is far from intensive . This should be increased to 30–40 hours per week, the amount recognized in the United States as being most beneficial. It's frustrating to no end, sitting and waiting. ALL kids with ASD should have access to this critical service."

Professional training

- "We've come along way, but the public school system is drastically lacking in support for students with autism as well as all children with disabilities. Educational Assistants not supported as team members, and very rarely supervised, and if supervision is done the people supervising are okay with strategies that went out decades ago, as the supervisors don't know any better either, if indeed there is any."
- "… Our second greatest concern is not listed above: Inadequate training of school staff (teachers, TAs, resource teachers) and the poor access to speech therapy (as opposed to consultation) and occupational therapy."
- "… I am concerned by the lack of support, treatment and assistance available to educators who want to effectively, efficiently and competently provide a viable education for children on all levels of the spectrum."
- "As an educator, I find the greatest challenge is to respond appropriately to the complicated academic, social, emotional, behavioural, and sensory needs of some of my students, without having more immediate and frequent contact with other professionals—especially Occupational Therapists and Psychologists knowledgeable of ASD."

- "I am a Senior Member of a Nova Scotia Police Department. Police often respond to persons who are dealing with disabilities (physical/mental). The Autism spectrum is quite broad and the severity of the disability also varies. From a policing perspective, there are two areas that I feel are important. First, is appropriate level of support from the government, by providing the services required, i.e., Early Intervention, Parent Support, educational programs, engagement with the community. The second area is awareness of autism by persons who will have contact with persons with autism, in this case police officers. Information/training provided to the front line officers would help them when interacting with persons with autism."
- "I teach an autistic child and would like to see more personal development available on how to deal with violent out of control students."
- "Our biggest need this year was a qualified and effective person working in our elementary school every day in the learning center. There was great expertise in the specialists that would visit the school (autism specialist and behvaviourist) but the home room teacher and learning center teacher were so inadequate our son eventually had to leave school and be taught at home."

Social programs

- "We would very much like to see our son involved in some type of intervention program for behaviour and frendship-relationships. Presently we are not receiving enough supports for him or for all of us as a family."
- "… Finally, we need summer camps that run all summer. These children thrive on routine. The fuller and more routine their days are, the better. Most of these children have their lives disrupted for two months or more through the summer, and lose some of the skills they had been working on during the school year. It is rare for a family to be able to provide the same direction and intensity that is provided at school. Too often these children don't know what to do with all the free time suddenly thrust upon them, and then the negative behaviours start, which begins the stress cycle for those living/working with them. A structured day camp throughout the summer months would go a long way to making life more enjoyable for all."
- "I want a dog to be my friend. I am quite lonely. I would go outside and feel safe with a dog. I would like to do soccer after school with the other kids. I am really good at kicking. I would really like to be able to

see some of my school friends not at school."

- "Autistic children need to become integrated into larger society at every aspect. Recently, some daycares are refusing to accept autistic children with high needs. This is having a very negative impact on autistic children because they need to interact with non-autistic children in order to learn socially acceptable behavior. I hope that the Autism Society will bring this issue to the attention of policy makers."
- "Teaching and having places where they can go to learn social skills to me is the most important skill for children to learn. I am an EA in a High School and it is heart breaking to watch my student suffer not having friends and he has no place to hang out and learn social skills, here at school or after school. He just goes home and looks at a computer."

Services for adults with autism/ASD

- "Transitioning students to the community is always a concern. The number and variety of employment opportunities and/or day programs are limited. As students approach the age they are ready to leave school the parents, staff, and students are often left asking, what next?"
- "There are no mental health services available to young adults over 19. If we've been fortunate enough to have been monitored by the IWK throughout school, we are cut off, cut loose, with no resource available for dealing with anxiety, depression, etc. We feel completely isolated in this regard."
- "Since our son is graduating from high school this year our biggest concern is the lack of employment opportunities/placement services. Since we are in our 50s we are concerned about the long term - who will look after our son, etc."
- "Once a person leaves school with ASD, we as parents need to be secure in knowing these people will be able to access the help they need to become productive members of society."
- "Mental and physical health services in the province of Nova Scotia evince an astounding epistemological gap in the area of developmental disorders (AS, HFA, AD/HD, etc). There are no diagnostic or treatment services available for adults. I am appalled by the ignorance demonstrated by those psychologists, psychiatrists, and physicians I have encountered. Tertiary-level resource facilitators are similarly undereducated and ill-equipped to offer assistance. The government provides limited resources, particularly for adults. We are invisible. Our struggles

are dismissed as the result of serious emotional issues or laziness; we are stigmatized and blamed for our difficulties even by (often especially by) health and educational professionals. When we express our frustration we are accused of exaggerating—again, even by health and educational professionals. Many of us are unusually gifted and have remarkable things to offer; society undermines itself by eliding us. Yes, it is important to diagnose and treat children early, but there are NO services for adults, we are struggling, and no one will help us. Frankly, I am utterly disgusted by this egregious state of affairs. It is inexcusable."

- "I would like to have a program in which autistic people can learn training skills and be able to be employed by people who understand the condition. I am trying to look for a job and I am getting nowhere. I also would like more services for dealing with the negative aspects of autism such as sensory issues and lack of social skills."
- "I am an adult who was diagnosed with Asperger's only 5 years ago and I wish I had more access to supports for adults with autism. I have found a lack of info for adults who have to cope. Autism is lifelong and not confined to childhood. While it is very important for early intervention, the concentration on children seems to have lead to a lack of adult services, which is a continuous worry, for both those with the condition and the loved ones. Thank you."
- "Have found that there is a great gap between the age of nineteen and twenty one. There is no support available at all. This is a most critical time as the child moves toward becoming a full fledged adult. Spoken to other parents who feel that for any special need child there is the same problem. Government seems to think these individuals drop off the face of the earth. These individuals need supports through all stages of life."
- "As we begin to plan for our son's life beyond high school, we are appalled at the long waiting lists for small options homes, and the fact that there is a moratorium and no new facilities are being built. We are determined that he should experience a life beyond our home but it seems community services would prefer he stay at home with us. This clearly seems the option that is easier for them as opposed to best for him. The situation will only worsen as the autism population increases in number. Across the board, not just in issues of housing, there is not enough attention given to the needs of ADULTS with autism."

- "As a high school learning center teacher, we are always struggling for options e.g., vocational, residential, activity-based, social and friendship recreational programs, crisis intervention for our students after graduation. There needs to be more options for work and living as well as community agencies to take on programming for our students after high school graduation."

Financial costs

- "Financial costs associated with private schools, private health care, private services (that are not being offered anywhere else), respite care. Costs associated with summer camps and social programs. Lack of government funding for programs and services."
- "I personally would like to see some financial help to assist in the upbringing of our special needs children. The disability benefit is nowhere near enough to cover dietary concerns or even transportation to and from appointments. There should not be clawbacks on respite care or the disability benefit due to increased income, or at the very least, clawbacks should begin at double the current rate. It is also very difficult for 2 spouses to work while taking care of a child with ASD. This fact places many families including my own, in financial dire straits, so not only do we have to worry about care for my children, but we have the added burden of not being able to make enough money to live properly, when I have to buy milk with rolls of pennies, something is wrong. I am also very angry at the fact that every single year the education department cuts the number of EAs and you have to fight every single year for the same amount that you had the previous year, it's disgusting and belittling. Some semblance of financial help is sorely needed."
- "… Then when they turn 18, there is NO child tax credit to help (unclear). How are we suppose to take care of our children and provide for them adequately with so little assistance."
- "I think our government could help us with that in the form of additional funds on our child disability tax credit or on our income tax."
- "Private speech and psychological services are extremely expensive."
- "We have requested respite care but are told we make too much money. This should be assessed on an individual basis and not on a monetary basis."

Support for families

- "We are fortunate, our marriage has survived for over 25 years but many people we know have marital breakdowns which I believe can be directly attributed to the feelings of isolation and confusion about the behaviour of children with undiagnosed autism ..."
- "... Mental health support is significantly missing in the area of managing anxiety, depression and behavioural concerns in the family home. I hope there doesn't need to be a tragedy before we step up to the plate and see the real need that exists in this area."
- "Parents of children with autism are overloaded with challenges. Finding appropriate services can be difficult and time consuming. With a system in place to navigate and create services, Nova Scotia could become a leader in the Autism field."
- "I worry about the increased strain, stressors, and lack of support for families (parents and siblings) living with a child with autism ..."
- "Early intervention is key, but so is training for parents ..."
- "As a professional working with children in care I see the struggles of families with children with Autism and marvel that they are coping as well as they are when there is so little support for them and their children. We have a need in this province to have more respite and community based housing to help these children meet their full potential in an environment that understands and supports children with Autism who have higher needs and who are not able to have that at home. The realization that there are more children with Autism today than ever before and with the increase of diagnosis as seen in the last two years it is even more imperative that we advocate for these children needing care and their families who need support."

Services in rural areas

- "Often times autistic students receive intervention before they enter school but services become drastically reduced once they enter school - depending on where you live. There is definitely not equity across the province when it comes to services!!"
- "... In times of crisis we were not able to get service because we were not in the city."

- "We live in Sackville and the summer camp is in Halifax, this is not feasible to travel to the city every morning and back in to pick them up. As well the cost of the camp."
- "A concerted effort needs to come to support regional offering of programs by PAC and IWK in coordination with local autism centres in each region (South Shore, Valley, Tri-county, Cape Breton, Eastern Shore and Northern, etc.) Geographic isolation is a huge social and financial barrier to access programs outside of HRM."
- "… If you have autism and want adequate services, you had better live in Metro—rural NS is woefully under-serviced!"
- "Nova Scotia needs to have better treatment plans like most of the other Canadian provinces. Why doesn't Nova Scotia have the same access to treatment plans like the other provinces?"
- "Supports are few and far between in some rural areas. What services are available are stretched to the limits."

Programs for high-functioning individuals with autism/ASD

- "Our son has AS and is very high functioning. This puts us low on the lists for many things we might like. It is just too exhausting and it takes too long to get through the system. We feel caught in a grey zone. He is too high functioning to get access to special services, and he actually does better with typically developing children. So the autism camp, for example, is not suitable for him. But he still has a lot of difficulties and needs, and it mostly falls on us to deal with these. The school does not have the resources to meet his needs."
- "… I have struggled with the schools time and time again, as he is high functioning and looks normal so therefore, teachers don't believe that he is autistic and do not understand he has a harder time relating to non-fiction and English."
- "My son is one of the children who fell through the cracks for inhome support because his IQ is over the recommended guidelines after four years of working with him although he does meet the recommended criterion for self care, etc."

Alternative treatment(s)

- "Need input and interventions from Naturopathic doctors, massage therapists and possibly chiropractors!! This should be in conjunction and interventions like EIBI offers children with ASD …"
- "I feel that these are the things that are needed:- Bloodwork at the time of diagnosis (see Defeat Autism Now (DAN) literature).- A DAN doctor even a visiting doctor from another province if one will not relocate …."

Medical care

- "… In fact my child was once taken to IWK by Ambulance (3 p.m.) and we were told there is no bed for children with Autism at the IWK. Go home and someone will call you tonight."
- "education for family doctors to send referrals on and appropriate training"
- "… We have been turned away from ER services because our son could not tolerate waiting in a crowded ER waiting area and there was no quiet area to wait. Does it seem right to anyone that there is one dentist who works with adults with autism and he does so by putting them under to do dental work? …"

Note: Some individuals signed their comments. Signed comments are included below.

- "Dear A.M.A.T., Thank-you for undertaking this valuable work. I hope you are able to gather the information necessary to help move us forward in the important field of autism treatment and advocacy. Found the first three pages of the survey helpful but must admit that I would think you will get a lot of checkmarks that are difficult to sort through because all or most of the programs listed will have a certain level of appeal for most families with a connection to autism. Seems page four of the survey will provide the most valuable information. The choices I have made on page 4 I would like to expand upon. Early detection—For the obvious reason of which we are all aware, increased possibility of recovery. Activity based (e.g. physical activity, art, music)—Physical activity should be a priority for these children. Our experience has been that it helps the child's systems regulate and balance and can ultimately have a calming effect. We have also found music and art to have great appeal for these children allowing them outlets for expression in unconventional ways. Parent Training—This

is the most important priority that I have listed. The parent's understanding of their child with autism is the number one factor in that child's ability to recover, to be motivated and to be happy. One should not undervalue the role of the parent. Therapists cannot provide the level of unconditional love and understanding that will be key to these children's success. The top program in training parents about autism that we have found is the Son-Rise Program out of Sheffield Massachusetts, USA. Although it is still considered an alternative therapy the lessons that it has for parents of autistic children has universal appeal. It ascribes to one on one therapy for the children led by parents and volunteers. Even if parents do not have the energy to adopt this program, the lessons that it teaches will serve anyone well. Parents cannot leave the start-up phase of this program without better tools to love, understand and work with their children. Because the program is alternative it is not well known. We may be one of only a few families in the Maritimes who have ever done it. However, we are so convinced of its value that we wish to be the advocates/ambassadors of Son-Rise for all of Nova Scotia. In fact we would like to be consulted within the context of this study to provide more information. The best place for anyone to find out more about this program is www.son-rise.org, you will be intrigued and perhaps amazed. We did not get a formal diagnosis of autism for our son until he was five years old (system back-up, and lack of knowledge of the symptoms). Shortly thereafter we found our way to the Autism Treatment Centre of America where we learned about this amazing program. Ourselves and over two dozen volunteers spent three and a half years and over 5,000 hours of one on one time with our son prior to registering him in regular school where his teachers and EAs report that he is learning language arts at a rate faster than they have yet seen (for children on the spectrum). In addition, he has not shown the same level of stress going to school as many kids on the spectrum. In a nutshell, his gains have been significant. Just as importantly, the Son-Rise program taught both my wife and I to value and grow on the journey with autism rather than to fight it. The program is responsible for keeping our marriage and family together through all of the challenging times. Its potential value in keeping other families together should not be overlooked. Over the years we have certainly come to learn that the Son-Rise program

may not be a good fit for many parents. The degree of discipline and dedication involved is significant and beyond where many parents want to go. However, for those so inclined this needs to be an option. Therefore, we are suggesting that any training funding set aside in a provincial program include the ability of a parent to request training or courses through the Autism Treatment Center of America. For those families that selected the Son-Rise option the cost to the government could be many times less then providing IBI therapy because much of the program is done with volunteers. The main costs of providing this option would be to provide funding or subsidies for those parents who displayed a genuine interest in pursuing the Son-Rise training at the Autism Treatment Center of America."

- "A priority would be a coordinated service delivery model that supports a range of services based on individual needs of both family and child/individual with ASD throughout the lifespan; many of the items above are priorities so it is difficult to identify just three as many are linked. Increased earlier identification is linked to diagnostics which impacts service needs; a goal would be to have timely and accessible services that can offer useful options for families. Thank you for this opportunity.
- "We live in Yarmouth-I would like to ensure our voice is heard. Is there representation on the Advisory Team from Yarmouth area?"
- "We would very much like to see our son involved in some type of intervention program for behaviour and frendship-relationships. Presently we are not receiving enough supports for him or for all of us as a family."
- "One of our priorities is appropriate educational programs that meet the needs of our young lady. Each one has to be individual and set our children up with a positive life outcome."

- "My son is 24 years old and lives at Emerald Hall/N.S. Hospital. He was in pretty rough shape when he fist arrived five years ago. Overall I am pleased with the progress that he had made. However, he is an adult now and I don't know of any services that would be beneficial to him (if they exist) apart from the unit where he lives. I am happy to see that children with autism these days have so much offered to them and their families. The services 20 years ago pale in comparison. That being said, I understand the importance of services for children, however childhood is short and what I would like to hear more about is what services would be available for autistic adults. Are there bridging programs that follow these kids into adulthood? Also, over the years I have noticed that standards followed by Community Services are much lower than the Dept of Health when it comes to training staff in small option homes and the like. I think that there needs to be a lot of improvements where these two depts are concerned. There is a lot more I could say but time is short. Thanks for offering this survey."
- "More Support required from NS Health Care System. Support is dropped after children finish their first year of school (Primary). Much time, effort and advances have taken place over the last two years and it is a shame it will be left up to the school system to provide support. Is there other supports for children after their primary year?
- "Hello, Our family has two beautiful boys with ASD ages 4 and 8 years old. Our 4 year old has not been lucky enough to 'win' the EIBI lottery. Why does medically required therapy have to be a lottery? This is immoral and the provincial government should be ashamed of themselves for allowing so many children in our province to go without this medically required intervention. Also, our family does not receive respite. We make over $40,000 per year and are a middle income family, yet we do not 'qualify' for respite. As you can imagine our family unit is under severe stress with the day to day challenges of raising two boys with autism, yet Community Services deems us unqualified for respite for our family. Both my husband and I had to get personal and marriage counselling to get through the reality and grief associated with having children with autism. I would be happy to ask any MLA or member of our Community Services department to spend just one day with our family and see if we are 'deserving' enough for respite funding. All we want is a few hours break a week.

In addition, we live in the Town of Truro. My son has literally nothing to do this summer for recreational activities. There is NOTHING for special needs children from a recreational point of view. Why do our special needs children have no recreational activities or provincially organized camps? They deserve to have a fun summer as much as any other child. We humbly ask that you review our family's comments carefully. We feel like nobody has taken any time to listen to our family and our childrens needs for the past 5 years."

Appendix III

Proposal for Regional Autism Centres

Submitted by
Norman J. Donovan
AMAT VAST Representative

Throughout this report the needs of the autism community have been clearly identified. The challenge to meet these needs is complex and at first glance appears to be overwhelming. With prevalence rates on the rise and increased demand on already limited services, it is obvious that autism is widespread throughout the province. The AMAT Lifespan Survey revealed that there is increased demand for basic services throughout the province, and the need for "total care centres" is clearly identified (see Appendix II for the AMAT Survey Results and Comments).

The Nova Scotia Council for Early Childhood Development also supports a "Centre Based" system as a means of "reducing isolation of parents by fostering community-based strategies that connect isolated parents with opportunities to participate in events, receive information on ASD, and become active within their region."

Based on extensive research, data collected in the AMAT Lifespan Survey and extensive literature reviews of other service models across North America, a recommendation supporting the creation of regional autism centres is proposed in the document below. This proposal to create regional autism centres is based on the state of Vermont's report, dated August 4, 2006. Vermont is faced with similar rural population challenges as Nova Scotia, making this model transferable to Nova Scotian communities.

Vision

The departments of Education, Health, and Community Services, working together, with advice from representatives from the autism community of Nova Scotia, will establish regional autism centres. These centres will create a comprehensive and "total system of care" for families and individuals affected by autism spectrum disorders (ASD) in both urban and rural areas of the province.

Mission

Regional autism centres (RAC) offer a range of professional services for families, caregivers and individuals with ASD from the time of identification and diagnosis until death. The centre's primary purpose is to offer a holistic approach to care that includes service providers from the departments of Education, Health, and Community Services, and community-based organizations. Each centre offers standardized information, evidence-based treatment approaches and consistent intervention support to families and persons with ASD, while building on existing programs and services already rooted in the community. The centres value family diversity and recognize the individualized needs of each person seeking care.

Expected outcomes

- Create an inclusive care model that will make sure high-quality, evidence-based services are accessible for families and individuals with ASD, regardless of demographics (urban versus rural).
- Offer access to needed care throughout the lifespan for families and individuals with ASD. This will have a positive effect on the quality of life of all family members, by increasing wellness and the long-term health of the family.
- Deliver a comprehensive "plan of care," with trained professionals that are consistent and sustainable throughout the province.

Establishment of regional centres

Intergovernmental collaboration is needed in forming the regional autism centres. The AMAT Committee recommends the Department of Health take the lead in developing and carrying out this initiative, as mental and physical health needs are a primary focus in the treatment of ASD across the lifespan.

In addition, it is recognized that

- Centres in rural areas of the province will have "satellite sites" if needed.
- Centres will build upon and work collaboratively with programs and services that are already established in Nova Scotia.
- Centres will promote intergovernmental collaboration to address the needs of families and individuals with ASD across the lifespan.

- Centres will be physical locations, anchored in various parts of the province. In the Vermont Report, it is suggested that a family not have to drive more than one hour from home to access a centre or satellite office.

  Centres could be located
  - within the HRM
  - within CBRM
  - in Middleton
  - in Yarmouth
  - in New Glasgow
  - in Port Hastings

  Satellites could be located
  - in Springhill
  - in Liverpool
  - in Digby
  - in Margaree Folks
- Each site will have a navigator dedicated to supporting each family and/or individual with ASD.
- Centres will carry out a process to make sure of standardized services, best practice approaches, and consistent quality of care across the province.
- Centres will employee a multi-disciplinary team that will provide support, care, and treatment for families and individuals with ASD.
- Centres will collaborate with community-based organizations, outside professionals, educators, and the community to bring together resources and expertise that will provide a full continuum of care.
- Centres will have an advisory committee consisting of key representatives from the local community, such as family members, schools, and service providers.

Services

Centres will collaborate with government departments, professionals, researchers, service providers, and the community to build capacity to address the needs of individuals with ASD and their families throughout Nova Scotia.

Direct services will include

- Identification and diagnosis
- Family and professional support

Centres will offer

- clinical support and education for families and caregivers
- one-on-one support
- training for professionals working with persons with ASD
- support for anyone looking to navigate the system of ASD services across the province
- after school hours support for families

Centres will maintain

- a current list of available autism resources for Nova Scotia
- relevant information on housing, employment, recreation and social programming, summer camps, respite workers, and daycare providers in surrounding communities.
- current ASD information

Training

Centres and satellites will offer

- education and training for professionals working with individuals with ASD
- professional development workshops and conferences to school boards, daycares, preschools, and community-based organizations; attendance would also be open to families, professionals, caregivers, and related service providers (OT, PT, SLP, and behaviour analysts and interventionists)
- parent information sessions, training programs, and workshops for caregivers

Services to Adults with ASD

Centres and satellites will offer access to

- health and mental health care
- residential options (group homes, apartment assistance)
- supported employment
- post-secondary/day programs
- respite, including emergency respite bed(s)
- coordinated service plans
- life skills training
- financial planning, review, and counselling for such items as
    - disability savings plan
    - education savings plan
    - estate planning
    - tax filing and deductions

Appendix IV

Access to the Nova Scotia Early Intensive Behavioural Intervention Program

The Nova Scotia EIBI (early intensive behavioural intervention) program is a treatment program for young children with autistic spectrum disorder (ASD). The program was established in stages, between the summer of 2005 and the fall of 2006, in eight district health authorities and the IWK Health Centre. All young children with a formal diagnosis of ASD are eligible for the program before school entry. The problem is that not all children with ASD have been able to access the program because of limited treatment resources. Evidence from an independent evaluation has revealed positive treatment effects that rival those of much more intensive and costly treatment programs. However, a reduction in our treatment intensity is likely to compromise treatment benefits, thus precluding this as a viable solution to the access problem.

The issue of limited access to EIBI has raised the question of how we can most fairly allocate existing treatment services. The common approach is to use a waiting list. However, in an attempt to be as fair as possible, and after consulting with a bioethicist, we have chosen to select children randomly for treatment. The advantage of random selection is that every child has an equal chance or opportunity to be selected. In contrast, waiting lists have been shown consistently to be biased against particular groups, particularly those who are disadvantaged from the outset (e.g., by limited access to diagnostic services). An additional advantage of random selection is that the problem of limited access to treatment is transparent. In contrast, waiting lists can mask the real problem, that is, they can give the impression that treatment will be available, when this is not necessarily the case (e.g., the child may reach school age before treatment is available).

We recognize that there is no ideal solution to most if not all ethical dilemmas. Having considered the advantages and disadvantages of alternative solutions, we have chosen random selection, on the grounds that this gives all children an equal opportunity to access the EIBI program. We have also chosen to be transparent. The need for evidence-based treatment for all young children with ASD is recognized widely. The government recently stated in the legislature that over the current year they will be reviewing their ability to enhance health programs, including the EIBI program.

Susan E. Bryson, PhD, RPsych
Craig Chair in Autism Research, departments of Pediatrics and Psychology, Dalhousie University, and Provincial Clinical Leader for the Nova Scotia EIBI Program

Appendix V

Identified Gaps in Supports and Services

Respite	• home respite program • group homes for autistic residents only • before school, lunchtime, after-school care (particularly for students beyond age 12) • competence of respite caregivers • lack of respite options for families • direct family support funding with a cap of $2,200/month; families who would like to have family member at home cannot because the maximum amount is not enough to meet the respite needs • community clinical support teams • expanded residential options to meet waiting list pressures • summer programming • recreation programming • adequate daycare options • appropriate housing options • day programs for adults
Health	**Professionals** • autism training for all health professionals • home support by social workers • more GPs, pediatricians, psychologists, psychiatrists, SLPs, OTs • GPs who understand and are trained in developmental delays and needs • psychologists for adults • adult diagnosis **Issues** • waiting lists for assessment/diagnosis; inadequate psychology services • late diagnosis and ability to efficiently address • health treatment and crisis intervention non-specific
Education	**Individuals** • post-secondary counselling for entry into NSCC or universities • programming across spectrum—student–focused • social skills programming and funding • transition planning to leave school for community • transition support for parents during transition process • continued programs for those still in skill development • inadequate resources (materials) to support students with ASD in school **Professionals** • more training for all staff • more awareness and training for NSCC and universities • no training for education students on autism and best practices • better training to help professionals find best school placements • standards for teaching assistants and learning centres to make sure of best placements for child and staff

Family Supports	• family education • family supports • support for families by specialist in autism and behaviour • community clinical support teams to provide support to individuals, particularly with complex/escalating behaviours
Employability	• work placement programs for teens leaving school • employment counselling, training, opportunities • vocational training
Intensive Intervention	• lack of qualified trained staff (EIBI or other) • intervention to begin within first month of diagnosis • lack of funds to properly provide intensive intervention to all children diagnosed in Nova Scotia • proper training for professionals (doctors, preschool staff) to recognize possible characteristics
Legal	• youth at risk—legal services and support • educating judicial system and policing
Miscellaneous	• financial counselling • road signs for autistic persons • lack of knowledge in Community Services staff • lack of awareness in public • lack of awareness/training in police services, first responders, fire services • parental and marital counselling • social support for families (parents/siblings) • appropriate recreation-based programming for ASD children and how to find programs that currently exist • appropriate housing • age for receiving disability supports • lack of parental awareness of available services (e.g., Revenue Canada tax credits, parking passes) • youth at risk—legal services and support • community-based recreation programming for ASD youth

Appendix VI

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Transition From School to Adulthood for Youth With Autism Spectrum Disorders

Review and Recommendations

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The transition from school services to adulthood can be particularly difficult for many adolescents with autism spectrum disorders (ASD). Although some individuals with ASD are able to successfully transition, most are faced with significant obstacles in multiple areas as they attempt to negotiate their way into college, work, community participation, and independent living. This article contains a review of research related to the transition from school to adulthood for youth with ASD in the areas of education, employment, community living, and community integration. These key areas of the transition process are crucial for success in adulthood. A summary of principal conclusions drawn from the current literature and suggestions for future research are provided.

Keywords: *postschool transition; autism spectrum disorders; community integration*

Leaving high school can be an exciting time for many individuals as they transition to new challenges such as work, community college, university, trade school, or the armed services. However, the transition from school services to adulthood can be a particularly difficult time for many adolescents with significant disabilities (deFur & Patton, 1999; Schall & Wehman, 2008; Sitlington & Clark, 2006). For young people with autism spectrum disorders (ASD), this is especially true inasmuch as the postsecondary and employment opportunities for those students have traditionally been very limited (O'Brien & Daggett, 2006; Schall, Cortijo-Doval, Targett, & Wehman, 2006). Transition typically includes completing school, gaining employment, participating in postsecondary education, contributing to a household, participating in the community, and experiencing satisfactory personal and social relationships (Wehman, 2006). Although transition planning and postschool outcomes have received growing attention for many students with disabilities in the educational research (e.g., Sitlington & Clark, 2006), the expanded interest in services for youth with ASD results in a critical need to assess what is known currently about their transition to adulthood.

ASD refers to a continuum of disorders that range from severe to mild (American Psychiatric Association, 1994; Neisworth & Wolfe, 2005). Fombonne (2003) estimated that in the United States between 55,602 and 121,324 adolescents between the ages of 15 and 19 have an ASD. It is believed to be a permanent developmental disorder that will continue into adulthood, creating lifelong challenges for the individual (Gilchrist et al., 2001; Volkmar, Stier, & Cohen, 1985). As Seltzer, Shattuck, Abbeduto, and Greenberg (2004) indicated in their review, despite reports highlighting improvements in core behavioral characteristics in adolescence and adulthood, functioning seldom leads to normal ability and significant deficits continue for most.

With appropriate training and education, individuals with ASD can integrate meaningfully into the community (Schall et al., 2006) and work competitively (Gerhardt & Holmes, 2005; Hurlbutt & Chalmers, 2002, 2004). It becomes essential that professionals carefully plan for the transition to adulthood to ensure success. Given the heterogeneity found in the disorder, adolescents and young adults will require a wide range of services and supports that are individualized and need driven.

A review of research related to the transition from school to adulthood for youth with ASD is provided to give insights into the transition process and help identify

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needed service delivery and intervention. Transition is defined as to include education, employment, community living, and community integration. These areas are crucial for success in adulthood for young people with disabilities, including those with ASD.

Method

Publications pertaining to transition from school to adulthood were obtained by conducting electronic and ancestral searches for the years 1996 to 2008, inclusive. An electronic database search of ERIC and PsycINFO was conducted using the following terms: *autism, autistic, pervasive developmental disorder, Asperger syndrome* (AS), *youth, adolescent, adolescence, high school, transition, post secondary, outcome, school, home, living, work, employment*, and *community*. Hand searches were conducted on journals that publish research on autism (i.e., *Autism*, *Focus on Autism and Other Developmental Disabilities*, *Journal of Autism and Developmental Disorders*, *Education and Training in Developmental Disabilities*, and *Journal for the Association of Behavior Analysis*). Because of the continuity across autistic disorders, this review addresses both the narrowly defined disorder of autism and the broader range of ASD, including pervasive developmental disorder–not otherwise specified and AS.

Articles selected for review met several inclusion criteria. First, they had to have been published in a peer-reviewed journal. Second, at least 50% of the participants in the study had to be identified as having an ASD. Third, at least 50% of the participants had to be 13 years of age or older. For studies evaluating specific intervention strategies, an additional criterion was utilized. The researchers had to employ a design that showed a functional relation between the independent variable and dependent variable.

Results

Preparing for Transition in School

The goals of education for individuals with ASD are the same as the goals for any other student, that is, to provide opportunities to acquire skills that increase personal independence and social responsibility (Kavale & Forness, 1999). For those with ASD this means acquisition of skills in academics, socialization, language and communication, self-management, self-determination, home living, employment, and community. Students must demonstrate competence in such skills by fluidly applying knowledge in a variety of life environments. Student achievement, transition planning, and educational services influence postschool outcomes.

Student achievement. Little research has focused on academic achievement of students with ASD. According to the U.S. Department of Education (USDOE, 2008), rates for graduating with a diploma are low. In the year 2005–2006, 38% of students with ASD graduated with a standard diploma or higher, 18% received a certificate, 6% reached maximum age, and another 6% dropped out of school altogether. Adolescents with autism do not fare nearly as well in academic achievement as their typically developing peers (Thoma & Sale, 2005; Wagner, Marder et al., 2003). Although those educated in the general education classroom are reported by teachers as having high grades and keeping up with academics, on average they are more than 4 years behind grade level in reading and nearly 5 years behind in mathematics (Myles & Simpson, 1998). Wagner, Newman, Cameto, and Levine (2006) evaluated academic achievement and functional performance for students with disabilities ages 16 to 18. Subtests of the *Woodcock-Johnson III* (Woodcock, McGrew, & Mather, 2001) were used to assess competency in language arts, mathematics, science, and social studies. Average assessment scores for adolescents with autism were three standard deviations below the mean of their peers in the general population. Scores were consistently lower in the four assessed areas for students with autism than all other disability categories with the exception of deaf-blindness, multiple disabilities, and intellectual disabilities. The *Scales of Independent Behavior–Revised* (Bruininks, Woodcock, Weatherman, & Hill, 1996) was given to students for whom assessment of academic skills was inappropriate. Only 16% scored equal to or above the mean and 65% scored more than six standard deviations below the mean of their peers. This indicated most had difficulty performing age-appropriate functional skills.

Transition planning. As adolescents with ASD prepare for life after school, transition planning is needed to dictate goals, courses of study, services, and supports. Effective plans require active involvement and participation from a multidisciplinary team (National Council on Disability, 2000). In a study commissioned by the Office for Special Education Programs of the USDOE, Cameto, Levine, and Wagner (2004) examined transition planning for students with disabilities. The findings suggested that nearly 85% of secondary students with autism had a transition plan and 71% had received instruction on skills needed for effective planning. Team member participation varied considerably. Predictably, special education teachers were the most common team member, with 96%

of meetings attended by a special educator. On a positive note, parents and guardians were next, with more than 90% of meetings attended by at least one caretaker. Active participation by other team members was significantly lower. In all, 58% of meetings were attended by related service personnel, 40% by a general education teacher, and 30% by any external support agency.

Effective transition planning provides the opportunity for adolescents to learn about themselves and plan for their futures. This requires student involvement as an active, respected participant and preferably as a team leader (Wehman, 2006). Cameto et al. (2004) found that fewer than one third of students with autism actively participated in transition planning meetings, whereas only 3% led the discussion. A variety of supports have been demonstrated to increase involvement. Fullerton and Coyne (1999) successfully used visual, social, and organizational supports to facilitate young adults' participation. Held, Thoma, and Thomas (2004) described one 17-year-old with autism who conducted his own transition meeting with the use of assistive technology.

Transition goals. Postsecondary goals dictate what students need to learn to function as an adult (Wehmeyer, 2002). Goals for students with ASD must be developed specifically for the individual and should be functional in nature, with a focus on skills needed in current and future environments (Iovannone, Dunlap, Huber, & Kincaid, 2003). It is recommended that goals for adolescents with ASD address communication and social skills in community, vocational, home, and leisure content (Schall et al., 2006) and academics related to transition goals (Downing, 2005; Nuehring & Sitlington, 2003). There is a limited amount of research evaluating goals contained within transition plans. The study by Cameto et al. (2004) evaluated the presence of goals related to postsecondary education, employment, living, and social development. For adolescents with autism, most plans contained employment-related goals. In all, 22% outlined goals for competitive employment, 39% supported employment, and another 39% sheltered employment. Goals related to living skills were also common, with 58% of such goals designed to maximize functional independence and 28% to live independently. Of transition plans, 23% included goals related to attending a 2- or 4- year college. Just more than half (57%) contained goals associated with social development needed to increase friendships and social interactions (Howlin, Goode, Hutton, & Rutter, 2004; Orsmond, Krauss, & Seltzer, 2004).

Services and supports. Many individuals with ASD need to access a variety of services and supports to make progress toward transition goals (Wolfe, 2005). According to Levine, Marder, and Wagner (2004), students receive related services to address a wide range of educational issues. Speech-language therapy needed to ameliorate language and social deficits is the most commonly reported, with 75% receiving such services. Occupational therapy designed to improve activities of daily living and provide strategies for managing sensory abnormalities (Smith, 1994) is received by less than half. Assistive technology that can be used to support and enhance functional capabilities and improve communication (Individuals with Disabilities Education Act [IDEA], 2004) was received by 16% of students. Extended school year services devised to provide continuous support were received by approximately 43%. Parents expressed dissatisfaction with the related services their son or daughter received as well as the effort required to obtain those services (Levine et al., 2004). Parents reported lack of information, lack of availability, transportation difficulties, scheduling conflicts, and services of poor quality as barriers to their child receiving appropriate services.

As students leave the safety of the educational system, postschool services may be needed to facilitate personal and professional development (Smith, 1994). According to Cameto et al. (2004), approximately 88% of adolescents with autism had postschool services identified as part of their transition plan. Just more than half of plans identified the need for vocational services and a third for supported living services. Because ASD is a lifelong disability (Seltzer et al., 2004), services may include those designed to ameliorate the core characteristics of the disorder. For example, 19% of plans documented a need for behavioral intervention and 23% speech or communication therapy. Adolescents with ASD are reported to become more depressed and suffer from increased anxiety (Bellini, 2004; Ghaziuddin, Ghaziuddin, & Greden, 2002; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Tantam, 1991). Mental health services needed for psychiatric comorbidity (Tsatsanis, Foley, & Donehower, 2004) were low, with 14% identifying this need. It is not enough to document the need for support services, but timely contacts to service agencies must be made to align programming between school and adult providers. Of students, 25% had job placement agencies contacted on their behalf, 36% supported employment agencies, 30% sheltered employment agencies, and 21% adult day programs. Of students, 21% had supported living agencies contacted and 5% congregate care facilities.

Implementation of transition plans. Cameto et al. (2004) reported that 66% of teachers surveyed had implemented an educational program to meet established transition goals. Transition plans lead to success only if the educational program is appropriately designed to help students achieve such goals. Transition plans dictate what students need to

learn. However, there are two other important considerations: where and how these skills will be taught so they will have meaning and be naturally occurring over time. Wagner, Newman, Cameto, Levine, and Marder (2003) surveyed teachers to determine secondary school experiences of students with disabilities. Results suggested that, on average, one third of the courses students take during high school are composed of general education courses and 62% special education courses. Regardless of the severity of the student's disability, learning can be enhanced by providing instruction in natural community-based environments (Wehman & Kregel, 2004). Wagner, Newman, et al. (2003) noted that instruction outside of the classroom occurs more frequently as part of special education classes. In general education classrooms, 23% of students "often" participated in school-based activities outside of the classroom and 4% "often" participated in community-based experiences. In special education classrooms 47% "often" participated in school-based activities and 40% "often" received community-based instruction.

Transition instruction requires educators to be knowledgeable of a variety of teaching techniques and strategies, each individually applied to meet the strengths of the adolescent (Iovannone et al., 2003). Educational programming for this group is constrained by limited research on teaching strategies and curricula (McClannahan, MacDuff, & Krantz, 2001; Simpson et al., 2005). There is an abundance of published studies documenting the efficacy of educational strategies for young children with ASD (e.g., Bondy & Frost, 1993; Goin-Kochel, Myers, Hendricks, Carr, & Wiley, 2007; Gray, 1998; Green, 1996; Lovaas, 1987; Sheinkopf & Siegel, 1998), but research specifically focused on adolescents and adults is limited (Hart, 1993; National Research Council [NRC], 2001). Research with this age group has focused on teaching a variety of skills in the educational arena, including language development (Heimann, Nelson, & Tjus, 1995; Krantz, Zalewski, Hall, Fenski, & McClannahan, 1981; McIlvane, Bass, O'Brien, Gerovac, & Stoddard, 1984), replacement of inappropriate behavior (Carr & Durand, 1985; Schreibman & Carr, 1978), and literacy (Bedrosian, Lasker, Speidel, & Politsch, 2003; Collins & Stinson, 1994; Kamps, Leonard, Potucek, & Garrison-Harrell, 1995; O'Connor & Klein, 2004). In recent years, strategies designed to increase independence and participation have received much-needed attention (Agran et al., 2005; Kay, Harchik, & Luiselli, 2006; Myles, Ferguson, & Hagiwara, 2007).

Home

Adolescents with ASD may wish to reside in more integrated and independent settings as they get older. Smith and Philippen (1999) describe a continuum of living arrangements that includes living with family, living with a foster family, living independently, partially supported living, and fully supported living. The nature of the disorder demands such a continuum, which enables individuals to live within the community while receiving the level of support needed to be successful. Research demonstrates benefit for moving away from home. Parents of adolescents with ASD experience elevated caregiving demands (Holmes & Carr, 1991) and have higher levels of stress and depression compared to parents of other disability categories (Abbeduto et al., 2004). In a study by Krauss, Seltzer, and Jacobson (2005), mothers reported great benefit for their child with ASD who lived away from home, whereas those who coresided reported negative consequences including lack of contentment, not being pushed to be independent, and social isolation. Residential programs designed specifically for adults with autism may provide appropriate living arrangement for those needing intensive support. Beginning in the 1970s, residential programs of this type were developed, incorporating the use of instructional techniques to develop new skills (Holmes, 1990; Van Bourgondien & Reichle, 1997; Wall, 1990). Research suggests these residential treatment models result in increased community participation (Luce & Dyer, 1995), increased independent functioning and interpersonal behavior (Persson, 2000), and higher quality of life (Van Bourgondien, Reichle, & Schopler, 2003).

Although an array of residential options is available, research on living outcomes yield disappointing results. A small percentage of adults with ASD live alone and some reside in long-stay hospitals or institutions, but most continue to live at home with their parents (Billstedt, Gillberg, & Gillberg, 2005; Howlin et al., 2004). Wagner, Newman, Cameto, Garza, and Levine (2005) surveyed out of school youth and found 80% of those who had an educational label of autism while in high school were still living at home and 4% were living on their own. Howlin et al. (2004) investigated the living conditions of adults who had a performance IQ of at least 50 (mean age 29.3 years). Participants were split into two IQ bands: those with an IQ of 70 or greater and those with an IQ of 50 to 69. Overall, nearly 40% of participants lived at home and less than 5% lived independently. However, findings showed that those with IQ scores of less than 70 faired much worse than those with scores greater than 70. In a study conducted in Sweden, Cedurland, Hagberg, Billstedt, Gillberg, and Gillberg (2008) compared the outcomes of adults who had been diagnosed as children with either AS (ages 16 to 36) or autistic disorder (ages 16 to 38). In the AS group, 64% were living independently, whereas 8% from the autism

group were doing so. Although living away from their families, participants from both groups were described as dependent on their parents for support.

A number of researchers have documented supports and interventions that improve independence in the home environment. Much of the research has focused on increasing self-help skills and participation in activities of daily living (Bledsoe, Smith, & Simpson, 2003; Lasater & Brady, 1995; Lee, Poston, & Poston, 2007; Smith & Belcher, 1985). Researchers have successfully increased independence by reducing inappropriate behaviors in the residential setting (Brown, 1991; Reese, Sherman, & Sheldon, 1998).

Work

The many challenging characteristics and behaviors that individuals with ASD present can make them appear unsuitable for employment. Experience has proven, however, that these individuals can work in a variety of businesses and industries (O'Brien & Daggett, 2006). A spectrum of employment options is now available that include segregated training centers, supported employment, and competitive employment (Smith, Belcher, & Juhrs, 1995). The supported employment framework provides a variety of individualized supports and provisions designed to increase participation in community work settings (Smith & Philippen, 1999). The onset of supported employment increased employment rates, raised salaries (Howlin, Alcock, & Burkin, 2005), and improved the quality of life of individuals with ASD (Garcia-Villamisar, Wehman, & Navarro, 2002). Recently, Garcia-Villamisar and Hughes (2007) found improvement in cognitive performance as a result of being in supported employment.

Despite research documenting the benefit of community-based employment, the vast majority of people with ASD continue to be unemployed (National Organization on Disability, 2004; Wagner et al., 2005). In a study with 187 young adults with autism (mean age of 21.5), only one fourth were employed (Kobayahsi & Murata, 1992). Mawhood, Howlin, and Rutter (2000) found that among 19 men with autism, only 1 was competitively employed and 3 worked in sheltered or voluntary jobs. The employment results for those with high-functioning autism (HFA) and AS indicate outcomes are generally much lower than would be expected on the basis of the individual's intellectual functioning. Howlin et al. (2004) discovered that those with an IQ greater than 70 had only slightly higher rates of employment than those with IQs of less than 70. In addition, the majority of jobs were in sheltered employment or voluntary in nature. Cedurland et al. (2008) found that only 20% of the men with AS held jobs, with 10% working in competitive employment and another 10% working in sheltered employment.

Adults with ASD experience high unemployment and underemployment, switch jobs frequently, have difficulty adjusting to new job settings, make less money than their counterparts, and are much less likely to be employed than typically developing peers (Howlin, 2000; Hurlbutt & Chalmers, 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006; Müller, Schuler, Burton, & Yates, 2003), individuals with less severe language disorders, or individuals with learning disabilities (Cameto et al., 2004). Even for those individuals who have postsecondary educational experience, employment difficulties are common (Howlin, 2000). According to self-reports, vocational success is not contingent on completing job duties but lies in the social aspect of employment (Hurlbutt & Chalmers, 2004; Müller et al., 2003).

Participation in secondary education may provide a suitable alternative to employment; however, limited research in this area indicates participation is low. Howlin (2000) provided a literature review of outcome studies of adults with HFA and AS. The proportion of participants who had received a college or university education ranged from 7% to 50%. Cedurland et al. (2008) documented 11% of the AS group attended or were attending college, whereas another 2% had received a degree. None of the individuals in the autism group had attended college. Factors contributing to successful employment include attainment of communication and interpersonal skills and management of stereotyped patterns of behavior (Burt, Fuller, & Lewis, 1991). Specialized interventions and treatments can prepare the individual for employment by teaching important skills needed in the vocational setting. Several researchers have focused on the unique needs of individuals with ASD in the workplace. Most have used behavior management strategies to reduce inappropriate behavior, including aggression, self-injury, property destruction, and pica (Berkman & Meyer, 1988; Kemp & Carr, 1995; Smith, 1986, 1987; Smith & Coleman, 1986). More recent research has focused on strategies designed to increase employment retention by matching the individual to a complimentary job. A variety of strategies have been successful in yielding an appropriate match, including offering choices (Nuehring & Sitlington, 2003), using assessments to determine task preferences (Lattimore, Parsons, & Reid, 2006; Nuehring & Sitlington, 2003), evaluating social and communication needs (Müller et al., 2003), and adding necessary modifications and adaptations (Hagner & Cooney, 2005).

Community

Community participation is a critical component of the transition planning process. Planning must involve the entire community in which the person wishes to take part

after high school and might include myriad activities, organizations, agencies, and institutions. Community participation includes productive engagement in these activities but, more important, encompasses the desired goal of integration into social networks and relationship development. For those with ASD, a variety of support services and interventions specifically designed to increase community participation likely are needed. Challenging behaviors (Smith, 1990; Van Bourgondien & Elgar, 1990), limited social skills (Arick, Krug, Fullerton, Loos, & Falco, 2005; Howlin, 2000; Orsmond et al., 2004), and low independence outside of the home (Wagner et al., 2005) are major deterrents. Luce and Dyer (1995) described the success of a decentralized community-based model that provided a full continuum of supports. Participants were assisted by trained staff and taught new skills using instructional and behavioral techniques. Individuals with ASD participated in the community at levels equal to or exceeding those without disabilities. This approach has been also used very successfully in the Life Long Inclusion for Everyone (Spence-Cochran & Pearl, 2006) for high school students with severe autism in Central Florida.

Little is known about the actual community integration experienced by individuals with ASD. The only data available in this area pertain to participation in recreation and leisure activities. For the adolescent or young adult with ASD, leisure pursuits are rarely community based and are likely to be isolated activities such as video games and watching television (Jennes-Coussens et al., 2006; Wagner et al., 2005). There are few studies that document supports and interventions that enhance community participation. Much of the research has focused on reducing the inappropriate behaviors that often accompany the disorder (Belcher, 1995; Carr & Carlson, 1993; Carr & Durand, 1985; Carr, Smith, Giacin, Whelan, & Pancari, 2003; McMorrow & Foxx, 1986). Other research has focused on strategies designed to increase safety skills (Taylor, Hughes, Richard, Hock, & Coello, 2004) as well as recreation and leisure participation (Jones & Block, 2006; Orsmond et al., 2004; Scheitner & Devine, 2001).

During adolescence, the social gap between individuals with ASD and typically developing peers often widens (Arick et al., 2005; Church, Alinsanski, & Amanullah, 2000; Collier & Schall, 2003). The prevalence of friendships and participation in social groups is low for these individuals despite where they are on the spectrum. Orsmond et al. (2004) investigated peer relationships among 235 adolescents and adults with autism. In all, 30% reported at least one friend, whereas nearly half reported no peer relationships. Mawhood et al. (2000) found that only 16% of young adults with HFA had at least one friend and almost half (47%) reported having no particular friends with whom they shared activities. Howlin et al. (2004) found only 26% of total participants with autism, regardless of intellectual functioning, were rated as having at least one friend, whereas the majority had neither friends nor acquaintances. More sophisticated relations are also sparse, as only a small portion of the population engage in intimate relations (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2006; Jennes-Coussens et al., 2006) or get married (Cederlund et al., 2008; Howlin, 2000).

Despite the low incidence of social relationships, it is important to note that the individual may desire such relations but not possess skills needed to cultivate them. Adolescents with ASD report wanting friends (Marks, Schrader, Longaker, & Levine, 2000), intimate relations (Hellemans et al., 2006; Jennes-Coussens et al., 2006; Ruef & Turnbull, 2002), and having higher levels of loneliness than their typically developing peers (Bauminger & Kasari, 2000; Bauminger, Shulman, & Agam, 2003). A lack of necessary social skills, including failure to comprehend social stimuli, social rules, and affect intrinsic to social interactions, leads to limited success in this area (Koning & Magill-Evans, 2001; Tantam, 1991). Success is further hindered by possession of less knowledge about romantic relationships and sexual behaviors than typically developing peers (Stokes & Kaur, 2005; Stokes, Newton, & Kaur, 2007; Van Bourgondien, Reichle, & Palmer, 1997).

A number of interventions have been used to improve social functioning. Research has demonstrated the efficacy of a variety of techniques, including peer-mediated approaches (Farmer-Dougan, 1994; Haring & Breen, 1992), self-management strategies (Koegel & Frea, 1993), Social Stories and Comic Strip Conversations (Rogers & Myles, 2001), and audiotaped social scripts (Stevenson, Krantz, & McClannahan, 2000). In recent years, technology has received increased attention, as researchers have utilized virtual environments to increase social skills (Moore, Cheng, McGrath, & Powell, 2005; Parsons, Leonard, & Mitchell, 2006; Parsons, Mitchell, & Leonard, 2004).

Recommendations for Effective Service Delivery Practices and Future Research

Examination of the current research on adolescents with ASD who transition from high school to adulthood yields sobering results. Although some individuals with ASD are able to successfully transition, most are faced with significant obstacles in multiple areas. Even for those considered to be more skilled, many obstacles exist

as they attempt to negotiate their way into college, work, community participation, and independent living.

Planning for transition needs to begin when students are between 10 and 13 years old, with more serious planning occurring as the child enters the early to middle teen years (Wehman, 2006). A successful transition requires thorough preparation and implementation. Furthermore, it requires resources within the school as well as adult service agencies that can provide needed support. These resources need to overlap with each other for a period of time. Continual involvement, planning, and careful coordination between the school and key community agencies are essential to improving outcomes through the transition process. There is obviously a great deal more for researchers and practitioners to learn to improve the quality of life for young people with ASD. What follows is a brief description of different research and service delivery practices needed in the areas of school, home, work, and community.

School

Efforts are needed to improve the transition planning process for adolescents with ASD. Placing the individual at the center of the transition process is a pivotal component of planning that has been greatly overlooked. Students should not be passive recipients and should have control over the intervention and support process (Everson & Reid, 1999). There is a need to explore methods for involving adolescents with ASD of all ability levels in transition planning and empowering individuals to become active change agents in their lives. Furthermore, efforts are needed to ensure transition goals help students reach their full potential. More opportunities exist than ever before. Student goals should include the full range of community pursuits and should not be based on perceived student limitations (Wehman, 2006).

Most students with ASD are not receiving a "seamless transition" experience, that is, one where the school services flow into adult services easily (e.g., Certo et al., 2003). There are currently a variety of postschool services designed to help adults with ASD live, work, and participate in the community (Rusch & Braddock, 2004). Efforts on the part of school personnel, parents, and service providers are needed to ensure collaboration and involvement of these agencies in the transition planning process. To prevent patterns of dependency and institutional care, it is necessary to establish measures for moving the individual systematically from the protected umbrella of the school to the adult service delivery system.

Efforts are undoubtedly needed to increase the academic achievement and rates of graduating with a diploma. This is a tremendous task, indeed, requiring efforts that stretch beyond the parameters of the transition period. At the heart of this issue, however, is the need for efficacious teaching strategies, as there is currently a dearth of research on instructional strategies effective with adolescents with ASD. Because there is not one single most effective method that works for all individuals on the spectrum (Heflin & Simpson, 1998; NRC, 2001), rigorous research on a variety of practices is needed. Adolescents require instruction in skills related to community, employment, home, and leisure (Schall et al., 2006) as well as academics related to the transition goals (Downing, 2005; Nuehring & Sitlington, 2003). Moreover, strategies for remedying communication, socialization, and behavioral deficits that profoundly and perpetually affect the individual are critical (Iovannone et al., 2003). Transition instruction is further complicated by the need for learning opportunities to be provided in a variety of settings, including the special education classroom, the general education classroom, out-of-classroom school environments, and community settings (Wehman & Kregel, 2004).

Home

Individuals with ASD should be assisted to live where they want and with whom they want. It is critical that ongoing planning and training take place beginning in the adolescent years (Wehman, 2006). This requires educators to begin planning during the transition period by exploring residential opportunities and working toward goals that will enable appropriate living situations within the community. Educators should collaborate with the individual and the parents to ensure the characteristics and goals of the individual, the role of the family, and the desired program components are at the heart of the planning process (Everson & Reid, 1999).

Although some individuals with ASD learn to live independently, many require ongoing supervision (Cedurland et al., 2008; Howlin, 2000). For those who are unable to access supported residential settings, parental and family support might be needed to allow the individual to remain in the community (Burt et al., 1991). Given the current state of affairs, it would be highly beneficial to educate family members and ensure they are well equipped to support their loved one. This includes providing up-to-date information about ASD and best practice as well as hands-on teaching of instructional strategies and implementation of much-needed behavior support plans.

There are a myriad of skills needed in the home setting. They include skills related to safety, activities of daily living, and financial accountability. For mastery, however, the individual must demonstrate increased levels of independence and self-sufficiency (Smith & Philippen, 1999).

Few strategies have undergone rigorous evaluation of their effectiveness with adolescents with ASD. This presents a tremendous need. Acquisition of such living skills night not only lead to better opportunities to stay in the community but also reduce stress in caregivers (Van Bourgondien & Reichle, 1997).

Work

Meaningful integrated employment should be a goal for all individuals with ASD who wish to work and should be the first choice offered (Luecking & Gramlich, 2003; Wehman, Inge, Revell, & Brooke, 2007; Wehman, Revell, & Brooke, 2003). Work experiences should begin while the student is in high school and include career exploration activities and assessments to determine task preferences (Smith, 1990). Furthermore, competitive work experience prior to graduation can help negate poor employment outcomes by helping the student develop relationships, learn valuable work skills, and create a strong work ethic (Targett, 2006).

For adolescents leaving school, learning specific work-related skills is necessary. Such skills should focus on not only job-related tasks but also, more important, the interpersonal skills that will foster a positive work experience (Fast, 2004). Currently, research on such strategies with adolescents with ASD is sparse and desperately needed.

An alternative to employment after high school might be postsecondary education. Involvement, however, is extremely limited for those with ASD (Wagner et al., 2005), and research on this topic is nearly nonexistent. Individuals with ASD likely will need specialized teaching strategies, supports, and accommodations in the postsecondary setting for a successful educational experience (Getzel & Wehman, 2005). Conducting investigations with individuals currently involved in higher education can yield valuable information about effective instructional and organizational measures needed to increase rates of participation and educational success.

Community

Full community integration is possible but is not yet a reality for many adolescents and young adults with ASD. This is especially true given that most have not achieved effective social integration (Howlin, 2000; Orsmond et al., 2004). The community is composed of myriad activities, organizations, agencies, and institutions, all of which involve different skills and competencies. For adolescents to learn requisite skills, education and training must be provided in the community during high school. Specifically, education must take place in community environments where the student is likely to frequent and utilize as an adult. This will ensure the student has opportunities to socialize in the community and learn applicable skills (Wehman & Thoma, 2006).

Progress in community integration is severely hampered by the limited research on efficacious strategies and supports needed to facilitate meaningful participation. Development of strategies specifically designed to increase community participation is essential to ensuring equal opportunities for this group. Rigorous research on a variety of practices that address the myriad of skills required in the wide array of community activities is needed.

The skills required for socialization are complex and are arguably the most difficult for an individual with ASD to learn, yet little empirical research has been conducted in this area. Unless social skills are taught, full community integration and social fulfillment remain a challenge. Much more is needed in this area, as extant research has focused on discrete skills, and little is known about methods for generalizing social skills across environments and people.

Conclusion

Federal measures have been put in place to ensure schools plan for transition (IDEA, 2004); however, transition planning and implementation is falling short of what the federal government intended for many with ASD (Certo et al., 2003; Luecking & Gramlich, 2003). Students often do not receive the services and supports needed to address the complex set of issues they possess. It is essential that professionals carefully plan for this transition to ensure adolescents and young adults are armed with the appropriate skills and supports needed to be successful. Individuals with ASD spend much more of their lifetime outside of the educational system than in the system; therefore, efforts to maximize this critical period are pivotal to improving outcomes.

Endnotes

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Acronyms

AMAT	Autism Management Advisory Team
ASD	autism spectrum disorder
AS	Asperger syndrome
CAYAC	Children & Youth Action Committee
CDC	Centers for Disease Control and Prevention
CECASN	Centre of Excellence for Children and Adolescents with Special Needs
CEECD	Centre for Excellence for Early Childhood Development
CME	Continuing Medical Education
DFS	Direct Family Support
DFSC	Direct Family Support for Children
DFSA	Direct Family Support for Adults
DHA	district health authority
DSEPS	Designated Special Education Private School
EIBI	Early Intensive Behavioural Intervention
EIIS	Early Identification and Intervention Services
IPP	individual program plan
GP	general practitioner
OT	occupational therapy
PDD-NOS	Pervasive Developmental Disorder, Not Otherwise Specified
PRT	pivotal response treatment
SLP	speech-language pathologist
SPD	Services for Persons with Disabilities
TA	teacher assistant

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