



# Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems

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**Date of Release:** February 5, 2013



UNIVERSITY OF  
TORONTO

**Cite as:** Stoddart, K.P., Burke, L., Muskat, B., Manett, J., Duhaime, S., Accardi, C., Burnham Riosa, P. & Bradley, E. (2013). Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems. Toronto, ON: The Redpath Centre.

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This report was printed through the generous sponsorship of Autism Ontario.

[www.autismontario.com](http://www.autismontario.com)

# In Appreciation

A study of this magnitude could not have been undertaken without the interest, support and encouragement of many Ontarians.

Our gratitude goes to the 480 individuals with ASDs, family members and care providers who completed this survey. Their poignant narratives on living with ASDs and seeking supports and services are reflected in this report.

The commitment of many service providers, advocacy groups and organizations to advertising the study and helping clients complete the survey was appreciated.

Finally, our sincere thanks goes to the funders of this project—Autism Ontario, Kerry's Place Autism Services, Ministry of Community and Social Services, and Geneva Centre for Autism Foundation. We have appreciated the many individuals at MCSS, Dr. Glenn Rampton, Margaret Spoelstra, and Dr. Lindy Zaretsky for their ongoing interest in this study, and valued contributions over these past two years.

**Kevin Stoddart, PhD**

The Redpath Centre  
Toronto, Ontario



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# Executive Summary

Two decades have passed since a survey occurred on the needs and characteristics of youth and adults with Autism Spectrum Disorders (ASDs) in Ontario. Since the 1990s, there have been major changes to the scope of ASDs included in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; APA, 1994). This has led to a wider range of ASDs being identified and studied, including Asperger Syndrome (AS) and other ‘milder’ presentations.

This report provides an introduction to the ASDs as they affect youth and adults. It then highlights seven areas of concern (i.e., diagnosis, life skills, mental health, physical health, medication use, social involvement, and daily activities), and reviews service use and needs of 480 youth (16+) and adults in Ontario. Finally, we make recommendations to address these findings.

The survey used to gather data for this report was accessible by a confidential and personalized Internet address (URL). Each survey completed reported on a single, unique individual diagnosed with an ASD. There were three versions of the survey: one for individuals with ASDs, the second for family members, and the third for service providers. All questions across the three versions were similar, but wording was changed as appropriate.

- This study reports on 480 individuals: 348 males (72.5%) and 132 females (27.5%). Their ages ranged from 16 to 66 years, with an average of 29.11 years. Of the whole sample, 80.6% were 40 years or younger
- 226 (47.1%) respondents (i.e., those who completed the survey) were family members, 217 (45.2%) were individuals with ASDs, and 37 (7.7%) were professionals
- The largest group of subjects was those considered “higher-functioning”, comprising 244 individuals (50.8% of the sample). The second largest diagnostic group of 114 individuals were those with autism (23.8%). 75 individuals (15.6%) had the broad diagnosis of ASD/PDD, and 47 were diagnosed with PDD-NOS. Only 71 (14.8%) had been diagnosed with an intellectual disability
- 75% of the adults 20 years and older had an annual income under \$30,000. The largest income source was Ontario Disability Support Program (ODSP) for 209 (58.2%) people. Full-time employment was the primary income source for 50 (13.9%), and part-time employment for 22 (6.1%)
- Only 51.8% with “high-functioning autism” or AS were diagnosed before 21 years

To address multiple unmet needs, research must be ongoing, significant changes must occur across multiple systems and provincial ministries, and regular feedback must be elicited from a wide range of consumers and stakeholders.

## Executive Summary, Continued

- Both family members and individuals with ASDs suggested services supporting functional life skills are lacking. Many said their family members with ASD need various supports with day-to-day functioning. Over 60% of the sample needed regular support finding and accessing services
- Respondents reported high rates of multiple mental health and neuro-developmental disorders. Anxiety was reported in 45% and depression in 27.9% of the sample
- 31% of respondents felt the individual had an undiagnosed mental health disorder
- 296 medical conditions were reported by respondents; 92 individuals (19.2%) had one, 48 (10%) had two, and 36 (7.5%) had three medical or health conditions
- 91 individuals (19.0%) were taking one medication, 83 (17.3%) were taking two, 47 (9.8%) were taking three, 29 (6.0%) were taking four, 43 (9.0%) were taking five, 7 (1.5%) were taking six, and 3 (0.6%) were taking seven. The average number of medications per person was 1.65; 63.1% of the entire sample was taking medication
- 38.4% of the sample took part in one social interaction or less a month
- 73 individuals (15.2%) had no regular structured activities outside their home. Degree of satisfaction with daily activities was: “Very Satisfying” 14.8%, “Satisfying” 40.0%, “Neutral/Undecided” 29.6%, “Unsatisfying” 9.9%, and “Very Unsatisfying” 5.0%
- 44.8% had taken some post-secondary education courses and 28.5% had completed a degree; for 5.8% their program was in progress. The highest academic level earned in post-secondary education was a diploma/certificate for 58 individuals (12.1%), a Bachelor’s degree for 57 (11.9%) individuals, a Master’s degree for 15 (3.1%) individuals and an MD/PHD/LLB for 9 (1.9%) individuals
- Many families and individuals expressed frustration with uncoordinated, lacking, or limited services and supports; efforts to find and oversee services and supports were often the role of the family; many families noted negative experiences with Developmental Services Ontario
- The cost of services were reported by 341 (71%) of the 580 respondents; the mean annual cost of services (not refunded) was \$4,800.00 and the range was \$0.00 to \$170,000.00

This report highlights the profiles and needs of this sample are both complex and diverse. Current systems of care and support are largely inadequate, although some positive experiences and supports exist in the province which can be expanded and emulated. To address these multiple unmet needs, research and data collection must be ongoing, significant changes must occur across multiple systems and provincial ministries, and regular feedback must be elicited from a wide range of consumers and stakeholders. Recommendations are made for: (i) *Multiple Systems Integration*, (ii) *Comprehensive and Effective Service Provision*, and (iii) *Knowledge Identification and Mobilization*.

# Introduction to this Report

Two decades have passed since a survey on the needs of youth and adults with Autism Spectrum Disorders (ASDs) was carried out in Ontario (Bryson & Autism Society Ontario, 1991). Since the 1990s, there have been major changes to the scope of ASDs included in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; APA, 1994). This has led to a wider range of ASDs being identified and studied, including Asperger Syndrome (AS) and other ‘milder’ presentations of autism.

Since this shift in our understanding, the last twenty years have witnessed a wave of youth and adults seeking a diagnosis of an ASD. Many (but not all) of these individuals are subsequently diagnosed with Asperger syndrome. The accompanying demand for services for this group is now an ever-present challenge both in Canada (Autism Society Canada, 2007; Munro & Burke, 2006; Autism Ontario, 2008; Stoddart, 2007, 2009; Stoddart, Burke, & King, 2012) and abroad (Barnard et al., 2001; Powell, 2002; Rosenblatt, 2008). Many youth and adults with ASDs have never had access to suitable services and supports. It is likely that this wave of “higher-functioning” youth and adults will become even larger as more children are diagnosed earlier, and some do well in early intervention services. However, despite their early intervention success, most of this group will continue to need services and supports throughout their lifetime.

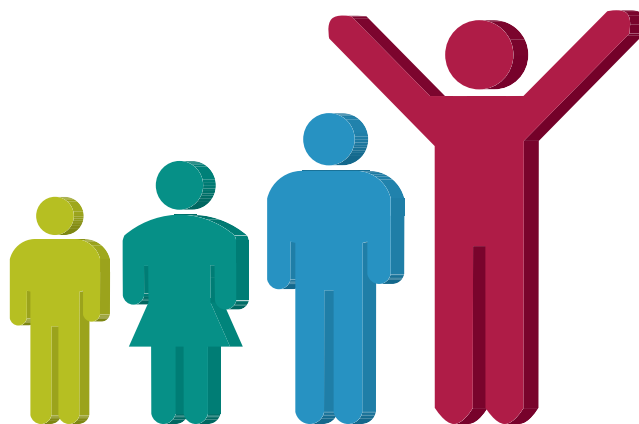
The needs of those who are more severely affected by ASD cannot be overlooked. This includes those who have little or no communication ability, a co-existing intellectual delay, and dependency on caregivers.

Although more accurate detection of those with concurrent intellectual disability and autism has occurred in recent years, many of these adults did not have access to early or effective treatment when they were young, and some were institutionalized. Although Ontario’s institutions for the developmentally disabled are now closed, the cumulative effects of multiple medications used to control seizures or behaviour, health problems that have gone undetected or unreported, intrusive means of behavioural control, institutional care and aging are largely unknown.

This report will provide an introduction to the ASDs, particularly as they affect youth and adults, highlight seven areas of concern for them and their families (i.e., diagnosis, life skills, mental health, physical health, medication use, social involvement, and daily activities), and summarize the service use and needs of 480 Ontario youth (16+) and adults. Finally, we make recommendations that address our findings.

Although we have attempted to address the range of needs of the individuals described in this report, further analysis will be required to fully understand the profiles of this diverse group. Therefore, this report provides the most significant findings in summary format. Further detailed descriptions will be published in peer-reviewed journals and presented at conferences.

It is our sincere hope that these findings will significantly further our understanding of this cohort and help to renew the landscape of services and supports for future generations of Ontarians living with ASDs.





# Autism Spectrum Disorders in Youth and Adults

*Pervasive Developmental Disorder* is the term used to describe a cluster of five disorders in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* of the American Psychiatric Association (APA, 1994). These include autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and Pervasive developmental disorder-not otherwise specified. In this report, we use the more popular terms Autism Spectrum Disorders (ASDs) and Asperger syndrome (AS). We have provided DSM-IV-TR (APA, 2000) diagnostic criteria for Asperger's disorder and autism in the APPENDIX.

“Pervasive Developmental Disorders are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, and the presence of stereotyped behavior, interests, and activities. The qualitative impairments that define these conditions are distinctively deviant relative to the individual's developmental level or mental age” (APA, 1994, p. 65).

The APA has proposed a new configuration of this cluster of disorders for the Fifth Edition of the *Diagnostic and Statistical Manual of Mental Disorders*, to be released in spring 2013 (APA, 2013). A new diagnostic category called *Autism Spectrum Disorder* will bring together several previously ‘separate’ diagnoses including Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not otherwise specified.

The APA asserts that symptoms of these four conditions represent a continuum from mild to severe, rather than sharply defined categories that lead to a diagnosis of a specific disorder (APA, 2013). The common use of the term *Autism Spectrum Disorder* has predated the official introduction of this term in the DSM 5; most clinicians and researchers now use this label instead of *Pervasive Developmental Disorder*.

## One Percent Affected

One of the most alarming areas of research in the autism community has been the study of the occurrence rates of ASDs—researchers have noted a dramatic increase in the identification of ASDs over the last 20 years. It is still a point of controversy as to whether we are now better at the detection and diagnosis of ASDs, if the occurrence of these disorders has increased, or both.

According to *Centers for Disease Control*, an estimate of the prevalence of ASDs in young children in the USA is roughly 1% (Rice et al, 2010). Since 2003, the *National Epidemiologic Database for the Study of Autism in Canada* (NEDSAC) has been monitoring the prevalence of ASDs in Newfoundland and Labrador, Prince Edward Island, and south-eastern Ontario. Based on information from their most recent year of data collection, the best estimate of the prevalence of ASDs in Canada is 1 in 94 children (NEDSAC, 2013). A recent landmark study in the United Kingdom suggested the prevalence of ASDs in adults there could be as high as 1% (Brugha et al., 2011). All the adults identified in this UK study as having an ASD had not previously been diagnosed except through this research. Although similar adult studies are required in other parts of the world, this finding reminds us that many youth and adults remain undiagnosed.

The estimated number of Ontarians between the ages of 16 and 64 in 2012 was 9,341,200 (Ontario, 2013). With the conservative prevalence of 1% of the population, as many as 93,412 Ontarians in this age range are affected by the lifelong challenges of ASDs. It is therefore vital that Ontario be prepared for the mounting need for services and supports required by youth and adults on the autism spectrum. The implications of not responding to this cohort are staggering—for families, secondary and post-secondary education, service providers in the autism, developmental, mental health, social service and medical fields and all levels of government.

## Diversity in Autism Spectrum Disorders

The extreme heterogeneity of ASDs presents challenges for many. Some have argued the diversity of presentation in ASDs in childhood is broad, while the presentation in adults is even wider—therefore it is difficult to precisely characterize all adults on the autism spectrum (Stoddart, Burke, & King, 2012). “Although few studies have analyzed the implications of the heterogeneity of both abilities and challenges exhibited by people on the autism spectrum for service provision, such heterogeneity is vast [and] has significant implications for service needs” (Shattuck et al., 2012a, p. 289).

To illustrate the diversity of youth and adults with ASDs, throughout this report we have included four case vignettes of adults—all with ASDs—but with different abilities and needs.

## Adult Outcomes

Over the past few decades, as concern has gradually turned to the needs of adults with ASDs, a series of international studies have focused on adult outcomes—most often looking at their success at finding employment, establishing relationships, and living independently. Only a handful of these studies have occurred in Canada.

Although this literature is largely limited to those individuals diagnosed in childhood (Stoddart, Burke, & King, 2012) they suggest that adults with ASDs have poor psychosocial outcomes. They often live alone, are unemployed, have few friends or social contacts, and need extensive support from their families and social services (Cedurland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Engstrom, Ekstrom, & Emilsson, 2003; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Orsmond, Krauss, & Seltzer, 2004; Renty & Royers, 2006). Adults with ASDs also have high rates of clinical depression, anxiety, related disorders, and suicidality (Barnhill, 2007; Engstrom, Ekstrom, & Emilsson, 2003; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989).

Factors such as good early language development, higher IQ and functioning levels are associated with better adult outcomes—including living independently, working without supports, and succeeding in post-secondary education (Billstedt, Gillberg & Gillberg, 2005; Eaves & Ho, 2008; Howlin, 2000; Howlin et al., 2004; Gillberg & Steffenburg, 1987). However, existing research suggests that outcomes are still relatively poor even among adults with average to above IQs, and for those who have attained higher academic levels (Billstedt, Gillberg, & Gillberg, 2005; Jennes-Coussens, Magill-Evans, & Koning, 2006). A majority have no close friends, are dependent on families for support and struggle with employment—that is, have little employment experience or work in short-term, low-paying jobs (Barnhill, 2007; Eaves & Ho, 2008; Engstrom, Ekstrom, & Emilsson, 2003; Howlin, 2000; Howlin et al., 2004).

# Previous Policy Recommendations and Changes

## Forgotten Report

In 2008, Autism Ontario, in collaboration with the Ontario Partnership for Adults with Aspergers and Autism (OPAAA) published the report: “*Forgotten: Ontario Adults with Autism and Adults with Aspergers*”. Many stakeholders perceive the provision of youth and adult services in Ontario is lagging significantly behind the evolution of this diagnostic category and the increasing recognition of the ASDs (Munro & Burke, 2006; Autism Ontario, 2008; Stoddart, Burke, & King, 2012). Lack of services and supports lead to unrealized potential, worsened symptom expression, and multiple long-term psychosocial sequelae.

### The report made three major recommendations:

1. *Ensure sufficient and regulated services for adults with ASD in the adult/child mental health, social service, colleges/universities and developmental sectors through an Ontario-wide cross-sector policy framework and devoted funding based on a provincial needs assessment. Specifically, this policy framework would ensure: (a) Financial supports which are not tied to “claw-backs” through ODSP, Registered Disability Savings, and welfare programs; (b) Day supports including vocational and employment, educational, social and recreational services/opportunities; (c) Programs devoted to monitoring the well-being and safety of adults with ASDs; (d) A range of supported living options; and (e) Professional supports including psychological, medical, and psychiatric assistance, dental care, person-centered planning, case coordination, respite care, crisis supports and legal assistance.*
2. *Implement standard eligibility criteria to services for adults with ASD based on their functional needs rather than intellectual functioning through an Ontario-wide cross-sector policy framework.*
3. *Facilitate access to best practices education and research specific to adults with ASD across adult/child mental health, social service, colleges/universities and developmental sectors through a provincial knowledge*

*exchange centre. This centre would: (a) Lead a provincial needs assessment; (b) Guide or seed, translate and disseminate best practice research; (c) Provide information to specialized and generic or developmental service providers; (d) Provide information to families and individuals with ASDs; and (e) Track adult services available throughout the province.*

## A New Provincial Act

In the last few years, Developmental Services Ontario (DSO) has been introduced to the province. This follows from the “*Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*” (2008). According to the Ministry of Community and Social Services (2013) the new act:

- Uses new, modern language;
- Uses a simpler application and assessment process;
- Includes person-directed planning;
- Allows people to receive direct funding;
- Gives a new definition for “developmental disabilities;”
- Sets out clear rules to increase accountability; and
- Gives the government the right to collect personal information.

Under the new Act, each Developmental Services office is required to confirm the service applicant is eligible to receive the requested services based on the findings or determination of a Psychologist or a Psychological Associate. Every client of DSO services must meet the cognitive criteria. Specifically, an individual must have a standard overall score of two Standard Deviations below the mean in IQ testing; OR, have a score of two standard deviations below the mean in two or more subscales; OR, due to difficulty in testing the assessor deems that they have “significant limitations in cognitive functioning” (DSO, 2013).

Additionally, the individual is required to meet the *adaptive functioning* criterion which is a score of at least

two standard deviations below the mean, in at least one of the following: conceptual skills, social skills or practical skills. Third, the person is required to have had the onset of limitations in cognitive or adaptive functioning occur before the age of 18 (DSO, 2013).

The Ontario Ombudsman has recently initiated an investigation into the care of adults with developmental disabilities and note that since the introduction of the new Act, complaints to the Ombudsman's office about the care of adults with developmental disabilities have more than doubled. "In many cases, parents of children with severe special needs complained that services for them essentially vanished when they turned 18. Many noted lack of planning and funding, lengthy delays... poor co-ordination of care [and] being refused support services because of their loved ones' high needs and challenging behaviours" (Ombudsman Ontario, 2012).

# Background to this Study

## Study Rationale

The purpose of this study was to gain a better understanding of the characteristics, service use and needs of youth (16+) and adults in Ontario who have been diagnosed with an ASD. This survey is a direct response to the recommendation for a provincial needs assessment in the *Forgotten* report (Autism Ontario, 2008) and provides a contemporary picture of this group in the following areas:

- i. Demographic Information;
- ii. Medical and Life Skills Information;
- iii. Service and Supports Use and Needs;
- iv. Social Involvement; and
- v. Daily Activities.

## Development of the Survey

As most of the investigators in the study are currently practicing full-time in the fields of ASDs and developmental disabilities, many of the questions in this survey evolved from our clinical experiences. Questions were also created after a review of other survey tools used to examine the needs and profiles of adults with ASDs and their results, specifically: (1) the Autism Society of Ontario survey completed in 1991 (Bryson & ASO, 1991), (2) the survey carried out in the UK (Barnard et al., 2001), (3) the survey of Newton (2009) in Manitoba, and (4) the review the first two authors carried out in a previous clinical study of adults with ASDs (Stoddart, Burke, & Temple, 2002). Also, advice on general survey themes and questions was sought from Autism Society Canada's *Advisory Committee of Adults on the Spectrum*.

Questions were clustered into themes that would improve the presentation and flow of the survey. We began with many questions and reduced these to the most significant items that addressed our key concerns. Feedback was sought from members of the *Ontario Partnership for Adults with Aspergers and*

*Autism* (OPAAA) and the study funders. The survey was then uploaded to a secure server with *Survey App*, a professional survey company. Finally, the survey was piloted by several individuals and family members.

## Data Collection

Advertising was carried out in a staged manner so we could understand the impact of advertising to certain groups by various methods. Many agencies promoted the survey in newsletters, on their websites, through direct email, and regular mail requests. The following were targeted:

- The Redpath Centre
- Autism Ontario
- Kerry's Place Autism Services
- Geneva Centre for Autism
- Surrey Place Centre
- Post-secondary disability offices
- Autism/IDD conferences
- Children's mental health agencies
- Press releases and media coverage
- Private service organizations
- Advocacy groups
- Research registries
- Provincial service provider listings
- Adult mental health services
- Respite services
- School boards
- Developmental Services Ontario agencies

In response to the study advertisement, individuals were asked to email The Redpath Centre requesting further information. In turn, a Research Assistant responded providing information on the study, eligibility, and how to complete the survey.

The survey was accessible by a *confidential* and personalized Internet address (URL) and was not available publicly. This ensured proper screening of potential respondents (i.e., that they had been professionally diagnosed with an ASD or were

reporting on behalf of somebody who had been professionally diagnosed). We emphasized that this was a case-based survey, meaning multiple members of families could not respond to the survey, with the objective that each survey completed would represent *one individual* with an ASD. Paper copies of the survey were provided if requested.

There were three versions of the survey: one for individuals with ASDs, the second for family members, and the third for service providers. All questions across the three versions were similar, but wording was changed as fitting. Identifying information was collected for all individuals completing the survey. This included their name, email address and telephone number for clarification of responses, if needed. On the family and the professional report versions, this identifying information was about the family member and the professional. On the self-report version, this identifying information was on the individual with ASD. Data were collected between August 2011 and August 2012.

### A Woman with Autism

Lina is a 35-year-old woman diagnosed with autism. She lives in an ensuite apartment attached to a group home for persons with intellectual disabilities. Lina prefers time alone and becomes agitated when she is with peers for an extended period. Since childhood, she has engaged in many obsessive behaviors and always insisted on having things in specific places. She works part-time in a ladies wear store, where she unpacks clothing. When she arrives home, she goes through the refrigerator, the bookshelves, and other areas of the house to ensure that nothing was moved while she was gone. She likes creating menus, reading about and making drawings of wildlife, and has volumes of medical books that she reads and rereads. She is obsessed with germs and illness and exerts considerable effort to ensure that her ensuite is spotless at all times.

*Stoddart, Burke, & King, 2012*

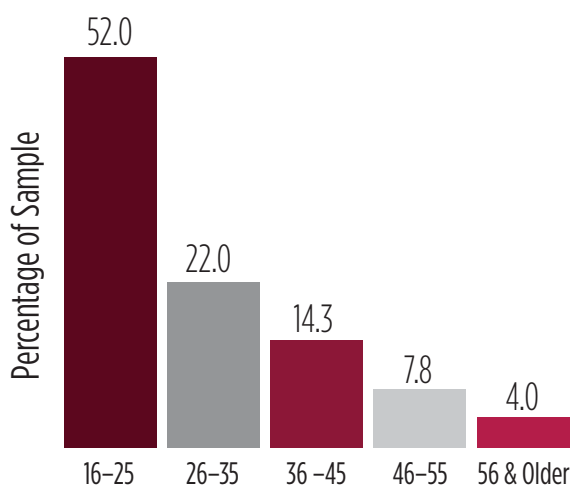


# Description of the Youth and Adults

## Gender and Age

The study was completed by 480 individuals. This provided data on 348 males (72.5%) and 132 females (27.5%). The age distribution of the youth and adults is seen in GRAPH 1. Their ages ranged from 16 to 66 years, with an average of 29.11 (SD=11.86). Of the sample, 80.6% were 40 years or younger.

GRAPH 1: Age Distribution of the Sample



## Autism Spectrum Diagnosis

All respondents were asked for the current Autism Spectrum diagnosis for the person they were reporting on. The largest diagnostic group were those with either high-functioning autism, high-functioning Pervasive Developmental Disorder, or Asperger Syndrome, comprising 244 individuals (50.8%). The second largest group of 114 (23.8%) were those with autism. Seventy five individuals (15.6%) had the broad diagnosis of Autism Spectrum Disorder/Pervasive Developmental Disorder, and 47 (9.8%) were diagnosed with Pervasive Developmental Disorder-Not otherwise specified.

## Intellectual Disability Diagnosis

We asked if the individual with ASD had been “accurately diagnosed with an intellectual disability.” Only 71 (14.8%) reported that they had been. Of those, 42.3% (n=30) had a diagnosis of autism, 33.8% (n=24) had the non-specific diagnosis of PDD/ASD, 12.7% (n=9) had a diagnosis of HFA/HF-PDD/AS, and the remaining 11.3% (n=8) were in the PDD-NOS group.

## Marital and Parental Status

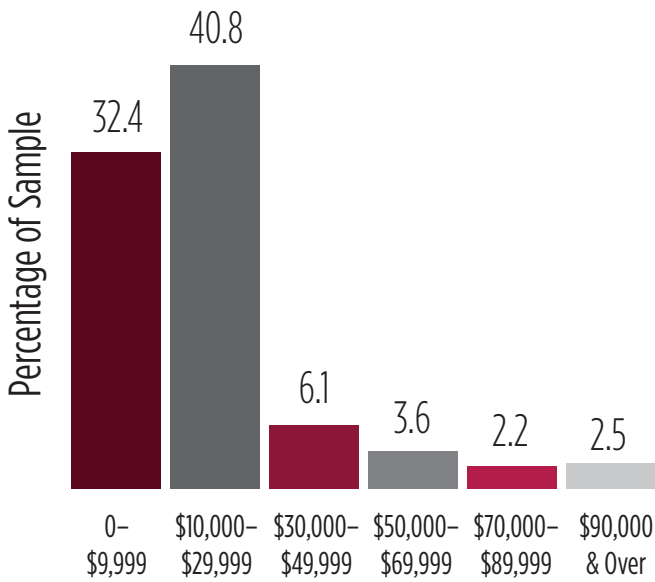
Marital status of the individuals with ASD was reported: 415 (86.5%) were single, 43 (9.0%) were married, 11 (2.3%) were separated or divorced, and 10 (2%) were living common-law. Respondents reported that 10% had biological children.

## Annual Income and Source

Annual income is reported for adults 20 years and older in GRAPH 2. Of this group, 10% preferred not to report income and 4.3% reported that they had no income. Almost 75% had an annual income under \$30,000. The largest source of income was Ontario Disability Support Program (ODSP) for 209 (58.2%) people. Full-time employment was the primary income source for 50 (13.9%) and part-time employment for 22 (6.1%). Source of income was ‘family’ for 47 (13.1%) and ‘other’ for 31 (8.6%). The latter category included: student loans, inheritance, Ontario Works, Canada Pension Plan (CPP), and Old Age Security (OAS). Income amount was not related to gender, but was associated with age ( $p<.001$ ) and income source ( $p<.001$ ).<sup>1</sup>

<sup>1</sup>The 2011 Low Income Cut-Off (LICO) for a single person before tax ranged from \$16,038 in rural areas to \$23,298 in Census Metropolitan Areas with 500,000 inhabitants or more. Source: *Statistics Canada (June 2012) Table 2, Low income cut-offs (1992 base) before tax.*

GRAPH 2: Annual Income for Adults 20 and Older (N=315)



### Type of Residence

We asked where the individual with ASD was residing: 286 (59.8%) were living with family, 65 (13.6%) were living on their own with no supports, 40 (8.4%) were in a group home, 31 (6.5%) were on their own with the support of family and friends, 28 (5.9%) lived on their own with the support of professionals, 11 (2.3%) lived in home share or with live-in supports, and 17 (3.6%) were in other living situations such as institutions and college residence.

### Provincial Region of Residence

Since postal codes were requested, we were determined where in the province the person with ASD was living. They were widely distributed across the province with 191 (39.9) in central Ontario, 138 (28.8%) in metropolitan Toronto, 78 (16.3%) in eastern Ontario, 55 (11.5%) in southwestern Ontario, and 17 (3.5%) in northern Ontario.

### Respondent Information

Information was gathered on who completed the survey. The largest group of 226 (47.1%) respondents was family, 217 (45.2%) were self-reports, and 37 (7.7%) were professionals. For the family report version, 199 (88.1%) respondents were the mother of the youth or adult with ASD, 17 (7.5%) were the father, and 10 (4.4%) were a sibling or other family member (e.g., step-mother, wife, or extended family). For the professional report, the most common professional relationship was group home worker (n=22), with others including behaviour therapists, social workers, respite workers, support workers, and agency representatives.

“People with disabilities are most intimately familiar with and most affected by barriers to health care access, and eliminating these barriers requires [their] input ....” (WHO, 2011, p. 65)



# Receiving an Autism Spectrum Diagnosis

## A Review

While many are diagnosed with an ASD at an early age, such as prior to school or during the primary grades, others may not receive a diagnosis until adolescence or adulthood (Stoddart, Burke, & King, 2012). This may be because of:

- Milder presentation of symptoms;
- Traits that were seen as admirable or unproblematic in childhood;
- Similar features present in family members;
- Misdiagnosis with another disorder;
- Lack of clinicians experienced in milder presentations;
- Little understanding of the presentation in females;
- Few clinicians experienced with older youth; and
- Lack of a diagnostic label (i.e., ‘Asperger Syndrome’) until 1994.

## A Professor with Asperger Syndrome

Robert, a university professor in philosophy, was experiencing increasing problems in social interaction at work. He had been productive in his academic work, despite his struggle of many years with anxiety and depression. Increasing departmental administrative responsibilities and meetings exacerbated his problems with social and organizational tasks. His ex-wife suggested to him that he be assessed for AS, and he agreed. A positive diagnosis of AS and social anxiety disorder resulted in social and organizational accommodations being suggested and used at his workplace. He has sought individual therapy with someone knowledgeable about AS, and his daughter is now being assessed for an ASD.

*Stoddart, Burke, & King, 2012*

Many adults at the ‘milder’ end of the autism spectrum are not diagnosed until they enter the mental health, post-secondary or justice systems, or in response to a psychosocial crisis. Examples of these crises include problems developing relationships, obtaining, or keeping employment. Many late-diagnosed adults recognize that their learning or mental health diagnosis is neither explaining their entire symptom profile, nor addressing the range of their support and intervention needs. An important survey in the UK by Barnard et al. (2001) highlighted the difficulty that higher-functioning individuals had in getting a suitable diagnosis—as many as 46% of their sample there was not accurately diagnosed until they were 16 years old.

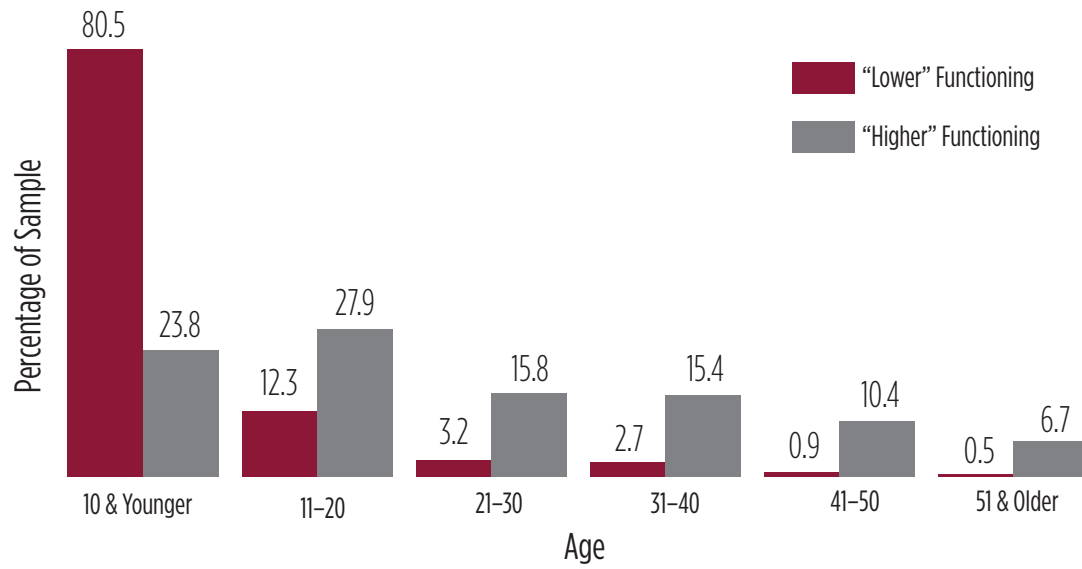
Some youth and adults diagnosed with autism, have a concurrent intellectual impairment (Stoddart, Burke, & King, 2012). Others who function in average or above average ranges of ability may be diagnosed as having AS, autism with a high functioning qualifier, PDD-NOS, or may have been identified as falling in the cluster of ASDs—Pervasive Developmental Disorder or Autism Spectrum Disorder—but are not given a specific diagnosis within the spectrum.

## What this Study Found

Individuals were asked for their age at the time of their first ASD diagnosis, and whether they had ever been reassessed. Of the total group, only 36.3% reported that they had been reassessed. The age of their first diagnosis differed based on the particular diagnosis: those with the diagnoses of autism at a mean age of 5.1 years ( $SD=0.51$ ) those with ASD/PDD (Nonspecific) at a mean age of 9.03 years ( $SD=10.17$ ), and those with PDD-NOS at a mean age of 9.66 ( $SD=11.24$ ). In contrast, the average age of those diagnosed with HFA/AS was 23.51 years ( $SD=16.03$ ;  $p<.001$ ).

In GRAPH 3, we show the age distribution at first ASD diagnosis for those with HFA/AS, contrasted to the rest of the sample. Only 51.7% of the individuals with “high-functioning autism” or AS were diagnosed before 21 years.

GRAPH 3: Age of First Diagnosis for those with HFA/AS vs. Autism/ASD



# Life Skills and Autism Spectrum Disorders

## A Review

Studies of life skills or adaptive skills (also called *functional skills*) in those with ASDs are more common in children who have a concurrent intellectual disability (ID). Adaptive skill deficits are a diagnostic feature of ID and are therefore evaluated during an assessment. However, almost two decades ago, the authors of the *Supplementary Norms for Autism* recognized that cognitive ability and adaptive skills were not necessarily related (Carter et al., 1998). They noted that while adaptive skills can be taught, an individual's cognitive disability may limit the degree to which this can be accomplished. Others have examined adaptive skills in those with autism and ID and found adaptive skills to be more impaired in those with autism, compared with other disorders concurrent to ID, such as mood disorders (Nuovo & Buono, 2007).

At the time of the publication of *DSM-IV* (APA, 1994) and the first inclusion of AS, it was believed that those on the milder end of the autism spectrum would not present with deficits in life skills, except for those which were socially-based. This was founded on an assumption that in this group who were cognitively competent, application of knowledge and skills would follow. However, our clinical knowledge now tells us that many individuals with ASDs do not generalize skills from one setting to another, may not attend to relevant environmental cues, can experience behavioural inflexibility, and may have problems translating skills into action (Stoddart, Burke, & King, 2012).

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“The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly.”  
(WHO, 2011, p. 7)

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Sometimes, the inability to carry out daily life skills is not related to the learning style of those with ASDs, but to other problems. For example, sensory sensitivities may prevent a person with ASD from using cleaning products, preparing food, or being in noisy and bright environments such as shopping malls. Many individuals with ASDs experience fine and gross motor difficulties, which can also limit ability to perform certain tasks, such as tying shoes, using a pen or pencil and navigating stairs safely.

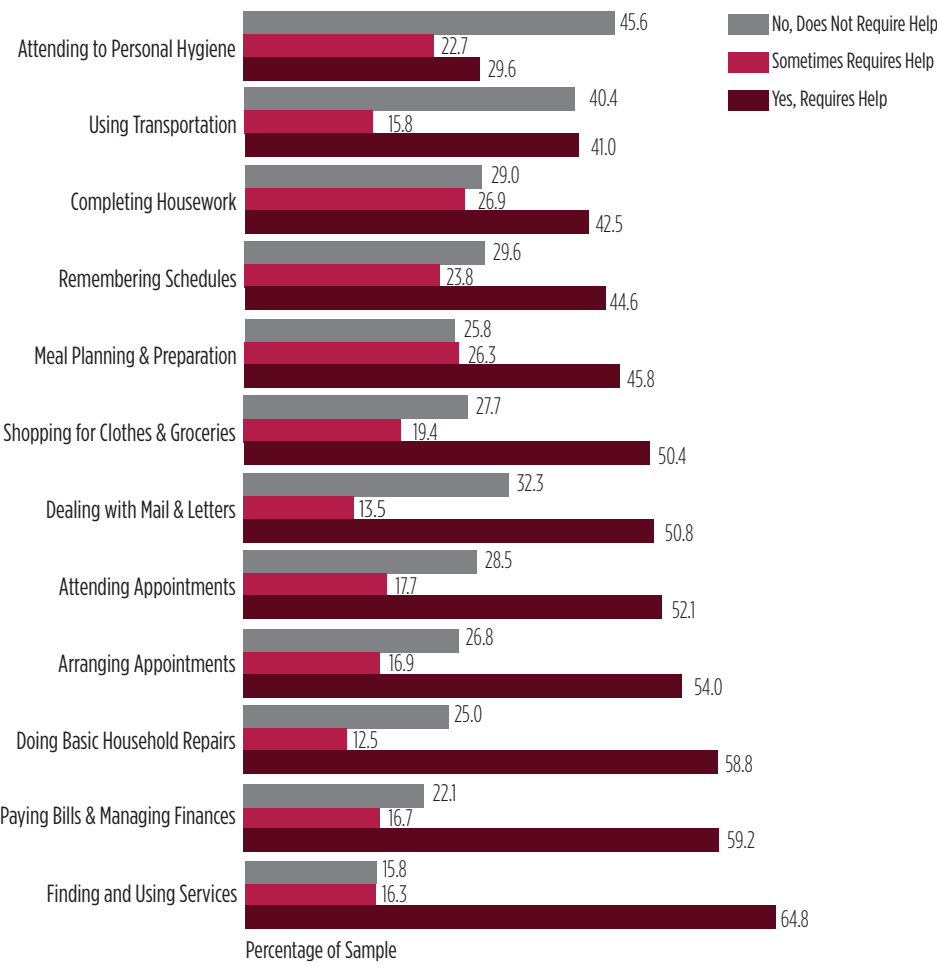
Stoddart, Burke, and King (2012) suggested that problems in basic life skills for those with AS may also relate to: obsessive and compulsive traits and behaviours (e.g., contacting germs); social anxiety; executive functioning impairments (e.g., difficulties organizing and/or initiating); perceptual difficulties (e.g., estimating time and distance); and lack of interest in an activity without the experience of social pressure to complete certain tasks as an adult (e.g., household chores). Those with ASDs may therefore need help with: planning and preparing meals, engaging in household chores, managing finances/paying bills, shopping for food and clothing, attending to personal care, scheduling activities, using transportation, identifying or expressing needs, and finding services.

## What this Study Found

For twelve life skills, respondents were asked whether the individual: ‘No, does not require help’-GRAY, ‘Sometimes requires help’-PLUM, or ‘Yes, requires help’-BURGUNDY. GRAPH 4 summarizes the results of this set of questions.

Through qualitative responses to this section of the survey, family members said that services and supports in the area of functional life skills are lacking. Many pointed out that their family members with ASD need various supports with day-to-day functioning:

GRAPH 4: Amount of Help Required with Daily Life Skills



*“Our daughter’s level of functioning is very low, so she is totally dependent on us for all of her daily needs.”*

*“My son needs care and help with every facet of his life.”*

Similarly, many youth and adults themselves identified personal struggles and areas of functioning where life skills supports would be helpful:

*“Since I was diagnosed as an adult over 30, much of my life has been spent fumbling and struggling with these things. I don’t get any more help for these skills than I ever have.”*

*“I do not generally need help with things like filling out forms, paying bills etc but I need help with overall management such as eating nutritious meals on a regular basis, dealing with clutter at my condo, remembering to open my mail, keeping within a budget, and especially not getting overwhelmed with all*

*the things I have to do...I have a very good psychiatrist I see three times a week and a couple of good friends who monitor me and help manage life issues.”*

The importance of family and the need for family-focused supports were highlighted. Parents described the pressures and stresses they face in supporting the family member with ASD:

*“Without the support of my family, I will need assistance and I’m not too sure where I will find it.”*

*“...as your child with ASD transitions into adulthood it feels even more like a second full time job; isolation for the family member unless part of a parent group is very likely; fear of when you are gone is constant.”*

*“The weight of keeping him alive, when he is sick, lies totally on me....Looking after my family member with autism is a full-time 18-20 hour a day job.”*

# Mental Health and Autism Spectrum Disorders

## A Review

Besides those with ASD and a co-existing ID, other co-occurring issues are commonly identified, particularly in those who have been comprehensively assessed by knowledgeable clinicians (Stoddart, Burke, & Temple, 2002; Stoddart, Burke, & King, 2012). Those problems which are cognitive or neuro-developmental in nature include learning disabilities (Stoddart, Burke, & King, 2012), communication disorders, and attention-deficit/hyperactivity disorder (ADHD; Gillberg & Billstedt, 2000).

Mental health disorders that may be seen alongside ASDs include depression, anxiety, schizophrenia or psychosis (Ghaziuddin & Zafar, 2008), delusional disorders or behaviours (Abell & Hare, 2005), obsessive compulsive disorder (Cath, Ran, Smit, van Balkom, & Comijs, 2008), bipolar disorder (Raja & Azzoni, 2001), eating disorder, Tourette syndrome or tic disorder (Gillberg & Billstedt, 2000), and personality disorder (PD; Lugnegard, Hallerbak, & Gillberg, 2012). Those with ASDs may exhibit sensory processing dysfunction and motor co-ordination disorders (Gillberg & Billstedt, 2000). Behaviour difficulties may also occur such as repetitive behaviours, aggression, self-injurious behaviour, and sleep difficulties. These can range from mild to severe, and sometimes significantly impair an individual's quality of life.

The prevalence of anxiety in those with ASDs reported in research ranges from 11% to 84%. People with AS appear to have a higher incidence of anxiety compared with those with other ASDs (Stoddart, Burke, & King, 2012). Attwood (2007) reports 25% of those with AS have clinical features of obsessive-compulsive disorder, and there is also a high incidence of post-traumatic stress disorder and social phobia. Tantum (2003) stated anxiety is "the most universal and persistent disorder associated with all of the [ASDs]" (p. 157). He further notes anxiety affects an individual's ability to perform socially and increases repetitive behaviours.

Depression is also seen in a significant number of those with ASDs, and is estimated to occur at a rate of 4% to 38% (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Those with depression may show changes in sleep and eating behaviours, avoidance of others, loss of interests and energy, and decreased emotional responsiveness.

The co-occurrence of schizophrenia or psychosis and ASD is a topic of debate. While it is possible for symptoms of psychosis to occur in those with ASDs, more often it appears that a diagnosis of a psychotic disorder has been given when an ASD diagnosis should have been given instead. In reviewing a series of adolescent and adult cases, Tantam (2003) stated that a significant percentage of those with a diagnosis of schizophrenia (10.3%) were later determined to not fulfill diagnostic criteria. He suggested the rate of diagnosis of schizophrenia made in those with ASDs is inflated, because of the presence of some similarities in symptoms across these disorders.

Although personality disorders (PDs) are a potential issue for adults with ASDs, there are few clinical reports of concurrent PDs and ASDs. When comparing PDs in specific ASD groups, Hofvander et al. (2009) suggested that Obsessive-Compulsive PD occurred more in the AS group and Anti-Social PD more in the PDD-NOS group. Another study identified borderline PD in women with ASDs who made suicide attempts (Ryden, Ryden, & Hetta, 2008).

## What this Study Found

In response to the question: "Have you ever been accurately diagnosed by a professional with the following?" respondents reported the frequency of each of the diagnoses, seen in GRAPH 5. Consistent with other research, the most common diagnoses were anxiety and depression. Despite the numbers of diagnoses reported, 31% of respondents felt that an undiagnosed mental health disorder also existed.

We requested information about hospital use. In the last decade, 14% of the youth and adults had a hospital stay (lasting more than 12 hours), and 20% needed emergency services for a “psychiatric, psychological or behaviour problem”. Lastly, individuals were asked about alcohol and drug consumption: 37.1% had an alcoholic drink in the previous six months, 7.9% had used cannabis, marijuana or hash in the previous six months, and 10 individuals (2.1%) had used cocaine (e.g., coke, crack), amphetamines (e.g., ecstasy), hallucinogens (e.g. acid, mushrooms) or opioids (e.g., heroin) in the past six months.

There was an option for respondents to state other “psychological disorders” (See TABLE 1). We calculated the total number of possible co-existing diagnoses that the group had been given, taking into account only the twelve that were specifically asked about in the survey. Of all the individuals, 146 (30.4%) reported no diagnosis other than ASD, 101 (21%) reported one, 111 (23.1%) reported two, 51 (10.6%) reported three, 41 (8.5%) reported four and 30 (6.3%) reported five or more mental health/ neurodevelopmental/intellectual disability diagnoses.

GRAPH 5: Frequency of Each Diagnosis

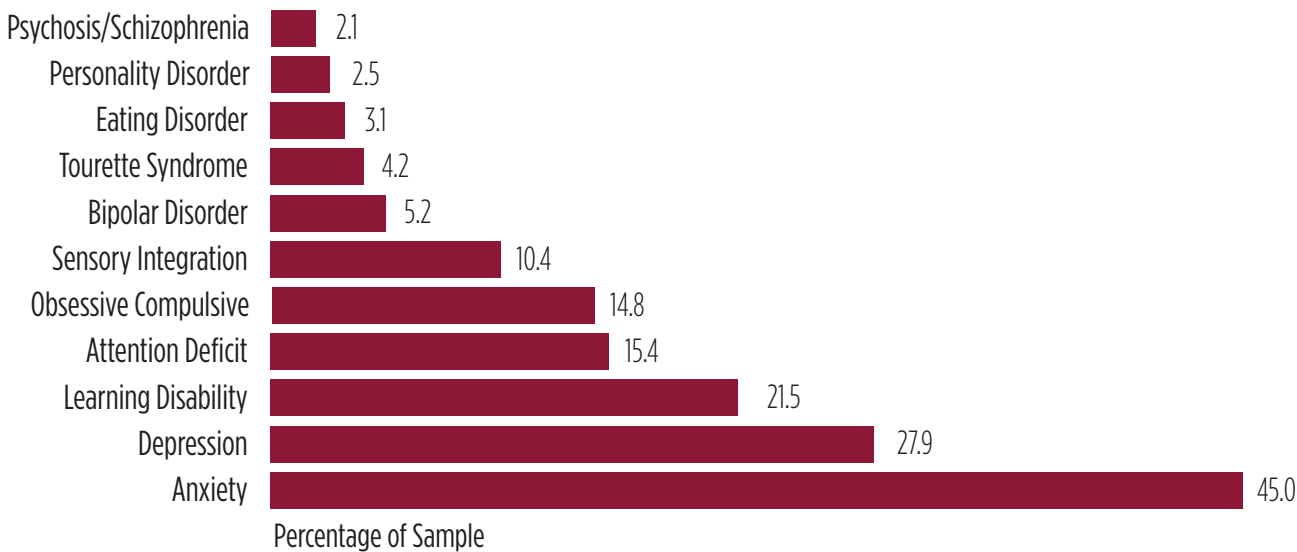


TABLE 1: Other Psychological Disorders

- |  |  |
|--|--|
| 1. Anxiety Disorders (Compulsive behaviour, OCD tendencies, Panic Disorder PTSD, Social Anxiety, Social Phobia, Attachment Disorder) | 8. Neurological Disorders (Dyspraxia, Apraxia, Speech Apraxia, Alexithymia, Central Auditory Processing Disorder)            |
| 2. Disorders First Diagnosed in Infancy, Childhood or Adolescence (Selective Mutism, Oppositional Defiant Disorder, Pica)            | 9. Personality Disorders (Avoidant Personality Disorder, Obsessive Compulsive Personality Disorder)                          |
| 3. Gender Identity Disorder (Gender dysphoria)   | 10. Schizophrenia and Psychotic Disorders (Schizo-Affective Disorder)  |
| 4. Genetic Disorders (Fragile X Syndrome, Rett's Disorder)   | 11. Sleep Disorder   |
| 5. Learning Exceptionalities (Dyslexia, Gifted)  | 12. Speech and Language Disorders (Speech Impairment, Speech and Language Delay, Developmental Speech and Language Disorder) |
| 6. Mood Disorders (Mood Dysregulation, Dysthymia)  | 13. Substance Use Disorder (Alcoholism)  |
| 7. Movement Disorders (Hypotonia, Tardive Dyskinesia)  |  |



# Physical Health, Medication Use and Autism Spectrum Disorders

## A Review

Those with ASDs can present with the same health or medical problems as anyone else; however, there are also medical concerns that appear to occur in those with ASDs at a higher rate than in the general population. Most of the research examining health issues in those with ASDs has focused on children, but a profile of adult health problems is beginning to emerge (Stoddart, Burke, & King, 2012). For example, Gastrointestinal (GI) problems are one of the commonly reported illnesses in children, and there is now general awareness of this in the autism community (Roberts & Kagan-Kushnir, 2005). GI problems can continue into adulthood from childhood, begin in adolescence, or in adulthood. Some have suggested adolescents with ASDs are at increased risk for developing health problems such as seizures and GI problems (Kring, Greenberg & Mailick Seltzer, 2010). More research about adult-onset health and wellness problems is needed.

Often studies on health and ASDs combine adults across functioning levels, so it is not clear what factors might be predictors of medical disorders in those more severely impaired, compared with those who are mildly affected, or if there is a difference (Stoddart, Burke & King, 2012). Several disorders, including those which are genetic disorders, metabolic disorders, as well as other developmental syndromes, exist in those who display more severe symptoms of autism (Miles, McCathern, Stichter & Shinawi, 2010). Some of these include Fragile X, Tuberous Sclerosis, Neurofibromatosis, Hypomelanosis of Ito and Moebius syndrome (Gillberg, 1992; Miles, McCathern, Stichter & Shinawi, 2010).

Gillberg and Ehlers (1998) suggest that fewer than 15% of those on the higher end of the autism spectrum present with comorbid medical conditions. Those most

likely to occur include Fragile X, neurofibromatosis, and tuberous sclerosis. In 2000, Gillberg and Billstedt proposed the following prevalence rates of disorders concurrent with an ASD: Epilepsy (30%), Tuberous Sclerosis (2 to 9%), Fragile X Syndrome (2 to 10%), and Thalidomide Syndrome (4%). In a study of individuals with AS and physical complaints reported by Balfe and Tantum (2010), respondents included vision problems (24%), hearing problems (24%), involuntary movements (36%), genetic problems (16%) and neurological problems (16%).

Medication use in youth and adults with ASDs is similarly unexplored terrain in our knowledge of frequency of medication use, dosing practices, how individuals are prescribed medication, and what, if any, specific symptoms are targeted and monitored in general clinical practice (Stoddart, Burke, & King, 2012).

Although we know little about medication use for physical ailments in youth and adults with ASDs, medication use for mental health, behavioural dysregulation, irritability and inattention are better researched, with the understanding there is no pharmacological remedy to alter the enduring and core features of ASDs. Research and reviews of the usefulness of medications examine their ability to target specific behavioural or mental health symptoms commonly associated with ASDs (Sloman, 2005; Stoddart, Burke, & King, 2012; Towbin, 2003). A recent systematic medication effectiveness review of research on 13 to 30 year olds with ASDs found only eight studies. Four of them were of 'fair' quality and four were labeled as 'poor' (Dove et al, 2012). A similar systematic review published five years earlier found only five double-blind, randomized controlled trials (Broadstock, Doughty, & Eggleston, 2007).

Blankenship, Erickson and McDougale (2010) note, "...many clinicians rely on results from treatment

studies of other psychiatric disorders (ADHD, schizophrenia, OCD) and extrapolate these findings to the [ASD] population” (p. 208). It is important however to understand that some youth and adults with ASDs may have idiosyncratic responses to medication, or respond optimally to lower doses (Sloman, 2005). Most adults with higher functioning ASDs rely on family doctors in Ontario to prescribe psychotropics, as access to knowledgeable psychiatrists is extremely limited (Stoddart, Burke, & King, 2012). Unfortunately, the use of more than one psychotropic medication in adults with ASDs is common. A recent Ontario study found that among predictors of polypharmacy among 142 adults with ASD who had experienced a “psychiatric crisis” 41 (28.9%) were taking three or more psychotropic medications simultaneously (Lake, Balough, & Lunskey, 2012).

Selective serotonin reuptake inhibitors (SSRIs) are one of the main treatments for depression and anxiety and other mental health disorders in the general population. Examples of SSRIs include Prozac, Luvox, Paxil, Zoloft, Cipralex and Celexa. A study in Toronto that examined medication use found these medications, sometimes combined with others, were frequently used to manage anxiety, behaviour and depression in adults on the autism spectrum (Stoddart, Burke & Temple, 2001). Studies of this group of medications for adults are at an early stage; they are often at an open label, small uncontrolled trials, or case report level (Dove et al, 2012; Stoddart, Burke, & King, 2012) although they are routinely used in clinical practice.

Another class of medications used in the youth and adult ASD population are anti-psychotics. The newer, atypical antipsychotics include Risperdal, Seroquel, Zyprexa, and Abilify. Many of these are used to address behavioural problems, irritability, anxiety, and psychosis. Again, compelling research on the usage, dosing and symptoms successfully treated in youth and adults is early, but promising results have been found for Risperdal, for example (Dove et al., 2012).

Finally, stimulants have gained increasing use with higher-functioning youth and adults with ASDs (such as Asperger Syndrome) since we have recognized that distractibility and inattentiveness

may successfully be reduced by medications such as Ritalin, Dexedrine, Adderal, Strattera and Concerta (Sloman, 2005; Stoddart, Burke, & King, 2012,).

## What this Study Found

The survey asked respondents to identify up to three medical or health issues. A total of 296 conditions were named and grouped into the categories seen in TABLE 2. Of these 296 conditions, 92 individuals (19.2% of the sample) had one, 48 (10% of the sample) had two, and 36 (7.5% of the sample) had three conditions. There was no relationship between numbers of illness reported for each person and diagnosis or gender. However, there was a weak but significant correlation between number of illnesses and age ( $r = 0.250$ ;  $p < .01$ ). In total, 176 (36.7%) respondents identified at least one medical or health condition.

### A Non-Verbal Man with Autism and Intellectual Disability

Thomas, now 40 years old, recently moved to a group home from a facility for those with developmental disabilities, where he had lived since age 6. Three other men live at Thomas's new home, which has 24-hour supervision. His meals are prepared and he receives assistance with his activities of daily living. Thomas has a history of severe self-injury, and there is a behavioral program in place to manage these episodes. Thomas does not use speech, but he does communicate with some sign language and pictures. He is aware of his housemates when they intrude on his space, but otherwise he appears uninterested in them. He enjoys the attention of staff members, however, and will let them know when he wants something by poking their arms or pulling their shirts. His preferred activities are rocking back and forth to music, drinking Coke, and assembling Legos and puzzles. He also enjoys flushing toilets, running water from taps, and flicking lights off and on. He has been diagnosed with a severe intellectual disability and autism.

*Stoddart, Burke, & King, 2012*



TABLE 2: Illnesses and Health Conditions (N=296)

Illness and Health Condition	Frequency of Illness	Percentage of Illnesses	Percentage of Sample
Brain and spinal cord disorders	51	17.23	10.62
Digestive system disorders	47	15.88	9.79
Lung and respiratory disorders	45	15.20	9.38
Hormonal and metabolic	31	10.47	6.46
Musculoskeletal disorders	31	10.47	6.46
Sleep disorders	14	4.73	2.92
Skin conditions	12	4.05	2.50
Weight disorders	12	4.05	2.50
Hypertension	11	3.72	2.29
Reproductive disorders	11	3.72	2.29
Vision and hearing disorders	11	3.72	2.29
Liver, kidney and urinary	6	2.03	1.25
Blood disorders	4	1.35	0.83
Immunological disorders	4	1.35	0.83
Cancer	3	1.01	0.63
Cardiac disorders	3	1.01	0.63

We asked if the youth and adults were prescribed medication and if so, what the medication(s) were. Of all respondents, 177 (36.9%) were on no medication, 91 (19.0%) were taking one, 83 (17.3%) were taking two, 47 (9.8%) were taking three, 29 (6.0%) were taking four, 43 (9.0%) were taking five, 7 (1.5%) were taking six, and 3 (0.6%) were taking seven medications. The mean number of medications was 1.65 (SD= 1.76); 63.1% of the entire sample was taking medication. A total of 792 prescribed medications were being taken by the entire group (M = 1.65; SD = 1.76). Medication use was correlated with age ( $r = 0.220$ ;  $p < .001$ ), number of physical illnesses ( $r = 0.348$ ;  $p < .001$ ), and number of psychological diagnoses ( $r = .283$ ;  $p < .01$ ). Number of medications used was not related to diagnostic group. In TABLE 3, we list the fifteen most frequently noted medications, used ten times or more in the sample.

Through the open-ended question related to medical health, many family members expressed their frustration locating knowledgeable medical professionals:

*“It is difficult to find medical doctors who will accept patients with ASD...”*

*“...last two years multiple health problems that were not investigated properly by his local Dr....Needed to be referred to specialists that do not exist in the area he lives in...lives in underserviced area...”*

*“Any medical services through the hospital have been very difficult, as nurses and doctors are very busy and are either unwilling or unable to provide the extra support and/or time needed to avoid major problems. We are very hesitant to take our son to the hospital for that reason.”*

*“Medical services for the autistic community are severely lacking. Mainstream doctors don’t know how to test for and treat underlying problems such as digestion and food and chemical sensitivities.”*

*“Shortage of knowledgeable physicians (particularly psychiatrists and neurologists) in the area.”*

Furthermore, families were concerned about healthy lifestyle issues:

*“Although there are not specific health issues, the individual does not have habits that contribute to good physical health (e.g. good eating habits and exercise). This in combination with current medication has contributed to excessive weight gain over the past couple of years.”*

Table 3: Medication in Use by Individuals 10 Times or More

Medication	Frequency	Percent
Risperidone	63	8.0
Seroquel	30	3.8
Zoloft	30	3.8
Celexa	27	3.4
Prozac	26	3.3
Cipralex	24	3.0
Effexor	19	2.4
Paxil	17	2.1
Lorazepam	15	1.9
Tegretol	12	1.5
Abilify	11	1.4
Clonazepam	11	1.4
Concerta	10	1.3
Divalproex	10	1.3
Wellbutrin	10	1.3

# Social Involvement and Autism Spectrum Disorders

## A Review

Struggles with social interaction are among the diagnostic criteria for ASDs (APA, 2000). While these difficulties are usually first noted in childhood, they may become more pronounced and complex as individuals with ASDs enter adolescence and adulthood. This is especially important, as it has been recognized that a lack of peer relationships may have a negative effect on mental health throughout the lifespan (Whitehouse, Durkin, Jaquet, & Ziatas, 2009).

Little is known about social interaction trends among youth and adults with ASD. An early study of peer relationships and participation in social and recreational activities by adolescents and adults with ASDs living at home found the likelihood of having peer relationships and engaging in social/recreational activities was low (Orsmond, Wyngaarden Krauss, & Malik Seltzer, 2004).

A more recent study (Liptak, Kennedy, Dosa, & Nienke, 2011) used data from the National Longitudinal Transition Study-2 to examine the social experiences of youth with ASD. Findings showed that many youth had not socialized, nor talked on the phone with friends in the previous year. The authors concluded that adolescents and young adults with autism may become increasingly isolated over time. Findings also revealed that poorer conversational and social communication skills were associated with a lower likelihood of social participation, speaking to friends by phone, being invited to social activities, and non-participation in out-of-school activities. Thus, the diversity of traits and abilities that are found among individuals with ASDs leads to differing quality of relationships and frequency of social interaction.

Research examining the experiences of youth and young adults with ASDs about their experiences with relationships and friendship also reveals a

range of outcomes. These include: retreating from friendships, feeling ambivalence about friendship, or pursuing friendships (Marks, Schrader, Longaker & Levine, 2000). Others, interested in socialization, have described using a technique of “masquerading” (Carrington, Templeton & Papinczak, 2003), to mask social difficulties in an attempt to conform and fit into the high school social milieu.

Studies of adults with ASDs have found similarly divergent responses (Jones, Zahl & Huws, 2003). Internet sites of adults with ASDs reveal that they experience a sense of alienation from society, frustration with the world, feelings of depression, and a pervasive sense of fear. In contrast, more positive themes were found by Hurlbutt and Chalmers (2002) where adults described valuing support systems offered through family and spiritual communities. Howlin, Goode, Hutton, and Rutter (2004) also found variable adult socialization outcomes with some individuals having meaningful social relationships while others remained isolated and dependent.

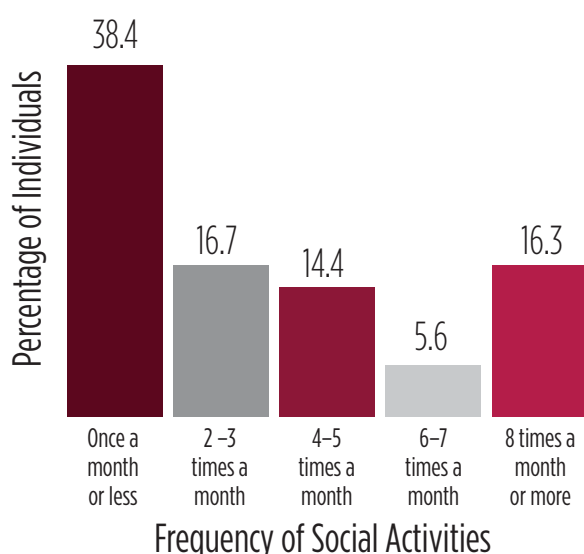
## What this Study Found

We asked respondents ten questions about social involvement:

- 81.8% indicated they had difficulties taking part in social activities
- 73.7% stated that they did not find it easy to make friends
- 60.9% indicated they did not have as many friends as they would like to have
- 59.1% said that they did not find it easy to keep friends
- 57.3% noted they did not have a “best friend”

- 43.6% felt that there were social groups for adults in their community
- 33.1% said that they engaged in on-line social networking
- 32.1% reported they have had a romantic or intimate relationship in the past
- 14.9% stated they were currently in a romantic relationship

GRAPH 6: Frequency of Social Activities



The frequency of participation in social activities is reported in GRAPH 6. Of the total number, 44 respondents were unsure or skipped the question.

In an open-ended question about social activities and involvement, both family members and individuals themselves were concerned about reluctance to participate in social activities as well as feelings of social isolation:

*"We are very concerned about his isolation/reclusion"*

*"I find it extremely difficult to meet people because of my isolation, and even when I do meet people, I have trouble forming and maintaining anything more than an acquaintance-level friendship for the most part. The few close friends that I have mostly live far away,*

*which again limits my social interaction drastically."*

*"I generally prefer one-on-one situations. I tend to feel left out, overlooked in groups. Still hard to fit in."*

Respondents also commented on avenues for socialization. Some individuals with ASD socialized online, others socialized in person:

*"Online he is fine and active with a sci-fi role play group, but in person he has great difficulties."*

*"I socialize mostly online."*

*"My son has 900 friends on Facebook but is rarely invited to any real social activities. I think his friends don't want to take responsibility for introducing him to bad habits that might get him into trouble. They are protecting him by not inviting him to parties etc."*

*"I am not too bad one on one with people but any social activity that involves several people is extremely draining for me and exhausts me quickly."*

Others reported a desire to be social and to have and maintain friendships:

*"My son does not really have any friends. He would like them but has no friends currently. His social activities are family gatherings or meeting with therapist and counselors. Currently he lives at home and does not have routine social activities that get him out."*

*"I'd like to have more friends because I am able to be a loyal and helpful friend to those I know. I just find it a challenge to make more friends."*

Some family members indicated that the family member with ASD required supports to facilitate and/or initiate social participation:

*"Social activities are not initiated by our son. He must be facilitated to participate successfully"*

*"Social activities do not exist for my son except for the time he spends with the support workers we pay for."*

*He has no friends – no one other than his family that spends time with him unless they are being paid.”*

In addition, individuals with communication challenges were limited in their social participation:

*“The level of my daughter’s ASD and having low verbal skills makes socializing hard”*

*“His lack of social and communication skills combined with inappropriate behaviors make it impossible to participate, in a significant way, in social activities.”*

Respondents indicated that there are few socialization programs for adults:

*“The only social interaction she gets is from her day program- weekends or evenings there really isn’t anything out there.”*

*“There is a great need for more social activities geared to individuals with a variety of needs and abilities.”*

*“Most groups for adults are for adults with developmental disabilities. It is difficult to find anything tailored just for adults with ASD. Our son doesn’t fit into these other groups because those adults have communication abilities and social skills.”*

Finally, respondents indicated that the family served as the primary social network for many adults with ASD:

*“His “best friend” is his mother”*

*“Actually, my son’s “Social Activities” are gathering with our family members and friends, he doesn’t have his own friends.”*

*“I do participate in social activities with my direct family, but I rarely interact with others.”*

“Progress on improving social participation can be made by addressing the barriers which hinder persons with disabilities in their day to day lives.” (WHO, 2011, p. 4)

## A Young Woman with Asperger Syndrome in University

Ellen, a young woman who reads fantasy novels voraciously, was struggling with the demands of university life in another city, and came for a psychological assessment. Her academic adviser had questioned if she had attention-deficit/hyperactivity disorder (ADHD). She still had a few close friends from early childhood and had managed to cope with the demands of both grade school and high school. As a child, she had been diagnosed with an unspecified learning disability and received numerous accommodations throughout her school years. With the support and advocacy efforts of her parents (both teachers), she was offered admission to a university. However, without academic supports and the assistance of her family, she failed her first year and was not offered admission for her second year. At our center, she was diagnosed with a learning disability and AS and now receives specialized academic counseling at her new college program.

*Stoddart, Burke, & King, 2012*

# Daily Activities and Autism Spectrum Disorders

## A Review

Adults with ASDs have difficulty finding suitable educational and occupational activities following high school (Taylor & Seltzer, 2010a). This problem is pronounced for individuals without IDs. Taylor and Seltzer (2010) found that one-quarter of individuals with ASD and no IDs had no occupational, educational or day activities, which is a rate three times higher than those with ASD and co-existing IDs. A longitudinal study of youth with ASD found that improvement of autism symptoms and maladaptive behaviours slowed significantly after high school exit, particularly for young adults without IDs. They attribute this to changes in disability-related services and less stimulating activities being available, versus those in their previous high school environment (Taylor & Seltzer, 2010a). Shattuck et al. (2012) found more than half of individuals with ASDs were not involved in either post-secondary education or employment two years after high school. This rate remained high at 34.9% six years after high school completion.

## Post-Secondary Education

Many adults with ASD are intellectually capable of post-secondary level education (Stoddart, Burke, & King, 2012; Vanbergeijk, Klin, & Volkmar, 2008) and indicate an interest in pursuing it (Camarena & Sarigiani, 2009). In addition, the specific and intense interests of individuals with ASD can lead to having extensive knowledge and motivation, potentially leading to academic success (Luckett & Powell, 2003). Post-secondary education offers a degree of predictability, structure, and routine that individuals with ASD seek, as well as providing social opportunities (Vanbergeijk, Klin, & Volkmar, 2008).

Despite their interest and skills, participation rates of individuals with ASDs in post-secondary education are lower than in the general population, and other disability groups. In a national representative survey in the United States, Shattuck's group (2012)

found that 34.7% of individuals with ASDs had attended college during the first six years after high school; an additional 9.3% had attended a vocational or technical education program. This is a substantially lower rate of post-secondary education participation than in the general population, as well as in comparison to those with speech and language impairments and learning disabilities. Figures from a recent study in the UK also suggest that post-secondary participation rates for individuals with ASDs are substantially lower than for the general population (OECD, 2012; Wittemeyer et al., 2012).

Post-secondary education involves personal, social, and academic challenges. Unconventional understanding and use of language, as well as difficulty interpreting and displaying nonverbal cues can lead to difficulties both inside and outside of classes. Social interaction during group work, presentations, and lectures may be especially challenging (Alcorn MacKay, 2010; Luckett & Powell, 2003; Taylor, 2005). Students with ASD may have problems managing courses unrelated to their interests and integrating their areas of focus into course expectations. This applies to completing tests and assignments, as well as interactions with classmates and teaching staff (Adreon & Durocher, 2007; Alcorn MacKay, 2010; Camarena & Sarigiani, 2009). In addition, many students with ASDs struggle with organization, study habits, writing and presentation skills (VanBergeijk, Klin, & Volkmar, 2008).

The transition to post-secondary education itself is a major challenge for students with ASDs. It involves entering a novel environment with new routines, reduced structure, a variable schedule, and decreased supports. These challenges come with increased academic and social demands and with a greater expectation of independence in life skills such as budgeting, meal preparation, transportation, cleaning and personal hygiene (Adreon & Durocher, 2007; Camarena & Sarigiani, 2009; VanBergeijk, Klin, & Volkmar, 2008). Because of these challenges alone, participation in post-secondary education



can cause considerable stress, the impact of which can aggravate existing (sometimes untreated or poorly treated) co-morbid conditions, particularly anxiety and depression (Luckett & Powell, 2003; VanBergeijk, Klin, & Volkmar, 2008).

## Vocational Activities and Employment

The ASD population struggles with securing and keeping meaningful employment. Underemployment is also an issue. Underemployment occurs when individuals are working in positions that they may be overqualified for based on their skill levels and education. Studies of the American Vocational Rehabilitation System point out significant increases of individuals with ASD (almost 300%) accessing supports over the past few years (Cimera & Cowan, 2009; Smith & Lougas, 2010; Stadifer, 2011). Stadifer (2011) argues the employment rate for people with ASDs is even lower than the rate for those with other disabilities. Dew and Alan (2007) suggest that roughly 90% of adults with autism are unemployed or underemployed. Similarly, Edmonds and Beardon (2008) suggest that more than 80% of adults with AS in the UK are un/under-employed.

Reviews of vocational supports show major gaps in current approaches to working with those with ASD. In a 2008 study, Lawler, Brusilovskiy, Salzer and Mandell examined the experiences of 382,221 adults accessing the Vocational Rehabilitation System in the US. Of this sample, 1,707 were diagnosed with ASD. It was determined that members of this subgroup were more likely to be denied services because they were considered too severely disabled. Further, Standifer argues in his 2009 analysis of Vocational Rehabilitative programs that one state had a 90% drop out rate of ASD participants

“Persons with disabilities experience worse educational and labour market outcomes and are more likely to be poor than persons without disabilities.” (WHO, 2011, p. 39)

enrolled in programming, theoretically attributable to the diversity of individuals with ASD.

Although it is evident the ASD population is not being sufficiently serviced through vocational supports, there is also limited research on ASD-specific vocational interventions. Mawhood and Howlin (1999) studied outcomes of an ASD vocational program compared to a control group which did not receive ASD specific employment supports. Those in the ASD group had higher salaries, worked longer and reported more satisfaction than the control group. Howlin, Alcock and Burkin (2005) note few employment programs are customized to those with ASDs. They conducted a longitudinal study on employment outcomes for individuals with ASD in 192 job placements. The ‘Prospects’ model enabled the greatest increase in salary and satisfaction, suggesting that customized ASD programming is helpful to ensuring meaningful employment.

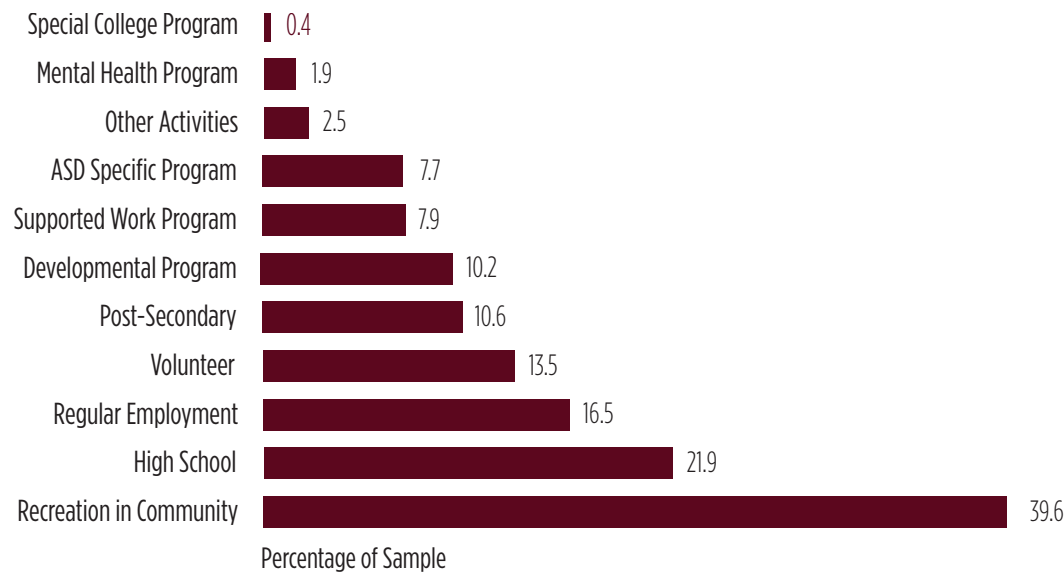
A limit of this review is the lack of information on individuals with ASDs who have not accessed vocational supports. Further limitations exist in the lack of Canadian content, although a Canada-wide study is currently underway (Nicholas, et al., in process).

## What this Study Found

GRAPH 7 depicts the daily activities of the sample in this study. Individuals were allowed to indicate as many activities as were applicable. An option for “other meaningful activities” was coded from narrative responses. A final category was created for those respondents who indicated that the individual engaged in no regular, structured meaningful activity outside of the home. Responses such as the following were included in this category:

- Stays at home with a live-in caregiver
- Listening to music, computer, TV
- Spends the day on the computer or sleeping
- Sits home with mom
- Eats, paces, tears up papers, sometimes gets violent
- ...in his room night and day will only come out when we are asleep...

GRAPH 7: Daily Activities Reported



There were 32 individuals (6.7% of the sample) in this category. It is notable that 41 individuals (8.5% of the sample) reported ONLY chores at home. Combining these groups, 73 individuals (15.2%) of the sample had NO regular meaningful or structured activities outside of their home.

Degree of satisfaction with the daily activities was asked, and the responses were: “Very Satisfying” 14.8%, “Satisfying” 40.0%, “Neutral/Undecided” 29.6%, “Unsatisfying” 9.9% and “Very Unsatisfying” 5.0%.

In terms of education, 57.9% of the sample graduated from high school, while 16.9% were in the process of completing high school. Of the entire sample, 44.8% had taken some post-secondary education courses and 28.5% had completed a degree; for 5.8% their program was in progress. The highest academic level earned in post-secondary education was a diploma/certificate for 58 individuals (12.1%), a Bachelor’s degree for 57 individuals (11.9%), a Master’s degree for 15 individuals (3.1%) and an MD/PHD/LLB for 9 individuals (1.9%).

Respondents were asked for their job title if they were employed. We have listed in TABLE 4, the job type as classified by National Occupation Classification Codes. In total, 139 reported full or part-time employment which is 30.2% of the total sample.

The final question in the “Daily Activities” section of the questionnaire was open-ended and asked if participants had any general comments on the questions in the section. Some parents of youth who were still attending high school worried about what the future held:

*“still a student...but anxious about the future.”*

*“My son is still in High School. I am quite concerned about what is going to happen with him when he is done High School and what services will be available to him at that time. I am close to retirement and need to know he will be taken care of if something should happen to me.”*

Participants who were employed on either a full-time or part-time basis elaborated on aspects of employment that were challenging, particularly their social experiences at work:

*“There are some aspects of the job that are satisfying, e.g. the social interactions however the work itself is not.”*

*“Although I am employed full time, I have great difficulty working with others and have changed jobs frequently throughout my adult life. Even when I explain to co-workers and managers, they do not*



Table 4: Occupation Types for Employed Individuals (N=139)

Occupational Category	Number Employed	Percent of Employed
Sales and Service Occupations	42	30.2
Business, Finance and Administration	21	15.1
Art, Culture, Recreation and Sport	19	13.7
Education, Law, Social, Community and Government Service	12	8.6
Natural and Applied Sciences	9	6.5
Management and Business Owner	8	5.8
Manufacturing and Utilities	8	5.8
Natural Resources and Agriculture	6	4.3
Cannot be Coded	6	4.3
Health Occupations	4	2.9
Trades, Transport and Equipment Operators	4	2.9

*understand my perspective and remain....vengeful of what they consider my rudeness and/or “bad attitude”. I am again in the position where I am seriously considering quitting my current job, even though it pays well and I’m quite good at it.”*

In terms of meaningful daily activities, aside from formal employment, respondents expressed concerns regarding limited satisfying daily activities:

*“When she is no longer in school she will have no meaningful activities to fill her day. She will not have a high school diploma. As for home leisure skills, unless we are taking her out with us, she spends most of her time at home on computer (Facebook etc) or watching TV.”*

*“[Family member] has a lot to offer if given the chance to broaden her horizons. She needs to keep progressing in life skills and to fulfill her dream of someday working in something she enjoys and has talent to do.”*

# Services and Supports for Autism Spectrum Disorders

## A Review

A recent paper on services for adults ASDs noted: “the evidence base about services for adults with ASD is underdeveloped and can be considered a field of inquiry that is relatively unformed” (Shattuck et al., 2012a, p. 288). When considering service provision for individuals with ASDs, it is necessary to address “their social and communication needs, their need for structure, for work and recreation/leisure, and their need for a safe and caring place of residence” (Bryson & ASO, 1991, p.11). In addition, personal safety, transportation, health/wellness and sexuality are other critical aspects of adult life that require programs, services, and supports (Gerhardt, n.d). Overall, “people with ASD face a scarcity of available services and supports when they become adults” (Autism Ontario, 2008, p. 9).

Bryson and ASO (1991) highlighted key components that have led the most innovative and specialized programs to success: “stable funding, a strong and supportive administration, dedicated and knowledgeable staff, family involvement, professional expertise, structured and well-staffed programs and, equally important, a mission to serve people with autism as well as possible” (p.19).

Considering residential supports and living arrangements, group homes, supported housing, and family homes are most commonly used. Research notes few adults with an ASD live alone—many live with their families, particularly their parents” (Piven et al., 2011). For example, a survey of 143 caregivers in the Midwest US supporting an individual with ASD reported that 54% lived with both parents (Graetz, 2010). Bennett and colleagues (2005) looked at the provision of care for adults with ASD and found that most of the autism diagnosed group lived in supported housing. In Ontario, for adults with intellectual

disabilities and psychiatric or behavioural co-morbidities “the most common living arrangement is living in a group home (33%), followed by living with parents or siblings (26%)” (Ouellette-Kunz et al., 2007, p.6).

The literature on the provision of financial supports is unanimous in saying that funding is rarely assured, even though it is critical for both families and service providers (Bryson & ASO, 1991). Even when financial supports are available, “individuals with IQs greater than 70 are routinely excluded from such funding and supports” (Autism Ontario, 2008, p.7). It has been recommended that financial supports be “not tied to claw-backs” through ODSP, Registered Disability Savings, and welfare programs” (Autism Ontario, 2008, p.8).

With respect to assessment and therapy services, Murphy et al. (2011), highlighted that “increasing awareness of autism has resulted in a large increase in people seeking a diagnosis of autism so that referrals to all services...have significantly increased in the last 2 years” (p.26). Yet, others pointed out there has been mostly “a focus towards the assessment and treatment of the psychiatric illness rather than offering an integrated approach that delivers interventions for the social and communication deficits” (Ward & Russell, 2007, p.24). Only 23.1% of adults with ID and ASD receiving mental health services in south-east London, were reported as receiving an adjunctive therapy, such as a behavioural intervention plan or other intervention (Tsakanikos et al., 2007), compared with 36.7% of the participants who took psychotropic medications. Further, behaviour therapy, sensory and occupational therapy, speech and language therapy, and physical therapy have been reported as services to which adults with ASD need access (AFAM, 2010; Crane et al., 2008). Interviews of families of adults with ASD showed that “only 8% received speech therapy, but this was a service that families regarded as highly desirable” (Hare et al., 2004, p.434).

When looking at other services including recreational programs, advocacy/case management, medical emergency services, psychiatric crisis services, recreational day program, and employment services, clinical experience and the literature suggests such services are widely needed by youth and adults with ASD (Stoddart, Burke, & King, 2012). Regarding recreational services, a survey of adults with ASD in Massachusetts reports that “92% of respondents need or will need a program that includes opportunities for social and recreational activities” (AFAM, 2010, p. 19).

With regard to medical care services, some studies have expressed concerns that “adults with developmental disabilities are not receiving suitable health care services that include preventative practices, screenings, and dental services (Bruder et al., 2012, p.1), and there is a scarcity of doctors and dentists who understand and deal with autism (Graetz, 2010). A study on the characteristics of adults with ASD admitted to a specialized Dual Diagnosis Program reported that “individuals with ASD comprised about a quarter (27%) of all clients who were admitted to the program” (Prichard et al., 2012, p. 6). Others have noticed the low representation of high-functioning/non-ID individuals in psychiatric hospitals and emergency psychiatric settings, which have led them to suggest that perhaps such diagnoses are unrecognized (Lunsky et al., 2009; Raja & Azzoni, 2001).

Lunsky, Gracey, and Bradley (2009) reported on adults with a concurrent ASD/ID in psychiatric hospitals in Ontario. This patient group tended to be younger than other patients, had a longer hospital stay, needed a higher level of care than those without an ID, and were less likely to have a diagnosed psychotic disorder. The authors concluded: “this small sub-group of individuals within the hospital population has high clinical needs that are not always well met” (p. 1006).

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“People with disabilities and their families often incur additional costs to achieve a standard of living equivalent to that of non-disabled people.” (WHO, 2011, p. 43)

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Considering service priorities for adults with AS, researchers and clinicians have identified support in employment, help in getting suitable accommodation and getting social skills training as highest priorities; counselling, getting a diagnosis, social groups as second highest priorities; followed by single point of contact/drop in centre, support to access benefits, AS specific mental health service, home help/supported living, and AS specialist staff as third highest priorities (Beardon & Edmonds, 2007). In those with concurrent ASDs, intellectual disability, and mental health disorders, treatment should depend on the developmental level of the person as well as the intensity of the presenting symptoms. For those with more severe symptoms, intensive behavioural approaches or inpatient treatment may be required.

In summary, “this population uses a wide variety of services but specific data about service access, cost, and effectiveness are sparse” (Shattuck et al., 2012, p. 284). The data on use of services by youth and adults with ASDs in Canada is virtually non-existent, although models are now being presented (Autism Ontario, 2008; Stoddart, Burke, & King, 2012)

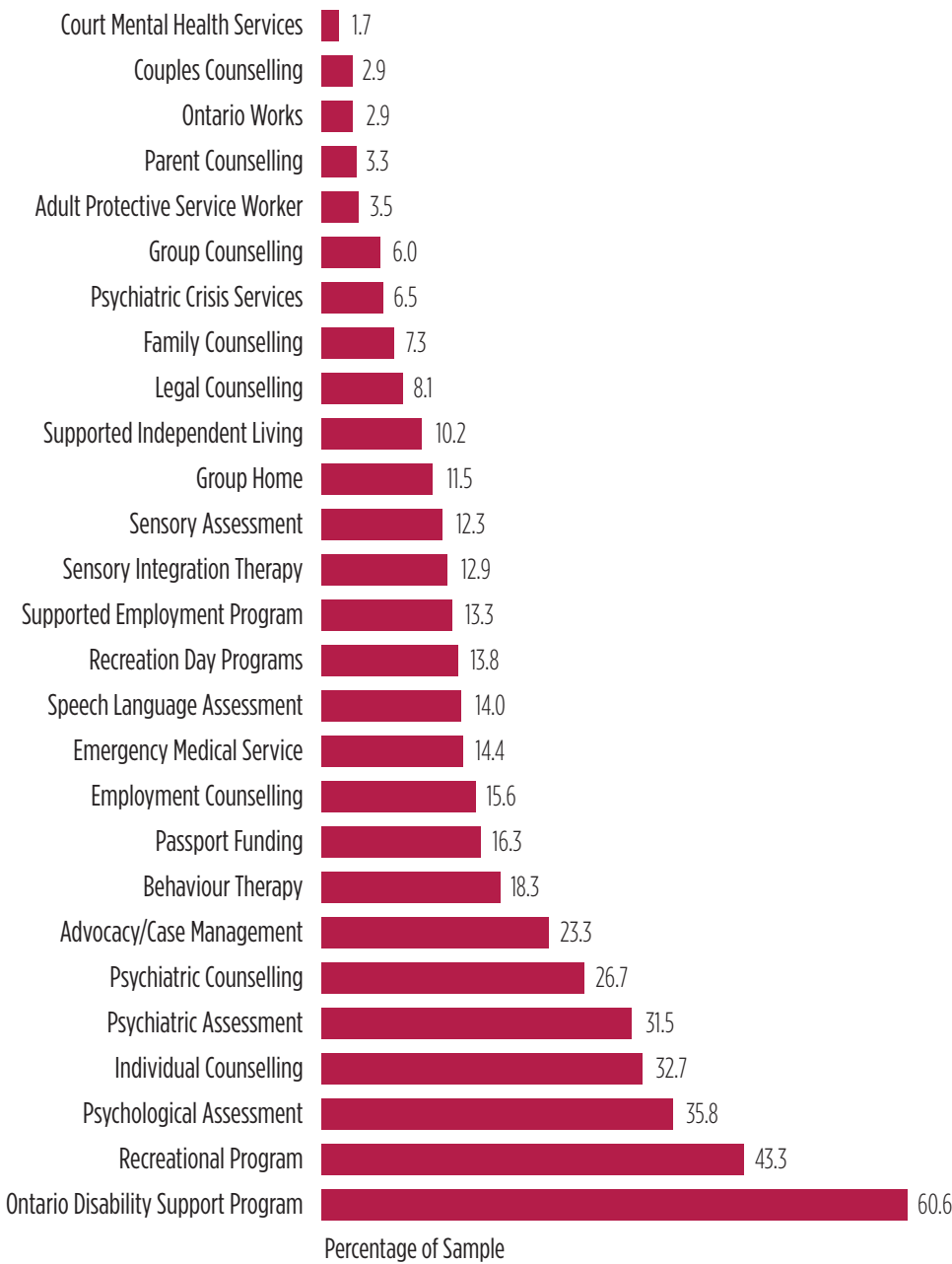
## What this Study Found

We asked respondents in an open-ended question: “Have you had any positive experiences or problems finding and accessing appropriate services and supports. Please describe your experiences”. Many expressed their frustration with uncoordinated, severely lacking, or limited services and supports. Efforts to find and monitor services and supports were often the role of families:

*“The positive experiences are few and far between... and the problems too long to list. We have had to fight for every single penny our son receives in support of his dignity, independence, integration, and equality of opportunity... I am completely frustrated by this system and know that the worse is yet to come.”*

*“It has fallen to his family to step in and fill the gap in hopes that somebody in [our area] will eventually get off their rear end and recognize he needs some assistance to live the independent life he has chosen...”*

GRAPH 8: Current Service Use by Youth and Adults (N=341)



*“I worry about long-term planning and financial supports for my [family member] given his ongoing needs.”*

*“My parents mostly do that, but I can tell it’s been frustrating.”*

*“Educational services were a positive experience in public school, and had to be fought for when entering secondary school. Once the secondary school services were in place however it has been a positive experience. All other services always seemed to be hidden and not readily found.”*

Similarly, others expressed frustration with respect to general service gaps, system navigation issues, and waiting lists:

*“...Once she leaves school, she’ll have only SSAH and we will truly feel “dropped off a cliff.”*

*“[Our] daughter was on waiting list for several years for OT; by the time she was accepted she was over 18 and unable to use the services.”*

*“It was a horrendous and arduous ordeal....we had to jump through a maze of hoops over two years time to access these services.”*

*“As a high-functioning adult, [family member] has always fallen through the cracks in the system vis-a-vis autism supports”*

*“Our experience is that there is very little available or accessible for young adults. Our goal is to find a day program that would support him in finding a meaningful way to contribute and be integrated into his community.”*

*“I have no idea what might be out there that could help, but it'd be nice to have some.”*

*“It's all very confusing and frustrating for me. There are so many things offered, but from different agencies. It's hard (for me, at least) to know where to go, and what to ask for.”*

*“The systems have failed to assist myself and my children partially due to waiting lists for services, inadequate funding and also due to the lack of understanding of the needs and capabilities of an Asperger Syndrome individual.”*

Respondents described the challenges finding qualified or helpful supports:

*“Hard to find good respite workers, very little experience with severe autism...”*

*“A major issue is training of staff (lack thereof). Agency states that all staff working with clients are trained but my observation is that none are really able to work with individual because of a lack of true understanding about the disability...”*

*“It was hard to find Psychologists who provide Asperger assessment of adults....”*

Respondents had difficulties finding the right service or program ‘fit’. Individuals were deemed ineligible, or services were not adequately tailored to their needs:

*“[It is] difficult to find services, for adults with autism. Often “rejected” by many agencies because does not meet their target client group”*

*“I am very newly diagnosed....I only know that, it takes a very long time. Also that a lot of the services are only available to very disabled individuals, enabling them to live independently and function as normally as possible in society (which is very expensive). On the other hand there is no help for those that can function, but not enough to get on their feet and be totally independent, which is very discouraging (hence the depression). ”*

*“I feel like all funding and groups and programs are all geared towards children not necessarily adults.”*

A major barrier to accessing services was the cost and accessibility of programs:

*“I am a single mother and I have to use my savings and I don't know how long I can keep this up”*

*“...The financial challenges are overwhelming and stressful; I am working full-time of course and struggling to pay these bills.”*

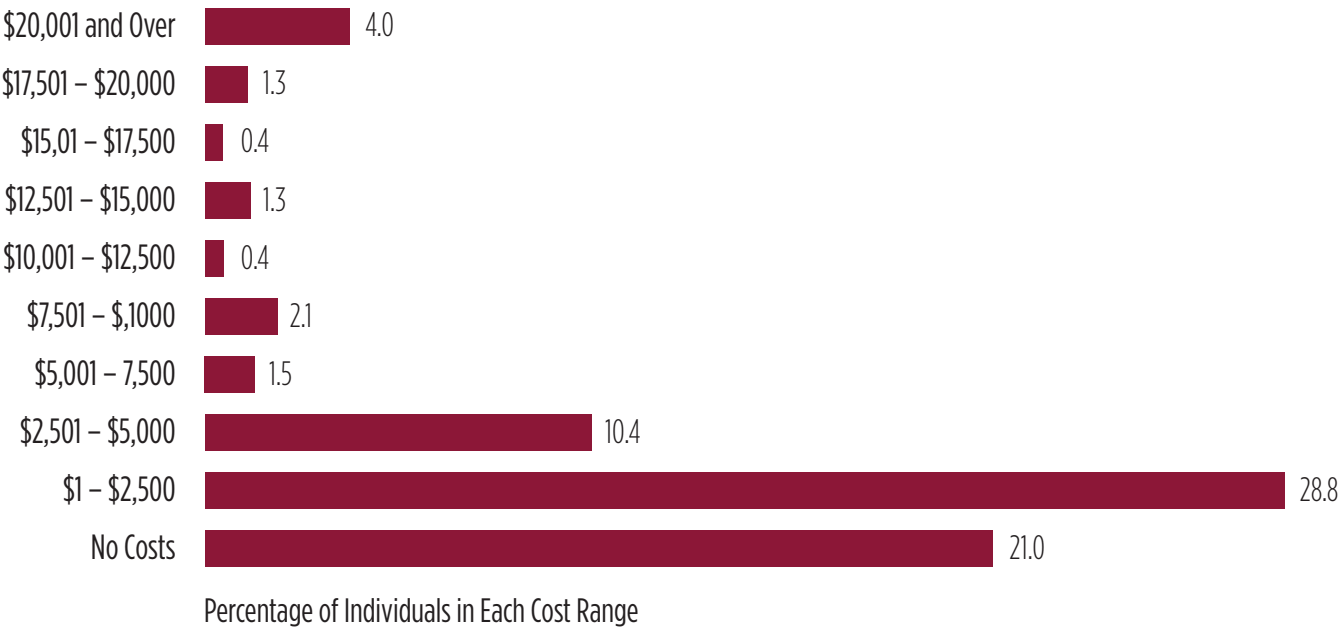
*“We live in a rural area where distance from available services, cost of transportation, and isolation are impediments to accessing services.”*

*“It is very hard to find services that will truly fit an individual that are (a) in my area (most are downtown, which I cannot get to alone due to difficulties with public transportation) and (b) affordable.”*

*“There is a PROFOUND LACK of appropriate supports and services for my family member. I have obtained virtually all help by paying for it privately out of my (mother) and my husband's (father) incomes.”*

In GRAPH 9, we report the distribution of costs reported by 341 of the 580 respondents. The mean costs of services (not refunded) was \$4,800.00 and the range was \$0.00 to \$170,000.00.

GRAPH 9: Costs Incurred in the Previous 12 Months for Services (N=341)



Some respondents reported positive experiences:

*"We were lucky that Community Living was able to accommodate our son in their day program. They have been wonderful by providing a program that takes advantage of his talents and strengths. They have also communicated with the family ensuring we are kept informed."*

*"Originally had difficulty finding an employment agency that could help me find employment that best suited my skills and personality. However, I have now found Hawkins Institute that is currently helping me to find this kind of a job as well as improving fundamental social skills that will help me succeed in the workplace and outside of it."*

*"I've been lucky that services and supports have usually been easy to access."*

Individuals were asked: "Please name up to three agencies or professionals that have provided the most support to you over the past five years and the service that they provided." In TABLE 5, we list the top five agencies. These agencies provided approximately 28% of the total services to the respondents. In total 1,036 listings of agencies and individual professionals were named.

Many families discussed their negative experiences with the new Developmental Services Ontario (DSO) system:

*"....there are too many levels and too much disorganization. It should be set up like a "Mall directory". One information intake and from there you are sent to the agency that could best meet your needs. Currently, there's [multiple service providers and Ministry offices] and a vast array of others that "offer" to tell you: you have a problem, but fail to help."*

*"....the Ministry has just created a new level of Red Tape. At one time, a developmental worker was assigned to a person with disability to assess his needs and would help the family provide [for] these needs. Then it went to Service Coordination.....we had to beg to have our needs go ahead of someone else's..... now they have another level.... more levels with management, less workers."*

*"....we have applied to them recently, seems like a lot of red tape and bureaucracy. There must be an easier way to get services for adults with Aspergers!!! He needs a psychological/psychiatric assessment but he does not easily co-operate for suggested supports that he needs and that will help."*



TABLE 5: Top Five Agencies Providing Most Support Over Previous Five Years

Agency Name	Number	Percent
The Redpath Centre	92	8.9
Kerry's Place Autism Services	84	8.1
Community Living	52	5.0
Woodview Mental Health & Autism Services	30	2.9
Geneva Centre for Autism	28	2.7

*"....He does not qualify for DSO because his overall cognitive level is above the threshold even though his adaptive living scores are within the threshold."*

*"DSO hasn't approved us yet - so we can't access anything until they finish approving us. Not impressed at all with the DSO, thank goodness our son is not in crisis!"*

*".....will the DSO find him a place to live...they sure aren't volunteering any help..."*

We asked respondents: if they were able, what services would they purchase? There were 915 responses to this question and we have listed 86% of them in TABLE 6, which are the most frequent responses by ten individuals or more.

Given transition services and supports are essential for youth and adults with ASDs, we asked: "Has your family member had services that help in transitions to a new service/stage in life (e.g., from child and youth services to adult services)? If yes, please describe them." Of the entire sample, only 136 (28.3%) reported that they had received transition services at all. These helpful services and supports came from various sectors:

*"York Region School Board provided support for transition. They held a transition planning seminar as well as visited the home to offer suggestions on what to do or whom to contact. York Support Services Network offered drop in sessions to apply for Passport Funding."*

*"Yes, Community Living helped us prepare a life plan for our daughter."*

*"[His] secondary school has a school-to-work program that [he] was part of during his last two years of high school. It was very beneficial for [him] to know what could happen when he no longer attended high school. They did job coaching, set up interview scenarios, taught good work habits and transitional skills to attend Community Living..."*

*"Developmental Services Ontario has been extremely helpful, navigating our family into the adult service sector, and meeting with us when it is truly convenient to our family. Family Respite guided us into the adult sector (for us that meant when our son turned 18), and the world of Passport."*

*"Woodview Manor has provided all the help with transitions from school to post school life and from home to assisted living/residential program."*

*"Algonquin had a day orientation just for Aspergers to help them transition to the school."*

A number of respondents felt that they would have benefitted from transition services had they been available historically:

*"I received no help from anyone as a child, teenager, or young adult. I just had to survive and tough it out as best I could, dealing with undiagnosed Asperger Syndrome and childhood abuse."*

*"There was nothing for me from child to adolescent. I was in a psychiatric hospital for 1.5 years when I was an adolescent. When I was 13 years old I stayed at a boarding school in Montreal"*

TABLE 6: Services Respondents would Purchase

Service Respondents Would Purchase	Number	Percentage of Services
Individual Counselling/Counselling	130	14.2
Employment Counselling/Program	104	11.4
Life Skills Coach	93	10.2
Recreational Program	76	8.3
Individual Support Workers	51	5.6
Housing/SIL/Group Home	43	4.7
Behaviour Therapy	41	4.5
Respite	40	4.4
Social Programs	34	3.7
Occupational Therapy	32	3.5
Day Program	30	3.3
Education Supports	22	2.4
Speech and Language Therapy	22	2.4
Transportation Support	22	2.4
Case Management	18	2.0
Medical Support/Care	15	1.2
Psychological Assessment	12	1.3
Community Worker	10	1.1
<b>Total</b>	<b>795</b>	<b>86.5</b>

A number of families noted that transition services only occurred when there was a crisis:

*“... [transitional supports were] crisis driven. Our son ended up hospitalized several times and we had to spend two years advocating in endless meetings with a dozen different people and many agencies as part of our “team” (some helpful, some not) in order to access the necessary and appropriate services”*

*“Were in the process now—that is why he is in the hospital. There are no crisis beds for adults with Autism/Fragile X/DD, and other various development disorders. There are “safe beds”... but one cannot use a safe bed unless they have a placement set up for the long term. He has been in the hospital for two months, unable to attend school....”*

Finally, family members and adults commented on the dramatic imbalance of services and supports for adults compared to children and youth:

*“As soon as our son hit age 18, he seems to disappear from the radar. There seem to be a lot more services and supports for children and youth, but hardly anything for adults. However, they are adults much longer than they are children. Our greatest fear is when we cannot look after him and his complex needs.”*

*“It seems like support for children with ASD is relatively abundant (although never as much as parents might wish for), but utterly lacking for adults. Wouldn’t it be better if I could contribute to the economy if someone could help me find a job? Underemployment is a serious problem for adults with Asperger’s.”*



# Summary and Recommendations

All Ontarians require and deserve access to a wide range of services and supports throughout their lifetime. Access to services and supports for individuals with disabilities is a right articulated in the *Ontarians with Disabilities Act* (2001) and the *Accessibility for Ontarians with Disabilities Act* (2005). Historically, not unlike the experiences of others living with developmental disabilities, access to appropriate services for those living with ASDs has been little understood and largely overlooked.

With our emerging understanding of the complex interaction of mental and physical conditions, diversity in presentation across the spectrum, changes related to aging, and the core social and functional problems for this at-risk group, stakeholders in our province must come together to address their needs. With 1% of the population affected, there could be a potential profound positive impact from effective systems transformation, including cost savings to multiple government agencies.

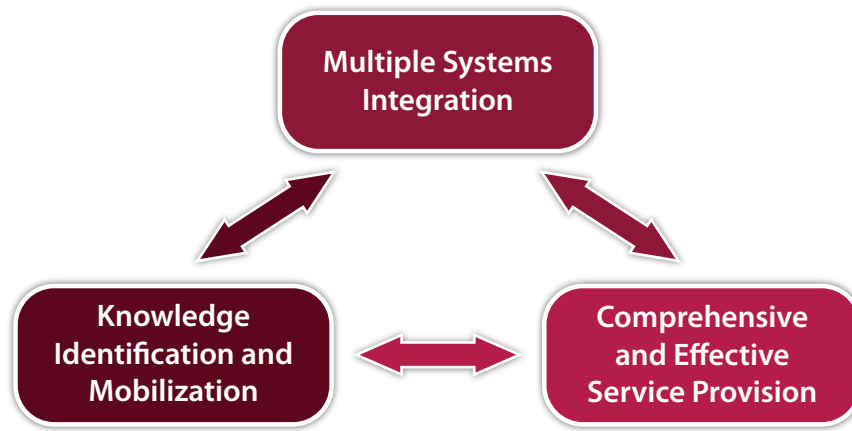
Increased early intervention, supports and services for infants and children with ASDs comprise only the first step in ensuring that these individuals, as much as they can, are experiencing a good quality of life, engaging with family and community, seeking and succeeding in post-secondary education, and finding and keeping social connections and employment. The current situation for adults with ASDs—social marginalization, long-term reliance on family and disability income, poor or little access to suitable and knowledgeable services—is untenable.

The collection of data on the profiles and needs of this group is long overdue. Ontario should continue to track needs and service use of this cohort by using comprehensive data sets, and identification of existing data that are currently not being utilized to more fully understand this group. The data collected here has its limitations: it depicts the experiences of those that are better connected to systems of supports and care and

have been diagnosed with an ASD. Other studies will need to address undiagnosed individuals in the mental health, education, corrections, and the developmental services systems, and in particular, females with ASDs. Data on the occurrence of specific illnesses or disorders is not compared with prevalence estimates in the general population in this report. This study also relies on self-report, as opposed to clinical file review or professional assessment. Finally, the data appears to under-represent those with co-occurring intellectual disability. Publications, reports and presentations examining these and other issues will be forthcoming.

The following twenty-five recommendations flow from the literature reviewed, our experiences as service providers, and the findings of this research. Each of the recommendations relate to at least one of three facets of an integrated and comprehensive strategy for Ontario youth and adults with ASDs, and their families.

- **Multiple Systems Integration:** Ministries, organizations and networks at regional and local levels engage in active forums to communicate about the needs of youth and adults with ASDs, increase service integration, identify systems deficiencies, and collaboratively develop strategies to address them.
- **Comprehensive and Effective Service Provision:** Services and supports, equally accessible and knowledgeable across the province, address the wide-ranging needs of adults with ASDs, and their families, communities and professional systems, in a comprehensive and evidence-informed manner.
- **Knowledge Identification and Mobilization:** Knowledge about individuals with ASDs, services, systems, and interventions is current, widely disseminated, relevant to multiple stakeholders, and founded on best practices.



## Multiple Systems Integration

1. System and service integration is not occurring at most local levels in Ontario. To our knowledge, multi-sectoral regional planning groups—specific to older youth and adults with ASDs—do not exist in the province.<sup>1</sup> The Networks of Specialized Care could be used, in part, to promote better cross-systems service coordination; however, the needs of adults with ASDs require specific attention at these Networks.
2. Given the significant barriers of decentralization and fragmentation of services, cross-sector consideration should be given to a clinical electronic records exchange system for adults with ASDs, and a centralized service database. This should focus on those who are not eligible for DSO.
3. The exclusion of some individuals with ASDs who could benefit from MCSS-funded adult developmental services requires further examination. If MCSS-funded adult developmental services continue to be inaccessible to many individuals with ASDs, other choices must be made available by multiple Ministries through: provision of extra individualized funding mechanisms, creation of new government funded services, expansion of existing services, and new public-private partnerships.
4. Concerns about the divide between children/youth services and adult services are pervasive. Transition plans are the responsibilities of all Ontario Ministries and are a ‘*best practice*’ repeatedly identified in ASD literature. Successful transitions in multiple sectors must be an area of focused interministerial collaboration and cooperation, and a targeted cross-ministerial outcome. Existing models within some sectors can be drawn on to develop part of a comprehensive transition standard across the province.<sup>2</sup>
5. The work of the Adult ASD Inter-Ministerial Working Group (IMWG) is critical in identifying areas requiring system change and identifying key issues where bridging responsibilities of Ministries can occur. The mandate of this group should be strengthened and their efforts communicated more broadly, with specific information disseminated about their impact.

## Comprehensive and Effective Service Provision

1. The autism sector in Ontario has fallen behind other sectors (e.g., Children’s Mental Health) in program development, evaluation and research in agencies funded to serve youth and adults. Service funding must be tied to continuing quality assurance and a program evaluation standard that is expected in other sectors.

<sup>1</sup> Exemplary models of cross-systems and cross-ministerial collaboration for children and youth currently exist in the regions of Peel and York. Dufferin Child and Family Services (Orangeville, Ontario) is an exemplary Children’s Mental Health Centre that has an integrated system response to children and youth with ASDs. In Toronto, the Asperger’s Community of Practice has recently been established.

<sup>2</sup> Problems relating to transition from the youth mental health system to the adult mental health system in Ontario have been identified in: Davidson, S. & Cappelli, M. (2011). We’ve got growing up to do: Transitioning youth from child and adolescent mental health services to adult mental health services. Ottawa, ON: Ontario Centre of Excellence for Child and Youth Mental Health. The issues and strategies identified in this report are equally applicable to youth with ASDs.

2. Successful models of service provision in the literature and occurring throughout the province need to be examined more closely, in order to inform best practice guideline development and implementation.
3. Some Ministry of Community and Social Service funded services that provide ASD services are not recognized by any accrediting organization; there are no provincial clinical or program standards for youth and adult providers. These need to be developed to ensure quality, evidence-informed care, and responsive, learning ASD organizations in Ontario.
4. Considering increasing enrollment of students with ASDs in post-secondary education, the knowledge exchange from the ASD community to post-secondary personnel in disability departments needs to continue through established post-secondary disability networks. Other campus personnel, such those at Career Centres, need to be included in this training.
5. Although many youth with ASDs are successful in post-secondary education, others struggle considerably and fail to get their degrees or diploma. Integrated residential and life skill support models may address some of these struggles. These are models which exist in the United States.
6. There is a significant training gap for individuals who do not pursue an academically-based post-secondary education. College and training programs that focus on life skills, social skills and work skills need to be developed for this group.
7. The positive influence of early experiences with volunteering, co-ops, summer employment and community hours in high school should be reinforced by youth vocational and summer programs that focus on work skills, life skills, and social skills. Development of these programs by the Ministry of Education will benefit all students with neurodevelopmental struggles.
8. Partnership needs to occur with ODSP Employment and Income Supports to reduce reliance on ODSP and understand the unique needs of individuals with ASDs in finding and keeping employment. Employment support programs geared to individuals with Asperger Syndrome are a priority.
9. Considering the dearth of expertise in the mental health and health care sectors, the Ontario Ministry of Health should carry out comprehensive needs analyses and sponsor investigations into their service provision role.
10. Comprehensive Health Care Provider Registries should be more widely available in a manner similar to *SPIRALE* (Autism Ontario) so communities can access specialized healthcare services. Considerable health systems outreach will be needed for this registry to be comprehensive in medical specialization and provincial region.
11. Increase to the Passport/SSAH funding and other person-centered funding streams must be provided to address the needs of individuals on the spectrum who are not well-served by DSO. Services that are required, but not funded could then be purchased.
12. Personal care support programs, funding streams, care registries or organizations which are available to people with other types of disabilities could be identified as models to promote life skills development and aid with personal care.
13. The potential benefit of integrated social and recreational opportunities for social skill development, and reduction of mental health symptoms and social isolation is significant.

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“[Supported employment’s] success has been documented for people with severe disabilities, including those with psychiatric or intellectual impairment...” (WHO, 2011, p. 242)

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Although local social and recreational groups exist in some jurisdictions, they are needed in other communities. Access to interest-based recreation could be a partnership activity at the municipal level, and local planning tables.

14. Considering the diverse needs of this group, services and supports for youth and adults with ASDs span multiple service models and paradigms. Although major inroads have been made in the provision of ABA-based services, this comprises a small fraction of services and supports required for individuals on the spectrum—and are neither applicable, nor suitable for all. Funded individual, family, couple and group therapy are service priorities for youth and adults with Asperger Syndrome.
15. To guide Ministries in the delivery of effective services and supports for adults with ASDs an *ASD Expert Advisory Committee* should be established, or specific experts seconded to Ministries for discrete periods and projects.

### Knowledge Identification and Mobilization

1. Adult ASD Centers of Clinical and Research Excellence need to be set up in all regions of the province. They would be the sources of accurate and current information for professionals, families and community members. These Centres would be components of networks of excellence for youth and adults with ASDs, and be both university- and service-provider affiliated.
2. Education and training of professionals from all disciplines in generic service organizations is inadequate. Given the pace at which new knowledge in the ASD field is generated, current research and best practices should be at the forefront of this training using e-learning technology and in collaboration with professional associations and regulatory colleges.
3. Although there has been significant inroads made with the Children's Mental Health Sector in the last decade with increased awareness and

treatment of ASDs, the need will continue to mount in this system. Training and consultation could be provided that would enable this sector to help in transitional services and supports for those youth that are aging out of that system.

4. Considering the large overlap of individuals with ASDs and those with mental health concerns, adult mental health service providers urgently need training in assessment and intervention relevant to youth and adults with ASDs.
5. Comprehensive ASD training of physicians across the province must occur by medical colleagues who are experienced and knowledgeable about key medical issues affecting youth and adults with ASDs, patient management, and available local resources.

### Conclusions

Throughout history, individuals with ASDs have made untold contributions to society through their creativity, intellectual acuity and unique worldview. They are equally deserving citizens who, when allowed to engage with their communities through access to comprehensive and knowledgeable supports, will demonstrate even better 'adult outcomes'.

Current systems of care and support for youth and adults with ASDs are largely inadequate in Ontario, and create barriers to personal well-being and quality of life. Some helpful and positive services and supports exist in the province—these need to be expanded and emulated. To adequately address this growing cohort's multiple unmet needs, significant changes must occur across multiple systems and provincial Ministries, through progressive feedback mechanisms elicited from a wide range of consumers and stakeholders.



# Appendix 1: DSM-IV-TR Diagnostic Criteria for Autistic Disorder

**A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):**

- (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
  - (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
  - (b) Failure to develop peer relationships appropriate to developmental level.
  - (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).
  - (d) Lack of social or emotional reciprocity.
- (2) Qualitative impairments in communication as manifested by at least one of the following:
  - (a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
  - (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - (c) Stereotyped and repetitive use of language or idiosyncratic language
  - (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

- (3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) Apparently inflexible adherence to specific, non-functional routines or rituals
- (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (d) persistent preoccupation with parts of objects

**B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.**

# Appendix 2: DSM-IV-TR Diagnostic Criteria for Asperger's Disorder

**A. Qualitative impairment in social interaction, as manifested by at least two of the following:**

- (1) Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (2) Failure to develop peer relationships appropriate to developmental level
- (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
- (4) Lack of social or emotional reciprocity

**B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:**

- (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (2) Apparently inflexible adherence to specific, non-functional routines or rituals
- (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
- (4) Persistent preoccupation with parts of objects

**C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.**

**D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).**

**E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.**

**F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.**



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