



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

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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.

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Table of Contents

In Appreciation	3
Executive Summary	6
Introduction to this Report	8
Autism Spectrum Disorders in Youth and Adults	9
One Percent Affected.....	9
Diversity in Autism Spectrum Disorders.....	10
Adult Outcomes	10
Previous Policy Recommendations and Changes.....	11
Forgotten Report	11
A New Provincial Act.....	11
Background to this Study	13
Study Rationale	13
Development of the Survey	13
Data Collection	13
Description of the Youth and Adults	15
Gender and Age.....	15
Autism Spectrum Diagnosis.....	15
Intellectual Disability Diagnosis	15
Marital and Parental Status.....	15
Annual Income and Source	15
Type of Residence.....	16
Provincial Region of Residence	16
Respondent Information.....	16
Receiving an Autism Spectrum Diagnosis.....	17
A Review	17
What this Study Found.....	17

Table of Contents, Continued

Life Skills and Autism Spectrum Disorders	19
A Review	19
What this Study Found.....	19
Mental Health and Autism Spectrum Disorders	21
A Review	21
What this Study Found.....	21
Physical Health, Medication Use and Autism Spectrum Disorders	23
A Review	23
What this Study Found.....	24
Social Involvement and Autism Spectrum Disorders	27
A Review	27
What this Study Found.....	27
Daily Activities and Autism Spectrum Disorders	30
A Review	30
What this Study Found.....	31
Services and Supports for Autism Spectrum Disorders	34
A Review	34
What this Study Found.....	35
Summary and Recommendations	41
Multiple Systems Integration	42
Comprehensive and Effective Service Provision	42
Knowledge Identification and Mobilization.....	44
Conclusions	44
Appendix 1: DSM-IV-TR Diagnostic Criteria for Autistic Disorder	45
Appendix 2: DSM-IV-TR Diagnostic Criteria for Asperger’s Disorder	46
Report Authors	47
References	48

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%) of the sample

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

- Only 51.8% with “high-functioning autism” or AS were diagnosed before 21 years
- 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 they 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%
- 4.8% had taken some post-secondary education courses and 28.5% had completed a degree; for 5.8% (n=28) 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*.