CASDA

NATIONAL NEEDS ASSESSMENT SURVEY

For Families, Individuals with Autism Spectrum Disorder & Professionals

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CASDA LEADERSHIP COMMITTEE:
Cynthia Carroll – Chair
Debbie Irish – Vice Chair
Laurie Mawlam – Past Chair
Richard Burelle – Treasurer
Jill Farber
Suzanne Jacobson
Dave Mikkelsen

PROJECT TEAM:
Cynthia Carroll, Margaret Lyons, Margaret Whelan

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PREFACE

Autism spectrum disorder (ASD) has been front and centre in Canada for the last decade. At all levels of discussion across the country – provincial governments, local communities, educational systems, researchers, service providers, families living with ASD, media and even the entertainment industry – there is a consensus that ASD is no longer a rare disorder, unknown to most. One is hard-pressed to find someone who does not have some link to an individual with ASD.

Despite the fact that ASD is now recognized more than ever and is having a profound impact on Canadians and Canada, there has been a serious vacuum in the availability of reliable data on what exists and what is needed. There has been a sense that some families and their children (of all ages) with ASD have better services than others; that some had better outcomes than others; that some parts of the country were better positioned to support families than others. However, to date, there has been no strong data to inform the discussion and evidenced-based policy development and decision making.

In 2006, the Federal Minister of Health, Tony Clement, announced a number of initiatives that would begin the national conversation about ASD. A research conference was held, an Autism Research Chair was announced, a consultation process was to be undertaken to inform the development of an ASD surveillance unit and a commitment was made to start the process of addressing the needs of families living with ASD.

As a result of the advocacy effort of Senator Jim Munson, and the support of Senators Art Eggleton and Wilbert Keon, 2007 witnessed the release of the Standing Senate Committee on Social Affairs, Science and Technology report entitled *Pay Now or Pay Later: Autism Families in Canada.*[1] That report heralded the first time that the issues facing Canadians living with ASD had been brought forward at the national level.

Following the release of the report, a number of leaders from ASD-specific organizations from across Canada met to discuss the necessity of ensuring that the momentum continued. In 2007, the Canadian Autism Spectrum Disorders Alliance (CASDA), a national coalition of autism related professionals, family members and community partners, was formed. Through CASDA, the intervening years have resulted in the autism community coming together to provide a strong and unified national voice to advance the collective messages of our sector. Together, CASDA undertook to secure the federal government's commitment to the development of a National Autism Action Plan.[2]

The Public Health Agency of Canada (PHAC) is currently leading and coordinating the development of a National ASD Surveillance System (NASS), in collaboration with provinces and territories, and with the guidance of an external, expert ASD Advisory Committee. NASS is a vital step towards understanding the impact of ASD in Canada and providing the evidence-based numbers needed to better inform policies and programs. CASDA has been represented on the ASD Advisory Committee since its inception in 2012, providing advice on the development and implementation of NASS.

In response to a call for submissions and a successful proposal, CASDA was awarded funding to conduct a national autism needs assessment survey. This study, ***Autism in Canada, National Needs Assessment Survey*** for Families, Individuals with Autism Spectrum Disorders and Professionals, canvassed the opinions of almost six thousand Canadians, from all provinces and territories.

The data gathered in this study will help support surveillance initiatives and identify existing services and service gaps. The survey also will provide perspectives based on factors such as regions within Canada, age of the individual with an ASD, family needs and views of the professional community.

In addition to sharing the reports and data with PHAC, CASDA will use the data to produce a series of reports which will be used by CASDA and its members to move forward with its work to achieve a National Autism Action Plan.[3]

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1. "Pay Now or Pay Later: Autism Families in Canada" is available on the Government of Canada website – www.parl.gc.ca -Committee Business — Senate — Recent Reports 39th Parliament — 1st Session

2. For further information about CASDA go to www.ASDalliance.org.

3. All data and materials contained in this report are the property of Autism Society Canada, held on behalf of CASDA, and may only be used with the written permission of Autism Society Canada, on behalf of CASDA, and such use must include appropriate acknowledgement of CASDA and the source report.

A MESSAGE FROM DR. JONATHAN WEISS

Over the past decade we have seen a tremendous rise in the awareness and acceptance of individuals with Autism Spectrum Disorder (ASD) in Canada and internationally. With it comes an increased recognition of the diverse needs of individuals with ASD, across the spectrum and the lifespan. Recent Canadian reports such as the 2010 Nova Scotia Department of Education LifeSpan Needs for Persons with Autism Spectrum Disorder, and the 2007 Standing Senate Committee on Social Affairs, Science and Technology's Pay Now or Pay Later: Autism Families in Crisis, highlighted service needs and gaps. We know that we need to provide opportunities to access effective supports, at the right time, in order to foster meaningful and successful outcomes. It is critical that we continue this national conversation.

CASDA's National Needs Assessment Survey is a significant step in this direction. It is the largest survey of stakeholders across Canada to date, with over 5600 respondents (including family members, adults with ASD, and professionals) reporting on their experiences and opinions. A sincere thank you goes out to all those who took the time to participate – your voices made a difference. Results highlight unique patterns of past and current service use and paint a picture of how a broad range of supports are needed to provide individualized and family centered care across educational, vocational, community and health sectors.

This report represents a research-community process, with a survey that was developed with direction from a national network of service providers and advocacy groups, data that was analyzed in an ongoing collaborative manner, and recommendations that were formed by the Canadian ASD Alliance, who represent the very stakeholders who participated in the survey in the first place.

The Chair in ASD Treatment and Care Research is funded to conduct community-engaged research to inform policies and interventions that target health and wellbeing, and thus was able to support CASDA's goals in developing Autism in Canada, the national needs assessment report, by providing ongoing research and knowledge mobilization support.

It is critical that we not let this be the end of the discussion on determining the supports and policies that are needed at local, provincial and national levels. Individuals with ASD, families, communities, service providers, and governments must work together to develop and sustain the range of services that are needed now and will be needed in the future. The conversation should be about what is needed so that Canadians of all ages and abilities can thrive in their communities and in ways that are right for them and their loved ones.

Jonathan A. Weiss, Ph.D., C.Psych.,
Chair in ASD Treatment and Care Research
Associate Professor, Dept. of Psychology, York University

ACKNOWLEDGEMENTS

CASDA would like to acknowledge and thank the Public Health Agency of Canada (PHAC) for its financial support to this project.

The following individuals were instrumental in the success of this survey project. Together they provided the leadership needed to get this ground breaking initiative from the idea stage, through its implementation and to its completion.

With thanks we recognize:

Senator Jim Munson, for starting the political conversation about the needs of Canadians facing the challenges associated with Autism Spectrum Disorder and for keeping that conversation alive.

Mike Lake, MP, for his tireless championing on behalf of parents of children with ASD and his pursuit of collaboration among all stakeholders with a role to play in the autism agenda in Canada.

Dr. Jonathan Weiss, Ph.D., C.Psych., Associate Professor in the Department of Psychology at York University and Chair in Autism Spectrum Disorders Treatment and Care Research,[4] and his research team: Carly McMorris, MA, PhD Candidate, Research Analyst; Casey Fulford and Carly Albaum, Lab Coordinators, for their excellence in research methodology and ensuring the integrity of the survey, the data collection and analysis for this project.

Dr. Yona Lunsky, Clinical Scientist at the Centre for Addiction and Mental Health, and Dr. Helene Ouellette-Kuntz, Associate Professor at Queen's University for advice on survey development and analysis.

The CASDA membership, who ensured that the survey had wide dissemination across the country.

Harmony Marketing, for their creative approach to promotion and distribution of the survey.

A very special thank you goes out to the families and individuals who provided photos to enrich the messages within this report.

And most important of all, we extend our deepest gratitude to the almost 6000 parents, family members, individuals with ASD and professionals in the ASD sector who completed the surveys, providing the data necessary to bring the ASD message forward in a powerful and coherent manner.

This report was prepared for CASDA by Margaret Whelan, Dr. Jonathan Weiss, Carly McMorris, Cynthia Carroll and Margaret Lyons.

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4. The Chair in Autism Spectrum Disorders Treatment and Care Research is funded by the Canadian Institutes of Health Research in partnership with Autism Speaks Canada, CASDA, Health Canada, NeuroDevNet and the Sinneave Family Foundation.

TABLE OF CONTENTS

EXECUTIVE SUMMARY

This national autism needs assessment was initiated to gather data from Canadians living with ASD. The report is organized to provide comprehensive data analysis at the national level and synopses of data at the provincial and territorial levels. All data from all respondents is included in the national presentations.

An emerging concern is the limited response received from Yukon, Northwest Territories and Nunavut. The responses for these communities were consolidated into a single report, but all data was included in the national report.

In order to gather information as extensively as possible from all stakeholders with an interest in this study, three (3) on-line needs assessment surveys were developed, one for each type of respondent. These included:

- Caregivers, whose data was further segmented by age
    - Children under 5
    - Children 5-17
    - Children over 18 (also referred to as adults with ASD)[5]
- Self-advocates
- Professionals working with individuals with ASD

Caregivers of preschool children, school age children, and adults, as well as Self-advocates, provided their perspectives on services used, needed and barriers to service. Professionals working in the ASD sector provided their own unique perspectives on the needs of individuals with ASD and their families.

Respondents included 3,273 Caregivers, 166 Self-advocates and 2,104 Professionals. Of note, 16% of Caregivers indicated that they had more than one child with ASD. The respondents were predominately educated, white or Caucasian and lived in urban or suburban communities.

Based on reports from the Caregiver respondents, the average age of diagnosis for younger individuals with ASD was 5.5 years. Caregivers of adults reported an average age at diagnosis of 8 years.

Caregivers also indicated that their children had used a number of different services at some point over their lives. Preschoolers used an average of 5.8 different services; school age children used an average of 7.8; adults had used an average of 8.9 different services. Self-advocates reported having used an average of 6 services. At the same time, there is substantial variability in the number of services individuals are using at any one moment in time, and there is a considerable range, from individuals receiving no or few services, to those who are accessing many.

Despite having used multiple services, all groups indicated they did not have sufficient services. Respondents identified which services they had wanted to receive, but had not received. Over half of all respondents indicated they wanted earlier identification. Almost three-quarters of parents of preschoolers who had not received early intensive behavioural intervention services noted wanting it for their child (74%). Life skills training (61%) and employment programs (64%) were noted service gaps by Caregivers of adults with ASD. The highest identified service gaps for Self-advocates were early detection of ASD (60%) and social skills programs (62%).

Each respondent group provided their perspective on the top 5 service needs of individuals at all ages. Caregivers and Self-advocates identified the following as the top 5 service needs:

FOR PRESCHOOLERS:

- Other forms of early intervention (69%)
- Early IBI (66%)
- Social skills programs (62%)
- Activity-based programs (55%)
- Daycare/preschool programs (46%)

FOR SCHOOL AGE CHILDREN:

- Social skills programs (73%)
- Activity-based programs (51%)
- Recreation programs (48%)
- Specialized summer programs (45%)
- Life skills training (39%)

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[5] All references to 'adults with ASD' are intended to denote those adults whose data was provided by their Caregivers. All Self-advocate respondents, who also were adults with ASD, are identified as 'Self-advocates' throughout the report.

FOR ADULTS WITH ASD:

- Employment or day programs (60%)
- Social skills programs (49%)
- Life skills training (48%)
- Recreation programs (37%)
- Post-secondary educational programs (34%)

FOR SELF-ADVOCATES:

- Mental health treatment (45%)
- Employment services (41%)
- Social skills (40%)
- Post-secondary education (37%)
- Housing/residential options (32%)

Obstacles to service included difficulty obtaining services, barriers to service access and financial challenges which limited access to services. The most difficult to access services reported by Caregivers were social skills programs, recreational leisure programs, activity-based programs, specialized summer camps, and early intensive behaviour intervention. The most common barriers across respondent type were a lack of resources and being on a wait list (for Caregivers at 75%; Self-advocates at 45%; and Professionals at 92%). With respect to financial challenges, approximately 32% of Caregivers and 45% of Self-advocates indicated that they could not afford services, with many others who could afford them struggled to do so.

The study also received a significant number of responses directly from adults who have ASD (Self-advocates). Most indicated they had a diagnosis of Asperger syndrome. The level of mental health problems they reported was significant. Their identification of issues related to anxiety, depression and ADHD provided dramatic insight into the need for more mental health support services and transition planning for this group of individuals with ASD. A small number of adults (21) completed the survey and indicated they did not have a formal diagnosis of ASD but identified themselves with this community.[6]

PRIORITIES ARISING FROM THE ANALYSIS OF THE EXTENSIVE DATA GATHERED IN THIS STUDY INCLUDE THE FOLLOWING:

- Increased early and timely access to diagnosis, intensive behavioural intervention, parent support, and other forms of evidence-based early intervention
- Social skills, behavioural, and adaptive behaviour supports across the life span
- The development of accessible mental health services for youth and adults with ASD that meet their level of need, which includes the involvement of the health, education, and community service sectors
- Targeted outreach to address the unique issues of Canada's northern communities,
- More outreach to Self-advocates, a large group of Canadians, many of whom are living on the periphery of their communities and often outside of the network of services,
- Comprehensive planning for adulthood, including transition support services,
- Targeted outreach to linguistically and culturally diverse communities, facilitating understanding of their service needs and improving their access to service.

QUESTIONS FOR FURTHER RESEARCH WHICH ARISE FROM THIS STUDY INCLUDE:

- Service needs in northern communities,
- Mental health interventions for adults with ASD,
- The need for a closer look at experiences in elementary, high school, and post secondary education
- Evaluation of what exists across Canada as measured against recognized best practices,
- Financial vulnerability among individuals with ASD.

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[6] The results from this group were separated from the main report and are presented in the appendix as its own synopsis report.

METHODOLOGY

SURVEY DEVELOPMENT

Dr. Jonathan Weiss, Associate Professor, Chair in Autism Spectrum Disorders Treatment and Care Research, Department of Psychology, York University, in collaboration with Cynthia Carroll, Executive Director, Autism Nova Scotia, developed the on-line survey for the CASDA needs assessment project.

The survey was based in large part on the success of the Autism Management Advisory Team (AMAT) Report, "Lifespan Needs for Persons with Autism Spectrum Disorder".[7] Conducted by the Department of Education, Nova Scotia and its community partners across Nova Scotia, the AMAT survey provided a model for soliciting data for planning purposes that was consistent with the goals of the CASDA initiative. The quality of the survey was such that CASDA requested permission to use it as the basis for building its needs assessment survey.

The CASDA National Autism Needs Assessment Survey was vetted by the Ethics Committee at York University, by the CASDA Leadership Committee and by a Steering Committee of community partners which included Debbie Irish from Geneva Centre for Autism, Toronto; Margaret Spoelstra from Autism Ontario, Toronto; Deborah Pugh from Autism Community Training, Vancouver; Suzanne Jacobson from QuickStart – Early Intervention for Autism, Ottawa, and Nathalie Garcin from The Gold Centre, Montreal. The Steering Committee and CASDA Leadership Committee also provided a dry run of the survey to ensure its ease of use.

SURVEY DISSEMINATION

CASDA members, approximately 60 organizations and community partners from across Canada, were notified of the survey two months before its release via the members' newsletters, special email notification of the release date and prominent display of the survey notice on the CASDA website home page. Autism Society of Canada notified its provincial and territorial members of the pending release one month ahead of the start date.

On April 2, 2014, World Autism Awareness Day, CASDA, with the assistance of Senator Munson, held a press conference on Parliament Hill, announcing the launch of the needs assessment survey. Subsequent to the formal launch, an email campaign was launched to reach out to families and service providers across the country. A special Twitter campaign was developed and launched on April 3, with daily updates.

CASDA members were provided with marketing materials to assist them with their dissemination efforts. Most CASDA members posted a hot button on their websites, linking their stakeholders to the survey. CASDA members also participated in the social media outreach campaign and distributed links to the survey to their professional and community networks. Within the first month, over 2500 surveys had been completed.

After the first month, a review of preliminary data illustrated where there were gaps in the survey penetration. A second strategy was developed which included targeted outreach to communities where the response rate was lower than expected. CASDA members made direct outreach calls to contacts in their communities for further distribution. The Twitter campaign was updated and re-launched and autism related blogs were contacted. By the end of the second month, the goal of 5000 responses had been reached.

A second examination of gaps in response types resulted in a third outreach strategy specifically targeting potential respondents in low response areas such as northern communities, French language communities, and individuals with ASD. Paper copies of the survey were made available upon request to those unable to complete it on-line. When the survey closed on June 30, almost 6000 survey response had been submitted.[8]

INCLUSION PROCESS

In order to include respondents' data in the survey analysis, a number of criteria needed to be met. Individuals with ASD who were self-reporting (referenced as Self-advocates in this report) and Caregivers who were completing the survey about a family member needed to confirm that a diagnosis of an Autism Spectrum Disorder (Autism, Asperger Syndrome, PDD-NOS, Pervasive Developmental Disorder - Not Otherwise Specified, or Autism Spectrum Disorder) had been received by a regulated professional qualified to make such a diagnosis. Professionals completing the survey had to affirm that they had worked with individuals with a confirmed diagnosis of Autism Spectrum Disorder, as defined above.

Caregivers were instructed to elect one family member to complete the information about their family members with ASD. Professionals did not report on specific individuals with ASD. Professionals provided opinions more broadly about service needs based on their experiences.

Individuals were excluded if:

- They had not received an official diagnosis or
- They had participated more than once for the same person or themselves.

Based on these criteria, 105 Caregiver surveys were eliminated from the project. From the Caregiver respondents, 63 were excluded because they reported that the individual with ASD did not have a diagnosis provided by a regulated professional qualified to provide the diagnosis. Forty-two (42) were duplicates (double entries as indicated by same initials of individual with ASD, date of birth, province lived in, and IP address).

From the Self-advocate respondents, 21 did not have an official diagnosis provided by a regulated professional qualified to provide the diagnosis. These individuals identified themselves as part of the ASD community. As a result, a decision was made to respect their participation and include them in the report appendix, but not within the national Self-advocates data as they did not meet the eligibility criteria.

No duplicates were noted from among the professional respondents group.

Despite the focused outreach efforts, there were some concerning gaps in the data which affected the inclusion of responses. Only nineteen (19) responses were secured from the northern regions of Northwest Territory, Yukon and Nunavut. On their own, none of the three exceeded the minimum threshold of five (5) respondents in any one category. While the study results include all the data from the northern communities in the national level analyses, it does not report on the territories separately. A consolidated report for the North was developed to include the combined data from the three northern jurisdictions, but nevertheless included less detail in the analysis, addressing only those areas where the numbers permitted reporting that could be meaningful.

Although the number of Self-advocates that completed the survey reached an impressive 166, all of the territories and some of the provinces did not meet a minimum threshold of 5 respondents in the Self-advocate category. All respondents and their data are included in the national analysis, but were not able to be included in some of the provincial and all the territorial breakdowns.

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7. http://www.ednet.ns.ca/pdfdocs/autism/autism_report_en.pdf

8. A copy of the marketing strategy report from Harmony Marketing is available upon request to info@asdalliance.org.

THE SURVEYS

INTRODUCTION TO THE SURVEYS

The National Autism Needs Assessment Survey Report provides data analysis at the national level. Regardless of the number of respondents in each category and each geographic area, all data from all eligible respondents is included in the national presentations.

Appendix A provides a briefer analysis for each province individually and for Yukon, Northwest Territories and Nunavut together as a combined area. An additional report is included to reflect the responses from the 21 Self-advocates that did not meet the eligibility criteria. The synopses of data and accompanying analyses are limited to the respondent groups where there were sufficient numbers to permit meaningful analysis of the data. The report presents on any group where there were at least twenty (20) individuals. The demographics of all three (3) respondent groups are reported provided there were more than five (5) respondents in the group. Respondent groups with fewer than 5 respondents were not included in the demographic analysis in order to ensure anonymity. Patterns, trends and priorities are addressed according to this format.

In order to gather information as extensively as possible from all stakeholders with an interest in this study, three (3) on-line needs assessment surveys were developed, one for each type of respondent. These included:

- Caregivers, whose data was further segmented by age
    - Children under 5
    - Children 5-17
    - Children over 18 (adults with ASD)
- Self-advocates
- Professionals working with individuals with ASD

Data from Caregivers, Self-advocates, and Professionals were analyzed and are presented separately.

SURVEY DATA AND ANALYSIS - NATIONAL

A. GEOGRAPHIC REPRESENTATION

Upon launch of the on-line survey, an ambitious target of **5000** respondents was set. A total of **5,608** completed surveys have been included in the report.

As shown in Table 1, **3,273** Caregivers of a person with ASD, reporting on **3,338** individuals with ASD (including children, youth, and adults)[9], **2,104** Professionals[10] who work with individuals with ASD, and **166** Self-advocates completed the survey. Seven percent of respondent completed the French version of the survey.

There were 522 Caregivers (15.9%) who noted that they were Caregivers of more than one person with ASD. While they were allowed to report on more than one individual with ASD, only 65 Caregivers elected to do so.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 68% school age youth, aged 5-17;
- 20% adults, 18 years of age and over, and
- 11% preschool age children, less than 5 years of age

As shown in Table 2, the majority of the respondents came from Ontario and Quebec, followed by the West, and then Atlantic Canada. Only .57% of respondents came from the North (Yukon, Northwest Territories, and Nunavut).

In many respects, the overall sample's regional distribution is similar to the distribution of the Canadian population (Statistics Canada 2013 Estimates). As shown in Figure 1, Quebec was under-represented at 7.1% of the total sample compared to an expected rate of 23.2%. Ontario, New Brunswick, and Nova Scotia were over-represented. This distribution appeared largely consistent across the respondent types – Caregivers, Self-advocates, and Professionals (see Figure 2). Most provinces had a sufficient number of responses to be able to look at patterns of service use and needs.

TABLE 1: FREQUENCY & PERCENTAGE OF EACH RESPONDENT TYPE BY LANGUAGE

	TOTAL	CAREGIVERS OF A PERSON DIAGNOSED WITH ASD	SELF-ADVOCATES (18 YRS OR ABOVE)	PROFESSIONALS WORKING WITH PERSONS WITH ASD
ENGLISH	5,217 *93%*	3,153 (*94.5%*)	155 (*93.3%*)	1909 (*90.7%*)
FRENCH	391 *7%*	185 (*5.5%*)	11 (*6.6%*)	195 (*9.3%*)
TOTAL	5,608	3,338	166	2,104

TABLE 2: FREQUENCY & PERCENTAGE OF EACH RESPONDENT TYPE BY REGION

	TOTAL	CAREGIVERS OF A PERSON DIAGNOSED WITH ASD	SELF-ADVOCATES (18 YRS OR ABOVE)	PROFESSIONALS WORKING WITH PERSONS WITH ASD
ATLANTIC[A]	698 *12.4%*	368 (*11%*)	29 (*17.5%*)	301 (*14.3%*)
CENTRAL[B]	3,224 *57.4%*	2,001 (*60%*)	98 (*59%*)	1,125 (*53.4%*)
WEST[C]	1,667 *29.7%*	960 (*28.8%*)	39 (*23.5%*)	668 (*31.7%*)
NORTH[D]	19 .34%	9 (*.27%*)	0	10 (*.48%*)
TOTAL	5,608	3,338	166	2,104

A = Prince Edward Island, New Brunswick, Nova Scotia, and Newfoundland and Labrador

B = Quebec and Ontario

C = Manitoba, Saskatchewan, Alberta, and British Columbia

D = Yukon, Northwest Territories, and Nunavut

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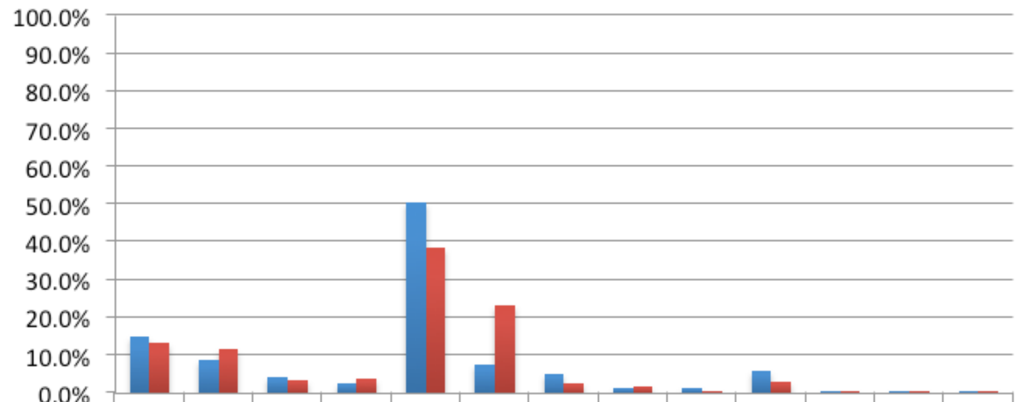
[9] Caregivers were instructed to provide the individual's initials, DOB, and other information which was used to ensure they were reporting on a different individual if they elected to complete the survey more than once

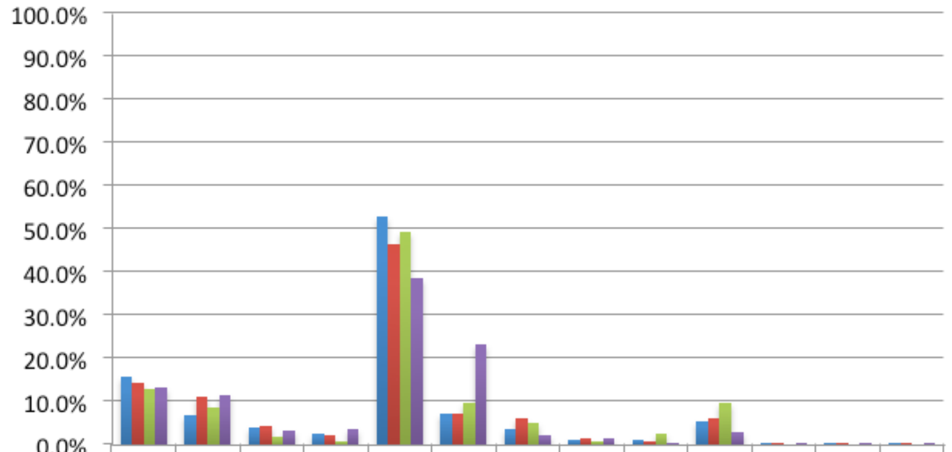
[10] Professionals did not report on specific individuals.

Figure 1. Total Actual and Expected Respondent Distribution



	BC	AB	SK	MB	ON	QC	NB	NL	PE	NS	NT	NU	YT
🟦 Actual	14.9%	8.4%	3.9%	2.4%	50.3%	7.1%	4.6%	1.2%	0.9%	5.8%	0.1%	0.1%	0.1%
🟥 Expected	13.0%	11.5%	3.2%	3.6%	38.5%	23.2%	2.2%	1.5%	0.4%	2.7%	0.1%	0.1%	0.1%

Figure 2. Actual respondent distributions and expected distributions



	BC	AB	SK	MB	ON	QC	NB	NL	PE	NS	NT	NU	YT
🟦 Caregivers	15.5%	6.8%	3.8%	2.6%	52.9%	7.0%	3.6%	1.1%	0.9%	5.4%	0.1%	0.1%	0.1%
🟥 Professionals	14.3%	11.1%	4.1%	2.2%	46.3%	7.2%	6.1%	1.4%	0.6%	6.1%	0.1%	0.1%	0.2%
🟩 Self-advocates	12.7%	8.4%	1.8%	0.6%	49.4%	9.6%	4.8%	0.6%	2.4%	9.6%	0.0%	0.0%	0.0%
🟪 Expected	13.0%	11.5%	3.2%	3.6%	38.5%	23.2%	2.2%	1.5%	0.4%	2.7%	0.1%	0.1%	0.1%

B. RESPONDENTS' DEMOGRAPHICS

CAREGIVERS' DEMOGRAPHICS

The Caregivers' demographic information reports are based on the 3,273 Caregivers, followed by 3,338 individuals with ASD, with the information sourced from the Caregiver reports.[11]

As shown in Table 3, most Caregiver respondents were mothers (85%), followed by fathers (10%). The average Caregiver age was approximately 45 years of age (SD[12]= 8.9), ranging from 20 to 82 years of age. Most Caregivers described themselves as White/Caucasian (84%).

A majority of the respondents achieved at least a college or university degree (86%), and had lived in Canada all their lives or for at least 20 years (91%). Respondents were evenly split between living in self-described urban (38%) and suburban (39%) areas. Approximately 24% of Caregivers reported that they were not managing well or were in deep financial trouble.

There were few large differences in comparing the demographics of the Caregivers of preschoolers, school age children, or adults. The exception, as would be expected, is in Caregiver age, which increases with the age groupings.

As shown in Table 4, four out of five individuals with ASD were male. Most individuals with ASD were born in Canada (94%). The average age of individuals with ASD, as reported by Caregivers, was 12.8 years (SD = 7.4 years), distributed as follows:

- 4.2 years for preschoolers
- 10.9 years for school age children
- 24.1 years for adults

The ASD label that best described the individual with ASD varied, with 41% being identified as having a diagnosis of Autism / Autistic Disorder, 21% noted as having Asperger syndrome, 14% PDD-NOS, and 21% being described with the broader term 'Autism Spectrum Disorder' or Pervasive Developmental Disorder.

This variance is seen most clearly when comparing the diagnoses of preschoolers to the other age groups:

- Preschoolers were more likely to have an Autism Spectrum Disorder diagnosis (38%) compared to school age children (21%) and adults (17%).
- Preschoolers were also more likely to have a diagnosis of Autism (54%) compared to the other groups (43% of school age youth and 33% of adults).
- Very few preschool age children had an Asperger syndrome diagnosis, while there were increasing rates in school age youth (21%) and adults (31%). This same increasing trend is evident with references to the PDD-NOS label.

Nearly all individuals with ASD lived at home with the Caregivers (94%). Significantly fewer adults with ASD were living at home (80%) compared to younger individuals with ASD (at > 99%). Those adults who did not live at home were living either in residential care (8%), or in their own apartment (7%).

TABLE 3: CAREGIVER REPORTED DEMOGRAPHIC INFORMATION

	TOTAL CAREGIVERS N = 3273	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 373	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2237	CAREGIVERS OF ADULTS (18+ YEARS) N = 663
Caregiver Age M *(SD) Range*	45.1 *(8.9)* *20-82*	37.6 *(6.9)* *23-74*	43.7 *(7.5)* *20-82*	54.1 *(7.4)* *23-79*
RELATIONSHIP TO INDIVIDUAL WITH ASD				
Mother	2798 *(85.9%)*	329 *(88.2%)*	1937 *(85.3%)*	581 *(86.3%)*
Father	333 *(10.2%)*	30 *(8%)*	241 *(10.8%)*	62 *(9.4%)*
Grandparent	79 *(2.4%)*	11 *(2.9%)*	63 *(2.8%)*	5 *(.8%)*
Sibling	20 *(.6%)*	0	4 *(.2%)*	16 *(2.4%)*
Other[13]	28 *(.9%)*	3 *(.8%)*	18 *(.8%)*	7 *(1.1%)*

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[11] In both cases, when responding was optional, % were calculated out of total number of existing responses.

[12] SD is an abbreviation for Standard Deviation.

[13] Included extended family (aunt, uncle, cousin), foster parents, and kinship guardian.

TABLE 3: CAREGIVER REPORTED DEMOGRAPHIC INFORMATION

	TOTAL CAREGIVERS N = 3273	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 373	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2237	CAREGIVERS OF ADULTS (18+ YEARS) N = 663
ETHNICITY				
Asian, Asian Canadian or Pacific Islander (e.g., Chinese, Japanese)	219 *(6.7%)*	37 *(9.9%*	149 *(6.7%)*	33 *(5%)*
Black/African-Canadian	36 *(1.1%)*	8 *(2.1%)*	23 *(1.0%)*	5 *(.8%)*
Hispanic	52 *(1.6%)*	6 *(1.6%)*	43 *(1.9%)*	3 *(.5%)*
White/Caucasian	2738 *(84.1%)*	282 *(75.6%)*	1865 *(83.9%)*	591 *(89.7%)*
First Nations/ Aboriginal	25 *(.8%)*	3 *(.8%)*	18 *(.8%)*	4 *(.6%)*
Multi-ethnic	92 *(2.8%)*	19 *(5.1%)*	60 *(2.7%)*	13 *(2%)*
Other	93 *(2.9%)*	18 *(4.8%)*	65 *(2.9%)*	10 *(1.5%)*
EDUCATION				
< High school	57 *(1.8%)*	9 *(2.4%)*	37 *(1.7%)*	11 *(1.7%)*
High school	393 *(12.1%)*	51 *(13.7%)*	250 *(11.2%)*	92 *(14%)*
>High school	2802 *(86.2%)*	312 *(83.9%)*	1937 *(87.1%)*	553 *(84.3%)*
TIME LIVING IN CAD				
Less than 4 years	38 *(1.1%)*	10 *(2.6%)*	25 *(1.1%)*	3 *(.5%)*
5-9 years	72 *(2.2%)*	14 *(3.8%)*	53 *(2.4%)*	5 *(.8%)*
10-14 years	93 *(2.8%)*	15 *(4.0%)*	75 *(3.4%)*	3 *(.5%)*
15-19 years	76 *(2.3%)*	12 *(3.2%)*	57 *(2.6%)*	7 *(1.1%)*
20 years or more	394 *(12.1%)*	32 *(8.6%)*	246 *(11%)*	116 *(17.5%)*
All my life	2594 *(79.4%)*	290 *(77.7%)*	1776 *(79.6%)*	528 *(79.8%)*
SIZE OF COMMUNITY				
Remote/ rural	692 *(21.3%)*	73 *(19.7%)*	482 *(21.7%)*	137 *(20.8%)*
Suburban	1299 *(40%)*	142 *(38.3%)*	910 *(41.0%)*	247 *(37.5%)*
Urban	1256 *(38.7%)*	156 *(42%)*	826 *(37.2%)*	274 *(41.6%)*
MANAGING FINANCIALLY				
We manage very well	287 *(8.8%)*	30 *(8.0%)*	159 *(7.1%)*	98 *(14.8%)*
We manage quite well	727 *(22.3%)*	76 *(20.4%)*	473 *(21.2%)*	178 *(27%)*
We get by alright	1233 *(37.8%)*	137 *(36.7%)*	840 *(37.6%)*	256 *(38.8%)*
We don't manage very well	234 *(7.2%)*	31 *(8.3%)*	171 *(7.7%)*	32 *(4.8%)*
We have some financial difficulties	628 *(19.2%)*	80 *(21.4%)*	471 *(21.1%)*	77 *(11.7%)*
We are in deep financial trouble	157 *(4.8%)*	19 *(5.1%)*	119 *(5.3%)*	19 *(2.9%)*

TABLE 4: CAREGIVER REPORTED DEMOGRAPHIC INFORMATION OF INDIVIDUALS WITH ASD

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676
Child Age M *(SD) Range*	12.8 *(7.4)* *2–61*	4.2 *(.8)* *2–4.99*	10.9 *(3.7)* *5–17.99*	24.1 *(6.7)* *18–61*
GENDER				
Male	2724 *(81.7%)*	294 *(77.4%)*	1884 *(82.6%)*	546 *(80.8%)*
Female	600 *(18%)*	84 *(22.1%)*	389 *(17%)*	127 *(18.8%)*
Transgendered	9 *(.3%)*	2 *.(5%)*	5 *(.2%)*	2 *(.3%)*
RESIDENCY				
Living at home	3165 *(94.9%)*	379 *(99.7%)*	2247 *(98.5%)*	539 *(80%)*
In residential care	70 *(2.1%)*	0	19 *(.8%)*	51 *(7.6%)*
Own apartment	47 *(1.4%)*	0	1	46 *(6.8%)*
Shared arrangement	9 *(.3%)*	0	0	9 *(1.3%)*
Other	45 (1.3%)	1 *(.3%)*	15 *(.7%)*	29 *(4.3%)*
ASD DIAGNOSIS				
Autism	1396 *(42.4%)*	204 *(54.1%)*	973 *(43.3%)*	219 *(32.8%)*
Asperger syndrome	695 *(21.1%)*	10 *(2.6%)*	478 *(21.2%)*	207 *(31%)*
ASD/PDD	739 *(22.4%)*	143 *(37.9%)*	480 *(21.3%)*	116 *(17.4%)*
PDD-NOS	464 *(14.1%)*	20 *(5.3%)*	318 *(14.1%)*	126 *(18.9%)*
COUNTRY BORN				
Canada	3153 *(94.6%)*	371 *(97.6%)*	2154 *(94.4%)*	628 *(92.9%)*
United States	57 *(1.7%)*	4 *(1.1%)*	41 *(1.8%)*	12 *(1.8%)*
Other	123 *(3.7%)*	5 *(1.3%)*	84 *(3.7%)*	34 *(5%)*

SELF-ADVOCATES' DEMOGRAPHICS

In addition to the reports by the many Caregivers of adults with ASD, there was self-reported demographic information from 166 adults with ASD. These adults all reported having official diagnoses of an ASD (Autism Spectrum Disorder, Autism, PDD-NOS or Asperger syndrome).[14]

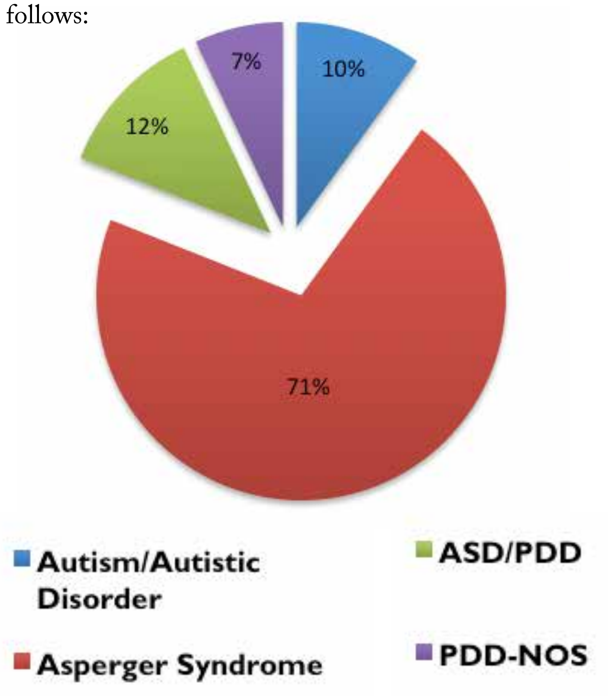
On average, Self-advocates were 35.1 years of age (SD = 11.1 years), ranging from 18 to 64 years of age. Twelve (7%) Self-advocates indicated that someone had helped them complete the survey, either a parent or sibling, professional, or friend.

Approximately half of the respondents were male, 45% were female, and 6% were transgendered. Most Self-advocates described themselves as White/Caucasian, followed by multi-ethnic (5%) and of Asian background (4%). Only one individual identified being of First Nations/Aboriginal ethnicity, and one individual of Black/African Canadian background. The majority of individuals lived in their own home or apartment (57%), followed by living with a family member (39%).

As shown in Figure 3, most Self-advocates had an Asperger syndrome diagnosis. Nearly all the Self-advocates were born in Canada (90%) or had been living in Canada for at least 20 years (7%).

Approximately 63% of respondents completed at least a college education. The employment and education profiles of Self-advocates are as follows:

- One in 3 Self-advocates (33%) indicated that they were not currently employed and not in school.
- The other two thirds of Self-advocates were involved in some form of education or employment, or combination of the two.
- Of those Self-advocates who were currently enrolled in school (26% of all Self-advocates), most were in post-secondary education (79%).
- Approximately 54% of Self-advocates were currently employed; of these, 42% of the employed Self-advocates in full-time work.



PROFESSIONALS' DEMOGRAPHICS

There was a wide age range of Professional respondents, from 19 to 74 years of age (M = 40.4 years, SD = 11.4 years). On average, they had been working with the ASD population for 11.3 years (SD = 8.1), with substantial variability, ranging from individuals just beginning their careers, to those who had been working for up to 42 years. They were asked them to estimate the number of individuals with ASD with whom they had worked. Given the number of years of experience noted, it is not surprising that this varied tremendously, up to an estimated 3,000 individuals. The majority of Professionals had worked with school age children (90%) and preschool age children (57%), while 38% had worked with adults. There was also considerable variability in the professions of the respondents, including medical doctors, educators, behaviour therapists or consultants, speech language pathologists, mental health care providers, allied health care, or paid residential Caregivers.

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[14] There were an additional 13 adults who did not have a diagnosis and 8 reported that they were not sure if they received a diagnosis. Their data is excluded from the national report.

C. PERSPECTIVES ON THE DIAGNOSTIC PROCESS

Table 5 provides a view of the diagnostic process. Based on reports from the Caregiver respondents, the average age of diagnosis for individuals with ASD was 5.5 years (with considerable variability, a standard deviation of 4 years and age range of 1 to 53 years). Caregivers of adults reported an average age at diagnosis of 8 years (SD = 7 years, ranging from 1 to 53 years of age), while school age children were diagnosed younger, at 5 years (SD = 3, ranging from 1 to 17 years of age). Almost all individuals were diagnosed in Canada (98%), and most individuals lived in the same province where they received the diagnosis, at approximately 90% across all provinces.

Overall, the most common diagnosticians were Psychologists (32%) and Pediatricians, including Developmental Pediatricians (32%), detailed as follows:

- Preschoolers were diagnosed more frequently by Pediatricians (40%) and Psychologists (33%) than by other diagnosticians. They were also more likely to be diagnosed by Pediatricians than other ASD age groups.
- The most common diagnosticians for school age youth were Psychologists (34%), followed by Pediatricians (33%).
- Adults were more likely to have been diagnosed by a Psychiatrist (41%) than other diagnosticians and more likely so than the other age groups.
- For Self-advocates, the most common diagnostician was a Psychiatrist (41%), followed by Psychologist (36%).

TABLE 5: INFORMATION ON DIAGNOSTIC PROCESS BY AGE CATEGORY

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF-ADVOCATES N = 166
Age of Diagnosis Mean *(SD) Range*	5.5 *(4.4)* *1-53*	2.9 *(1.0)* *1-4*	5.2 *(3.1)* *1-17*	8.1 *(7.1)* *1-53*	*Not available*
PROFESSIONAL MAKING DIAGNOSIS					
Family doctor	29 *(.9%)*	1 *(.3%)*	17 *(.7%)*	11 *(1.6%)*	15 *(9%)*
Psychiatrist	747 *(22.3%)*	46 *(12.1%)*	464 *(20.4%)*	237 *(35.1%)*	68 *(41%)*
Pediatrician	1058 *(31.6%)*	153 *(40.3%)*	755 *(33.1%)*	150 *(22.2%)*	9 *(5.4%)*
Neurologist	138 *(4.1%)*	11 *(2.9%)*	84 *(3.7%)*	43 *(6.4%)*	6 *(3.6%)*
Other medical doctor not listed above	86 *(2.6%)*	8 *(2.1%)*	57 *(2.5%)*	21 *(3.1%)*	2 *(1.2%)*
Psychologist	1080 *(32.3%)*	126 *(33.2%)*	773 *(33.9%)*	181 *(26.8%)*	60 *(36.1%)*
Nurse practitioner	7 *(.2%)*	3 *(.8%)*	4 *(.2%)*	0	1 *(.6%)*
Other type of clinician not listed above	48 *(4.3%)*	10 *(2.6%)*	27 *(1.2%)*	11 *(1.6%)*	4 *(2.4%)*
Multidisciplinary team	143 *(4.3%)*	22 *(5.8%)*	99 *(4.3%)*	22 *(3.3%)*	0
COUNTRY OF DIAGNOSIS					
Canada	3263 *(97.6%)*	378 *(99.5%)*	2232 *(97.8%)*	653 *(96.6%)*	162 *(97.6%)*
United States	33 *(1%)*	2 *(.5%)*	21 *(.9%)*	10 *(1.5%)*	2 *(1.2%)*
Other country	32 *(1%)*	0	19 *(.8%)*	13 *(1.9%)*	2 *(1.2%)*
PROVINCE					
BC	479 *(14.3%)*	62 *(16.3%)*	245 *(15.1%)*	72 *(10.7%)*	19 *(11.7%)*
AB	203 *(6.1%)*	31 *(8.2%)*	120 *(5.3%)*	52 *(7.7%)*	14 *(8.6%)*
SK	117 *(3.5%)*	16 *(4.2%)*	79 *(3.5%)*	22 *(3.3%)*	2 *(1.2%)*
MB	88 *(2.6%)*	9 *(2.4%)*	61 *(2.7%)*	18 *(2.7%)*	1 (.6%)
ON	1668 *(49.9%)*	162 *(42.6%)*	1155 *(50.6%)*	351 *(51.9%)*	83 *(50%)*
QC	226 *(6.8%)*	35 *(9.2%)*	159 *(7%)*	32 *(4.7%)*	14 (8.6%)
NB	117 *(3.5%)*	19 *(5%)*	82 *(3.6%)*	16 *(2.4%)*	8
PE	23 *(.7%)*	1 *(.3%)*	17 *(.7%)*	5 *(.7%)*	4 *(2.5%)*
NS	177 *(5.3%)*	25 *(6.6%)*	106 *(4.6%)*	46 *(6.8%)*	14 *(8.6%)*
NL	38 *(1.1%)*	9 *(2.4%)*	18 *(.8%)*	11 *(1.6%)*	2 *(1.2%)*
NT	3 *(.1%)*	0	3 *(.1%)*	1 *(.1%)*	0
NU	5 *(.1%)*	0	4 *(.2%)*	1 *(.1%)*	0
YU	1	0	1	0	0

D. HEALTH STATUS

OVERALL HEALTH

A set of questions similar to the U.S. National Survey of Children's Health (Gurney, McPheeters, & Davis, 2006)[15] was used to assess for common health conditions.

As shown in Table 6, according to Caregivers, most of the individuals with ASD were in fair to excellent health, with only 1.5% being rated as 'poor'. Even for adults with ASD, who were more likely to have poor health, this rate was relatively low, at 2.5%. Of the 166 Self-advocates, 6.6% noted being in poor health, considerably more than those reported by Caregivers.

ASSOCIATED DIAGNOSES

Caregivers reported that health care providers had identified a number of associated diagnoses about the person with ASD. These included:

- Intellectual disability (53%),
- Anxiety (52%),
- Behaviour problems (47%),
- Attentional problems (33%),
- Sleep problems (30%),
- Gastrointestinal problems (28%).

In comparison to other age groups, Caregivers reported that adults with ASD had more problems with:

- Anxiety (71%),
- Intellectual disability (65%),
- Behaviour (55%),
- Sleep (39%),
- Depression (33%),
- Gastrointestinal problems (31%),
- Seizure disorder (19%),
- Bone, joint and muscle problems (15%),
- Hearing problems (13%),
- Tourette syndrome (8%),
- Diabetes (3%).

Caregivers also reported that individuals with ASD received a number of formal psychiatric diagnoses, including:

- Anxiety Disorders (23%),
- Obsessive Compulsive Disorder (10%),
- Depression (9%).

Approximately 14% of Caregivers of adults reported that the adults with ASD had been diagnosed with more than one psychiatric disorder, followed by 3% of school age children, and less than 1% of preschoolers.

Preschool age children with ASD were less likely to be identified as having anxiety, ADHD, depression, behaviour problems, Tourette syndrome or seizure disorder than other age groups.

Among the Self-advocates, 22% reported having received a diagnosis of an intellectual disability by a health care provider. The most common problems communicated by health care providers for this group were anxiety (77%), followed by depression (66%) and sleep problems (49%).

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[15] Gurney, J.G., McPheeters, M.L., Davis, M.M. (2006). Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. Archives of Pediatric and Adolescence Medicine, 160, 825-830.

Over half reported receiving a formal psychiatric diagnosis of an anxiety disorder or of depression. As well, over half of the Self-advocates (52%) reported receiving more than one psychiatric diagnosis. Gastrointestinal problems were also quite common, reported in over one third of the Self-advocate respondents.

CURRENT CONCERNS ABOUT EMOTIONAL OR BEHAVIOURAL PROBLEMS

Caregivers were asked about any current concerns they had about emotional or behavioural problems in the individual with ASD, and Self-advocates were asked about their concerns about themselves.

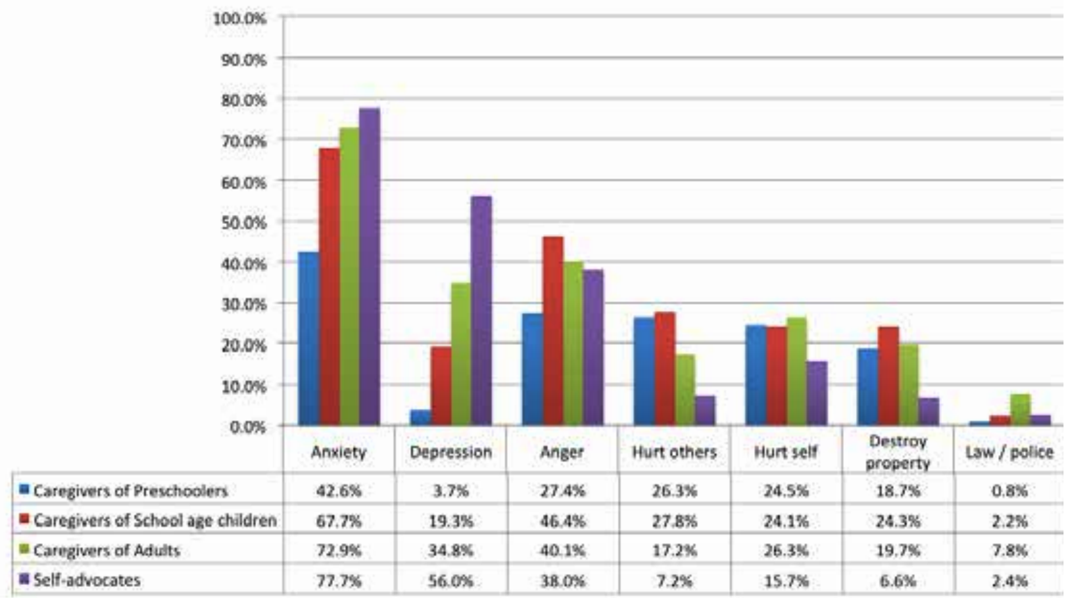
As shown in Figure 4, Caregivers of preschool age children were less likely to be concerned about anxiety, anger and depression than Caregivers from other age groups, and less likely to report concern than Self-advocates. The breakdown of health concerns is as follows:

- 42.6% of Caregivers of preschool age children reported concerns about anxiety, and this rises to approximately 68% for school age children, 70% for adults with ASD, and 78% for Self-advocates.
- 19% of Caregivers of school age youth were concerned about depression, and this rise to 35% of adults and 40% of Self-advocates
- 28% of Caregivers of preschoolers were concerned about anger, increasing to 46% for school age youth, and approximately 40% for adults and Self-advocates.
- Approximately one quarter of Caregivers were concerned about individuals with ASD hurting themselves or others. Self-advocates were less likely to report concern about hurting themselves, others, or destroying property compared to Caregivers.
- Caregivers of adults were far more likely to report a concern around the police or law (7.8%) compared to Caregivers of younger individuals or Self-advocates.

TABLE 6: REPORTED PHYSICAL AND MENTAL HEALTH

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166
Health rating as poor	51 (*1.5%*)	1 (*.3%*)	33 (*1.4%*)	17 (*2.5%*)	11 (*6.6%*)
DOCTOR OR HEATH CARE PROVIDER EVER TOLD THAT PERSON HAS:					
Anxiety	1736 (*52%*)	72 (*18.9%*)	1187 (*52%*)	477 (*70.6%*)	128 (*77.1%*)
ADHD	1114 (*33.4%*)	43 (*11.3%*)	836 (*36.7%*)	235 (*34.8%*)	48 (*28.9%*)
Depression	439 (*13.1%*)	2 (*.5%*)	212 (*9.3%*)	225 (*33.3%*)	110 (*66.3%*)
Brain Injury	119 (*3.6%*)	12 (*3.2%*)	79 (*3.5%*)	28 (*4.1%*)	22 (*13.3%*)
Cerebral Palsy	48 (*1.4%*)	1 (*.3%*)	31 (*1.4%*)	16 (*2.4%*)	1 (*.6%*)
Intellectual Disability	1763 (*52.7%*)	206 (*54.2%*)	1118 (*49%*)	439 (*64.9%*)	36 (*21.7%*)
Behaviour problems	1556 (*46.5%*)	127 (*33.4%*)	1060 (*46.5%*)	369 (*54.6%*)	33 (*19.9%*)
Tourette syndrome	135 (*4%*)	2 (*.5%*)	82 (*3.6%*)	51 (*7.5%*)	9 (*5.4%*)
Asthma	517 (*15.5%*)	41 (*10.8%*)	370 (*16.2%*)	106 (*15.7%*)	46 (*27.7%*)
Diabetes	36 (*1.1%*)	0	16 (*.7%*)	20 (*3%*)	7 (*4.2%*)
Epilepsy	328 (*9.8%*)	14 (*3.7%*)	186 (*8.2%*)	128 (*18.9%*)	17 (*10.2%*)
Hearing problems	314 (*9.4%*)	24 (*6.3%*)	200 (*8.8%*)	90 (*13.3%*)	27 (*16.3%*)
Vision problems	231 (*6.9%*)	21 (*5.5%*)	163 (*7.1%*)	47 (*7%*)	19 (*11.4%*)
Bone, joint, muscle problems	408 (*12.2%*)	36 (*9.5%*)	268 (*11.7%*)	104 (*15.4%*)	52 (*31.3%*)
Gastrointestinal	936 (*28%*)	99 (*26.1%*)	625 (*27.4%*)	212 (*39.1%*)	66 (*39.8%*)
Sleep problems	1034 (*31%*)	89 (*23.4%*)	681 (*29.8%*)	264 (*39.1%*)	81 (*48.8%*)
PSYCHIATRIC DIAGNOSES (EVER)					
Anxiety	767 (*23%*)	10 (*2.6%*)	472 (*20.7%*)	285 (*42.2%*)	91 (*54.8%*)
Depression	308 (*9.2%*)	2 (*.5%*)	127 (*5.6%*)	179 (*26.5%*)	91 (*54.8%*)
Psychosis/ Schizophrenia	54 (*1.6%*)	3 (*.8%*)	27 (*1.2%*)	24 (*3.6%*)	8 (*4.8%*)
Obsessive-Compulsive Disorder	348 (*10.4%*)	6 (*1.6%*)	180 (*7.9%*)	162 (*24%*)	27 (*16.3%*)
Other	353 (*10.6%*)	19 (*5%*)	219 (*9.6%*)	115 (*17%*)	39 (*23.5%*)

Figure 4. Percent of Caregivers and Self-advocates who are Currently Concerned about Emotional and Behavioural Problems



	Anxiety	Depression	Anger	Hurt others	Hurt self	Destroy property	Law / police
🟦 Caregivers of Preschoolers	42.6%	3.7%	27.4%	26.3%	24.5%	18.7%	0.8%
🟥 Caregivers of School age children	67.7%	19.3%	46.4%	27.8%	24.1%	24.3%	2.2%
🟩 Caregivers of Adults	72.9%	34.8%	40.1%	17.2%	26.3%	19.7%	7.8%
🟪 Self-advocates	77.7%	56.0%	38.0%	7.2%	15.7%	6.6%	2.4%

E. HEALTH SERVICE USE

PREVENTATIVE HEALTH CARE

The survey asked individuals whether they had accessed health services, as identified in a provided list, in the previous 12 months (Table 7). Only one quarter of individuals with ASD received a flu shot in the last year (26%), with higher rates in preschoolers (31%) and adults (32%) compared to school age children (24%). Self-advocates were the most likely to report having received a flu shot, at 35.5%.

There was a decreasing trend in having a routine annual physical exam across age groups, going from 87% of preschoolers to 62% of adults, and with the lowest rates in Self-advocates, at 53%. This same trend existed in terms of accessing a family doctor, although it was less pronounced than with receiving an annual physical. Approximately half of individuals accessed at least one medical specialist in the last year, including many who accessed psychiatrists, neurologists, developmental pediatricians, and allied health professionals.

Approximately 1 in 4 individuals had gone to the emergency room in the last year, with a high rate of preschoolers (43%), and fewer school age youth (23%) or adults (19%). Self-advocates also reported high rates of emergency room attendance (27.7%). Most school age individuals and adults had an annual dentist appointment (85%), with lower rates in Self-advocates (71%) and preschool age youth (61%).

TABLE 7: REPORTED PREVENTATIVE HEALTH CARE

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF-ADVOCATES N = 166
DURING THE LAST 12 MONTHS					
Had a flu shot	867 *(26%)*	117 *(30.8%)*	537 *(23.5%)*	213 *(31.5%)*	59 *(35.5%)*
Had a physical exam	2415 *(72.2%)*	329 *(86.6%)*	1665 *(73%)*	421 *(62.3%)*	88 *(53%)*
Accessed a family doctor	2909 *(87.2%)*	362 *(95.3%)*	1993 *(87.3%)*	554 *(82%)*	129 *(77.7%)*
Had an annual dentist appointment	2706 *(81.1%)*	188 *(49.5%)*	1944 *(85.2%)*	574 *(84.9%)*	118 *(71.1%)*
Accessed at least one medical specialist	1782 *(53.3%)*	231 *(60.8%)*	1176 *(51.5%)*	375 *(55.5%)*	97 *(58.4%)*
Been hospitalized	181 *(5.4%)*	23 *(6.1%)*	108 *(4.7%)*	50 *(7.4%)*	*16* *(9.6%)*
Gone to the Emergency Room **	761 *(24.1%)*	153 *(42.9%)*	486 *(22.6%)*	122 *(18.7%)*	46 *(27.7%)*

F. DEVELOPMENTAL AND COMMUNITY SERVICE USE

SERVICE USE - RECENT

The survey asked about services that were received in the last 6 months. These are described as recent receipt (Table 8).

On average, Caregivers of preschool age children reported recently using 3.8 services (SD = 2.2) in the last 6 months, more than Caregivers of school age youth or adults. Notably, the total number of recent services ranged from no service to 13 services. Caregivers reported that the most recently received services for preschoolers were:

- Non-IBI[16] early intervention (77%),
- Daycare or preschool programs (60%),
- Early intensive behavioural intervention (37%),
- Diagnostic or developmental assessment (36%).

School age youth used on average 3.2 services (SD = 2.4) in the last 6 months, but ranged from no services to 13 services. The most commonly used were:

- Activity-based programs (47%),
- Recreation / leisure programs (41%),
- Social skills programs (32%),
- Respite care (28%).

Reports by Caregivers of adults showed that adults used significantly fewer services (M = 2.6, SD = 2.5) in the last 6 months compared to other age groups. For adults with ASD, the most common services used were:

- Mental health treatment (28%),
- Respite (27%),
- Activity-based programs (25%),
- Recreation programs (22%).

Self-advocates reported recently using the least total number of services (M = 1.5 services, SD = 1.7), which ranged from no services to 8 services. For Self-advocates, the most common services were:

- Mental health treatment (40%),
- Post-secondary education programs (21%),
- Employment supports (15%).

SERVICE USE - EVER

Respondents were asked to report on services that individuals with ASD had ever received across their entire lifespan, combining both recently used and in the past. Table 9 shows that, overall, the majority of individuals with ASD have used some form of the following services:

- Diagnostic and developmental assessments (80%),
- Early intervention (75%),
- Daycare/preschool program (54%).

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16. IBI is used to connote Intensive Behavioural Intervention, defined in the survey as: An intensive application of behaviour therapy to teach new skills, which involves a step-by-step process that teaches language, social interaction, play, fine motor skills and self-help skills. Each skill is broken down into its components and taught through principles of learning and behaviour, such as repetition, support, and reinforcement. It is based on the science of Applied Behaviour Analysis.

On average, Caregivers reported that preschool age children had used 5.8 services to date (SD = 2.4). Among preschool age children with ASD, the most common services ever used by at least half of the group, included:

- Non-IBI early intervention (93%),
- Diagnostic services (80%),
- Early detection of ASD (76%),
- Daycare/preschool programs (75%),
- Activity-based programs (52%).

Caregivers reported that school age youth had used on average 7.8 services to date (SD = 3.2). The most common services, used by at least half of the sample, were:

- Diagnostic services (81%),
- Non-IBI early intervention (75%),
- Daycare (71%),
- Activity-based programs (70%),
- Recreation/leisure programs (68%),
- Social skills program (58%),
- Behaviour intervention for behaviour management (53%),
- Specialized summer programs (51%).

Caregivers of adults reported that adults with ASD, across their lives, had used on average 8.9 services (SD = 3.9). The most common services ever received, used by at least half of the sample, included:

- Diagnostic services (78%),
- Activity-based programs (67%),
- Recreation / leisure programs (67%),
- Non-IBI early interventions (64%),
- Social skills / friendship programs (61%),
- Specialized summer camps/activities (60%),
- Daycare programs (60%),
- Life skills training (58%),
- Mental health treatment (54%),
- Respite (52.4%),
- Behavioural intervention for behaviour management (50%).

Self-advocates reported using a similar number of services across their lifespan (M = 6, SD = 4.2). This includes over half the sample having used:

- Post-education programs (66%),
- Diagnostic services (62%),
- Mental health treatment (64%).

CAREGIVER SUPPORT SERVICE USE

Caregivers were asked what kinds of supports or services they, themselves, had received in the past or were currently receiving that were related to caring for their child. Table 10 shows that many Caregivers indicated they had received Parent/Caregiver training programs (39%) and respite care (34%). However, these rates varied by child age category. Almost half of the Caregivers of preschoolers (48%) reported accessing Parent/Caregiver training programs, compared to 42% of school age children and 24% of adults. Respite had been accessed by 42% of Caregivers of adults, compared to 34% of school age children and 18% of preschool age children.

TABLE 8: CAREGIVER AND SELF-ADVOCATES REPORTED SERVICES RECENTLY RECEIVED (IN THE LAST 6 MONTHS)

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166
Early detection of ASD	173 (*5.2%*)	112 (*29.5%*)	55 (*2.4%*)	6 (*.9%*)	1 (*.6%*)
Early IBI program	394 (*11.8%*)	140 (*36.8%*)	249 (*10.9%*)	5 (*.7%*)	0
Other forms of early intervention	756 (*22.6%*)	294 (*77.4%*)	451 (*19.8%*)	11 (*1.6%*)	0
Daycare/preschool program	495 (*14.8%*)	228 (*60%*)	263 (*11.5%*)	4 (*.6%*)	0
After-school programs	401 (*12%*)	18 (*4.7%*)	365 (*16%*)	18 (*2.7%*)	1 (*.6%*)
Recreational / leisure program	1207 (*36.1%*)	136 (*35.8%*)	925 (*40.5%*)	146 (*21.6%*)	19 (*11.4%*)
Social skills / friendship programs	930 (*27.8%*)	66 (*17.4%*)	731 (*32%*)	133 (*19.7%*)	19 (*11.4%*)
Activity-based programs (e.g., music)	1399 (*41.8%*)	155 (*40.8%*)	1,076 (*47.2%*)	168 (*24.9%*)	20 (*12%*)
Specialized summer camps / activities	284 (*8.5%*)	13 (*3.4%*)	232 (*10.2%*)	39 (*5.8%*)	2 (*1.2%*)
Housing / residential options	93 (*2.8%*)	3 (*.8%*)	35 (*1.5%*)	55 (*8.1%*)	5 (*3%*)
Diagnostic / developmental / skill assessment services (incl. ASD diagnosis)	473 (*14.1%*)	138 (*36.3%*)	293 (*12.8%*)	42 (*6.2%*)	14 (*8.4%*)
Respite care (in- and –out-of-home)	878 (*26.3%*)	62 (*16.3%*)	633 (*27.8%*)	183 (*27.1%*)	5 (*3%*)
Specialized transportation	454 (*13.6%*)	23 (*6.1%*)	331 (*14.5%*)	100 (*14.8%*)	1 (*.6%*)
Mental health treatment	506 (*15.1%*)	6 (*1.6%*)	311 (*13.6%*)	*189* (28%)	66 (*39.8%*)
Crisis intervention / management	175 (*5.2%*)	5 (*1.3%*)	114 (*5%*)	56 (*8.3%*)	11 (*6.6%*)
Behavioural intervention programs for behaviour management	704 (*21.1%*)	86 (*22.6%*)	544 (*23.8%*)	74 (*10.9%*)	4 (*2.4%*)
Community safety training	219 (*6.6%*)	9 (*2.4%*)	157 (*6.9%*)	53 (*7.8%*)	1 (*.6%*)
Life skills training	568 (*17%*)	31 (*8.2%*)	370 (*16.2%*)	167 (*24.7%*)	11 (*6.6%*)
Post-secondary education programs	116 (*3.5%*)	0	0	116 (*17.2%*)	35 (*21.1%*)
Employment or adult day programs	154 (*4.6%*)	0	0	154 (*22.8%*)	25 (*15.1%*)
Other services not listed here	291 (*8.7%*)	36 (*9.5%*)	196 (*8.6%*)	59 (*8.7%*)	15 (*9%*)

TABLE 9: REPORTED SERVICES EVER RECEIVED BY CAREGIVERS AND SELF-ADVOCATES

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166
Early detection of ASD	1,593 (*47.7%*)	288 (*75.9%*)	1,080 (*47.3%*)	225 (*33.3%*)	30 (*18.1%*)
Early IBI program	1,036 (*31%*)	172 (*45.3%*)	717 (*42.6%*)	147 (*21.7%*)	6 (*3.6%*)
Other forms of early intervention	2,503 (*75%*)	353 (*92.9%*)	1,721 (*75.4%*)	429 (*63.5%*)	36 (*21.7%*)
Daycare/preschool program	2,313 (*69.1%*)	285 (*75%*)	1623 (*71.1%*)	405 (*59.9%*)	41 (*24.7%*)
After-school programs	977 (*29.3%*)	26 (*6.7%*)	751 (*32.9%*)	200 (*29.6%*)	32 (*19.3%*)
Recreational / leisure program	2180 (*65.3%*)	181 (*47.6%*)	1548 (*67.8%*)	451 (*66.7%*)	67 (*40.4%*)
Social skills / friendship programs	1825 (*54.7%*)	92 (*24.2%*)	1,322 (*57.9%*)	411 (*60.8%*)	58 (*34.9%*)
Activity-based programs (e.g., music)	2239 (*67.1%*)	196 (*51.7%*)	1,588 (*69.6%*)	455 (*67.3%*)	67 (*40.1%*)
Specialized summer camps / activities	1,615 (*48.4%*)	49 (*12.9%*)	1,158 (*50.7%*)	408 (*60.4%*)	41 (*24.7%*)
Housing / residential options	107 (*5.1%*)	3 (*.8%*)	64 (*2.8%*)	103 (*15.2%*)	16 (*9.6%*)
Diagnostic / developmental / skill assessment services (incl. ASD diagnosis)	2,678 (*80.3%*)	305 (*80.3%*)	1,844 (*80.8%*)	529 (*78.3%*)	103 (*62%*)
Respite care (in- and –out-of-home)	1,368 (*41%*)	78 (*20.5%*)	936 (*41.1%*)	354 (*52.4%*)	17 (*10.2%*)
Specialized transportation	756 (*22.7%*)	25 (*6.6%*)	489 (*21.8%*)	242 (*35.8%*)	16 (*9.6%*)
Mental health treatment	914 (*27.4%*)	9 (*2.3%*)	539 (*24.5%*)	366 (*54.1%*)	105 (*63.3%*)
Crisis intervention / management	535 (*16%*)	10 (*2.6%*)	314 (*13.8%*)	211 (*31.2%*)	48 (*28.9%*)
Behavioural intervention programs for behaviour management	1,672 (*50%*)	116 (*30.5%*)	1,217 (*53.3%*)	339 (*50.1%*)	34 (*20.5%*)
Community safety training	534 (*16%*)	10 (*2.6%*)	336 (*14.7%*)	188 (*27.8%*)	20 (*12%*)
Life skills training	995 (*29.5%*)	32 (*8.4%*)	570 (*25%*)	393 (*58.1%*)	45 (*27.1%*)
Post-secondary education programs	236 (*7.1%*)	0	0	236 (*34.9%*)	110 (*66.3%*)
Employment or adult day programs	253 (*7.6%*)	0	0	253 (*37.4%*)	76 (*35.8%*)
Other services not listed here	451 (*13.5%*)	42 (*11.1%*)	303 (*13.3%*)	106 (*15.7%*)	23 (*13.9%*)

TABLE 10: SERVICES AND SUPPORTS UTILIZED BY CAREGIVERS

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676
WHAT KINDS OF SERVICES OR SUPPORTS HAVE YOU RECEIVED IN THE PAST/CURRENTLY RECEIVING THAT ARE RELATED TO CARING FOR YOUR CHILD?				
Parent/Caregiver training programs	1300 (*38.9%*)	181 (*47.6%*)	958 (*42%*)	161 (*23.8%*)
Family support/counselling	619 (*18.5%*)	50 (*13.2%*)	438 (*19.2%*)	131 (*19.4%*)
Any other supports/services	584 (*17.5%*)	61 (*16.1%*)	377 (*16.5%*)	146 (*21.6%*)
Respite care	1130 (*33.8%*)	69 (*18.2%*)	777 (*34%*)	284 (*42%*)

SERVICES WANTED BUT NOT RECEIVED

Respondents were asked to report on the services they would like to have received but did not. Having not received service is not the same thing as not needing the service – many individuals who did not receive a service noted having wanted it.

As evident in Table 11, 56% of individuals who did not receive early detection of ASD would have wanted it. Similarly, 51% of the sample who did not receive Early Intensive Behavioural Intervention (EIBI) would have wanted to receive it, with this need being the highest among Caregivers of preschoolers who had not received early IBI (74%). A similar trend emerged for other forms of early intervention.

Other common unmet service needs included:

- Social skills programs (79%),
- Activity-based programs (72%),
- Recreation programs (64%),
- Specialized summer activities (54%).

Community-safety training was often wanted for school age children and adults (41% and 43%, respectively). Life skills training (61%) and employment programs (64%) were noted service gaps particularly among adults with ASD. The highest service gaps for Self-advocates was early detection of ASD (at 60%) and social skills programs (62%).

TABLE 11: SERVICES WANTED BUT NOT RECEIVED, BY CAREGIVER AND SELF-ADVOCATES

	TOTAL CAREGIVERS	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS)	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS)	CAREGIVERS OF ADULTS (18+ YEARS)	SELF -ADVOCATES
Early detection of ASD	982 *(56.3%)*	41 *(44.6%)*	668 *(55.6%)*	273 *(60.5%)*	81 *(59.6%)*
Early IBI program	1042 *(50.9%)*	154 *(74%)*	619 *(47.3%)*	269 *(50.9%)*	35 *(21.9%)*
Other forms of early intervention	394 *(47.2%)*	25 *(92.6%)*	249 *(44.5%)*	120 *(48.6%)*	29 *(22.3%)*
Daycare/preschool program	255 *(24.9%)*	45 *(47.4%)*	140 *(21.3%)*	70 *(25.8%)*	14 *(11.2%)*
After-school programs	902 *(38.2%)*	63 *(17.8%)*	663 *(43.3%)*	176 *(37%)*	24 *(17.9%)*
Recreational / leisure program	745 *(64.4%)*	122 *(61.3%)*	476 *(64.9%)*	147 *(65.3%)*	35 *(35.4%)*
Social skills / friendship programs	1190 *(78.7%)*	219 *(76%)*	768 *(80.1%)*	203 *(76.6%)*	67 *(62%)*
Activity-based programs (e.g., music)	789 *(71.9%)*	140 *(76.1%)*	506 *(73%)*	143 *(64.7%)*	33 *(33.3%)*
Specialized summer camps / activities	941 *(54.2%)*	172 *(50%)*	656 *(58.4%)*	113 *(42.2%)*	28 *(22.4%)*
Housing / residential options	429 *(13.5%)*	10 *(2.7%)*	172 *(7.8%)*	247 *(43.1%)*	65 *(43.3%)*
Diagnostic / developmental / skill assessment services (incl. ASD diagnosis)	208 *(31.6%)*	16 *(21.3%)*	134 *(30.7%)*	58 *(39.5%)*	28 *(44.4%)*
Respite care (in- and –out-of-home)	682 *(34.6%)*	126 *(41.7%)*	470 *(34.9%)*	86 *(26.7%)*	10 *(6.7%)*
Specialized transportation	233 *(9%)*	30 *(8.5%)*	144 *(8%)*	59 *(13.6%)*	11 *(7.3%)*
Mental health treatment	537 *(22.2%)*	32 *(8.6%)*	417 *(23.9)*	88 *(28.4%)*	20 *(32.8%)*
Crisis intervention / management	349 *(12.5%)*	19 *(5.1%)*	247 *(12.6%)*	83 *(17.8%)*	21 *(17.8%)*
Behavioural intervention programs for behaviour management	656 *(39.4%)*	109 *(41.3%)*	432 *(40.6%)*	115 *(34.1%)*	23 *(17.4%)*
Community safety training	1110 *(39.6%)*	92 *(24.9%)*	804 *(41.3%)*	214 *(43.9%)*	25 *(17.1%)*
Life skills training	1075 *(45.9%)*	77 *(22.1%)*	826 *(48.3%)*	172 *(60.8%)*	54 *(44.6%)*
Post-secondary education programs	174 *(39.5%)*	0	0	174 *(39.5%)*	21 *(37.5%)*
Employment or adult day programs	272 *(64.3%)*	0	0	272 *(64.3%)*	37 *(41.1%)*
Other services not listed here	529 *(18.3%)*	34 *(10.1%)*	364 *(18.4%)*	131 *(23%)*	24 *(16.8%)*

G. TOP FIVE SERVICE NEEDS

Caregivers and Self-advocates were asked to pick their top 5 current service needs (see Table 12).

Caregivers identified the following as the top 5 service needs of preschoolers:

- Non-IBI forms of early intervention (69%),
- Early IBI (66%),
- Social skills programs (62%),
- Activity-based programs (55%),
- Daycare/preschool programs (46%).

For school age children, the top service needs identified were:

- Social skills programs (73%),
- Activity-based programs (51%),
- Recreation programs (48%),
- Specialized summer programs (45%),
- Life skills training (39%).

For adults with ASD, the most common top 5 service needs were:

- Employment or day programs (60%),
- Life skills training (48%),
- Social skills programs (49%),
- Recreation programs (37%),
- Post-secondary educational programs (34%).

Self-advocates identified the following as their top 5 needs service needs:

- Mental health treatment (45%),
- Employment services (41%),
- Social skills (40%),
- Post-secondary education (37%),
- Housing/residential options (32%).

TABLE 12: THE TOP 5 NEEDED SERVICES IDENTIFIED BY CAREGIVERS AND SELF-ADVOCATES

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166
Early detection of ASD	84 (2.5%)	27 (7.1%)	46 (2%)	11 (1.6%)	11 (6.6%)
Early IBI program	443 (13.3%)	251 (66.1%)	187 (8.2%)	5 (.7%)	3 (1.8%)
Other forms of early intervention	556 (16.6%)	262 (68.9%)	290 (12.7%)	4 (.6%)	4 (2.4%)
Daycare/preschool program	256 (7.7%)	176 (46.3%)	78 (3.4%)	2 (.3%)	0
After-school programs	604 (18.1%)	31 (8.2%)	558 (24.5%)	15 (2.2%)	3 (1.8%)
Recreational / leisure program	1505 (45%)	160 (42.1%)	1096 (48%)	249 (36.8%)	45 (27.1%)
Social skills / friendship programs	2232 (66.8%)	235 (61.8%)	1666 (73%)	331 (49%)	67 (40.4%)
Activity-based programs (e.g., music)	1584 (47.4%)	208 (54.7%)	1164 (51%)	213 (31.4%)	48 (28.9%)
Specialized summer camps / activities	1200 (35.9%)	93 (24.5%)	1016 (44.5%)	91 (13.5%)	5 (3%)
Housing / residential options	402 (12%)	4 (1.1%)	117 (5.1%)	281 (41.6%)	53 (31.9%)
Diagnostic / developmental / skill assessment services (incl. ASD diagnosis)	406 (12.1%)	38 (10%)	295 (12.9%)	73 (10.8%)	29 (17.5%)
Respite care (in- and –out-of-home)	874 (26.1%)	113 (29.7%)	624 (27.3%)	137 (20.3%)	7 (4.2%)
Specialized transportation	153 (4.6%)	13 (3.4%)	82 (3.6%)	58 (8.6%)	1 (.6%)
Mental health treatment	650 (19.4%)	11 (2.9%)	449 (19.7%)	190 (28.1%)	74 (44.6%)
Crisis intervention / management	145 (4.3%)	3 (.8%)	97 (4.3%)	45 (6.7%)	14 (8.4%)
Behavioural intervention programs for behaviour management	973 (29.1%)	89 (23.4%)	764 (33.5%)	120 (17.8%)	20 (12%)
Community safety training	615 (18.4%)	31 (8.2%)	463 (20.3%)	121 (17.9%)	11 (6.6%)
Life skills training	1249 (37.4%)	40 (10.5%)	887 (38.9%)	322 (47.6%)	51 (30.7%)
Post-secondary education programs	536 (16%)	5 (1.3%)	299 (13.1%)	232 (34.3%)	61 (36.7%)
Employment or adult day programs	612 (18.3%)	3 (.8%)	201 (8.8%)	408 (60.4%)	68 (41%)
Other services not listed here	314 (9.4%)	9 (2.4%)	219 (9.6%)	86 (12.7%)	29 (17.5%)

Professionals were asked to identify the top 5 current service needs for individuals with ASD and their families. As noted in Figure 5, they noted the most common top 5 services needed as:

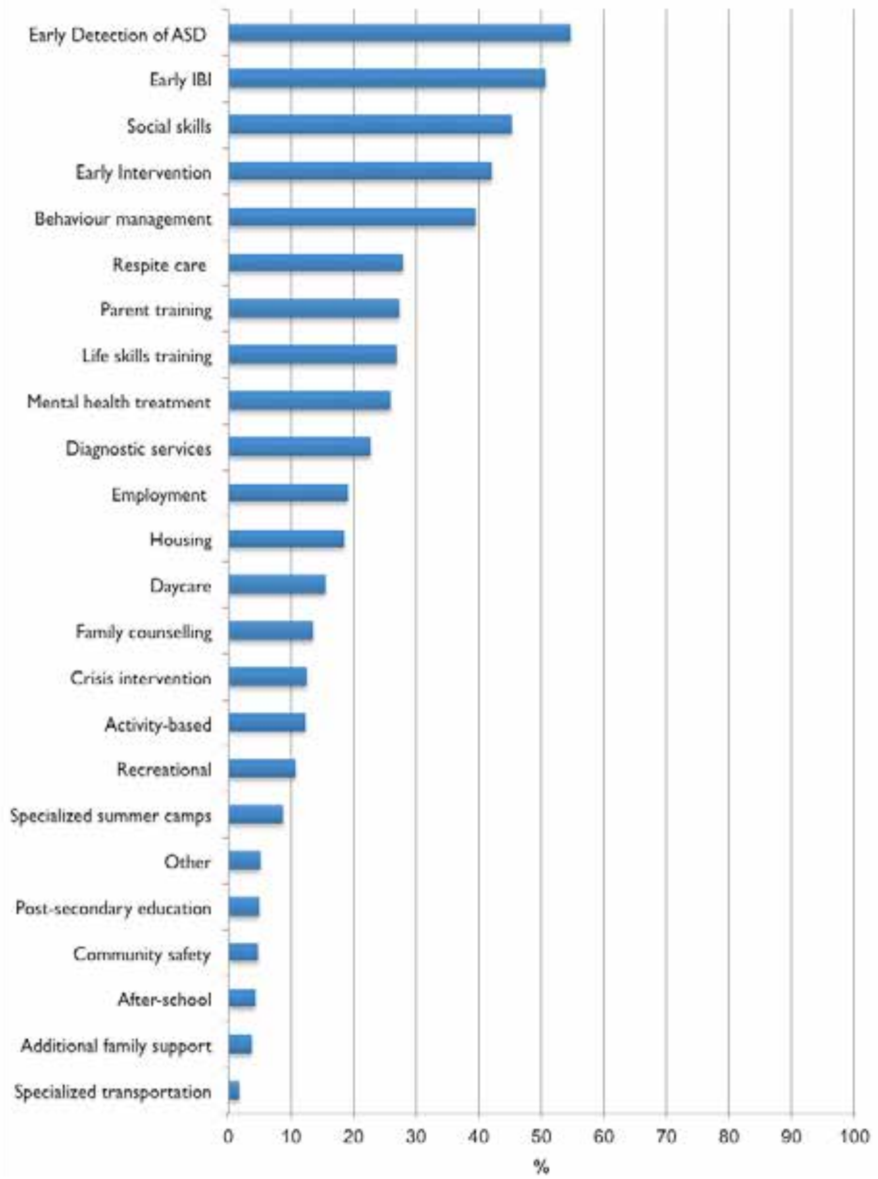
- Early detection of ASD (55%),
- Early IBI (51%),
- Social skills programs (45%),
- Behavioural intervention programs for behaviour management (40%),
- Respite care (28%).

Support services for families, including parent training programs (27%) and family counseling e.g., for grief or marital issues (14%), were also prevalent service needs identified by Professionals.

Further, Professionals were asked to rate how important they felt each service was for individuals with ASD. Nearly every service was rated between Very Important and Extremely Important.

The most important services identified by Professionals were early detection of ASD (M = 4.7, SD = .6), early intervention (M = 4.6, SD = .8), and diagnostic services (M = 4.6, SD = .7), followed closely by intensive behavioural intervention, social skill programs, crisis management, behaviour management, and parent training (all with means of 4.4).

Figure 5. Top 5 services as rated by Professionals



H. OBSTACLES TO RECEIVING SERVICE

DIFFICULT TO OBTAIN

Many services are difficult to obtain by Caregivers and Self-advocates, across all age groups. Table 13 illustrates the responses from all respondent groups, with a remarkable degree of consistency across all groups, except in some cases with regard to the responses from Self-advocates.

The top five most difficult to access services reported by Caregivers were social skills programs (55%), recreational leisure programs (43%), activity-based programs (43%), specialized summer camps (41%), and early intensive behaviour intervention (40%).

In particular, Caregivers of preschoolers reported difficulty receiving:

- Early IBI (50%),
- Social skills programs(48%),
- Other forms of early intervention (46%),
- Activity-based programs (44%),
- Recreational programs (38%).

Similarly, but with slightly different priorities given, Caregivers of school age children considered the following as most difficult to obtain:

- Social skills (55%),
- Specialized summer camps (44%),
- Activity based programs (44%),
- Early IBI (40%),
- Other forms of early intervention (38%),
- After school programs (38%).

Caregivers of adults identified priorities that were more relevant to the age of the individual with ASD:

- Social skills programs (58%),
- Employment services (55%),
- Recreational activities (46%),
- Life skills (46%),
- Obtaining housing/residential options (44%).

The Self-advocates identified the following as being difficult to obtain:

- Mental health treatment (40%),
- Diagnostic and assessment services (40%),
- Housing and residential options (38%),
- Employment services (38%),
- Social skills (33%).

Professionals also were asked to identify which services they believed families of individuals with ASD had difficulty obtaining. Overall, the top services identified were:

- Respite care (59%),
- Social skills programs (58%),
- Housing (55%),
- Mental health treatment (53%),
- Employment services (51%),
- After school programs (51%).

Additionally, Professionals were asked about the services for Caregivers/families that were difficult to obtain. They identified parent/caregiving training programs (44%) and family support or counseling (43%) as most pressing.

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services (Table 14). Overall, the most common barriers across respondent type were a lack of resources and being on a wait list (for Caregivers at 75%; Self-advocates at 45%; and Professionals at 92%).

The majority of Caregivers of preschoolers most commonly reported:

- A lack of resources (83%)
- Difficulty affording services (52%),
- Being too young to access services (34%).

For Caregivers of school age youth, the most common barriers included:

- Lack of resources (76%)
- Difficulty affording services (55%),
- Lack of trained professionals (49%).

Most commonly, Caregivers of adults identified:

- Lack of services (67%),
- Lack of trained health professionals (53%),
- Difficulty affording services (40%).

Unlike the other age groups, Caregivers of adults indicated that being too old to access service (51%) was a barrier for attaining services.

Self-advocates noted the most common barriers as:

- Not being able to afford services (57%),
- Lack of trained professionals (48%),
- Negative experiences with professionals (46%).

A majority of professionals identified difficulty affording services (81%), and a lack of trained health Professionals (56%) as major barriers.

TABLE 13: SERVICES IDENTIFIED AS BEING DIFFICULT TO OBTAIN

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166	PROFESSIONALS N = 2104
Early detection of ASD	1159 (34.7%)	105 (27.6%)	810 (35.5%)	244 (36.1%)	49 (29.5%)	979 (46.5%)
Early IBI program	1344 (40.2%)	188 (49.5%)	907 (39.7%)	249 (36.8%)	31 (18.7%)	1113 (52.9%)
Other forms of early intervention	1256 (37.6%)	174 (45.8%)	856 (37.5%)	226 (33.4%)	29 (17.5%)	938 (46.7%)
Daycare/preschool program	839 (25.1%)	127 (33.4%)	561 (24.6%)	151 (22.3%)	23 (13.9%)	849 (40.4%)
After-school programs	1169 (35%)	54 (14.2%)	864 (37.9%)	251 (37.1%)	27 (16.3%)	1074 (51%)
Recreational / leisure program	1436 (43%)	144 (37.9%)	979 (42.9%)	313 (46.3%)	42 (25.3%)	1008 (47.9%)
Social skills / friendship programs	1841 (55.1%)	183 (48.2%)	1264 (55.4%)	394 (58.3%)	55 (33.1%)	1221 (58%)
Activity-based programs (e.g., music)	1452 (43.4%)	168 (44.2%)	995 (43.6%)	289 (42.8%)	35 (21.1%)	855 (40.6%)
Specialized summer camps / activities	1361 (40.7%)	119 (31.3%)	1007 (44.1%)	235 (34.8%)	31 (18.7%)	937 (44.5%)
Housing / residential options	545 (16.3%)	20 (5.3%)	227 (9.9%)	298 (44.1%)	63 (38%)	1160 (55.1%)
Diagnostic / developmental / skill assessment services (incl. ASD diagnosis)	1084 (32.4%)	88 (23.2%)	760 (33.3%)	236 (34.9%)	66 (39.8%)	827 (39.3%)
Respite care (in- and –out-of-home)	1192 (35.7%)	138 (36.3%)	823 (36.1%)	231 (34.2%)	20 (12%)	1231 (58.5%)
Specialized transportation	409 (12.2%)	32 (8.4%)	250 (11%)	127 (18.8%)	17 (10.2%)	658 (31.3%)
Mental health treatment	826 (24.7%)	30 (7.9%)	564 (24.7%)	232 (34.3%)	67 (40.4%)	1114 (52.9%)
Crisis intervention / management	602 (18%)	27 (7.1%)	392 (17.2%)	183 (27.1%)	31 (18.7%)	911 (43.3%)
Behavioural intervention programs for behaviour management	1162 (34.8%)	94 (24.7%)	835 (36.6%)	233 (34.5%)	34 (20.5%)	974 (46.3%)
Community safety training	795 (23.8%)	44 (11.6%)	558 (24.5%)	193 (28.6%)	19 (11.4%)	741 (35.2%)
Life skills training	1089 (32.6%)	50 (13.2%)	728 (31.9%)	311 (46%)	54 (32.5%)	877 (41.7%)
Post-secondary education programs	414 (12.4%)	7 (1.8%)	207 (9.1%)	200 (29.6%)	50 (30.1%)	794 (37.7%)
Employment or adult day programs	571 (17.1%)	7 (1.8%)	190 (8.3%)	374 (55.3%)	61 (36.7%)	1080 (51.3%)
Other services not listed here	359 (10.7%)	20 (5.3%)	234 (10.3%)	105 (15.5%)	29 (17.5%)	145 (6.9%)

TABLE 14: BARRIERS TO ACCESSING SERVICES

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF -ADVOCATES N = 166	PROFESSIONALS N = 2104
Cannot afford services	1720 (51.5%)	198 (52.1%)	1253 (54.9%)	269 (39.8%)	95 (57.2%)	1693 (80.5%)
Negative experiences with Professionals in the past	731 (21.9%)	41 (10.8%)	496 (21.7%)	194 (28.7%)	77 (46.4%)	645 (30.7%)
Not enough resources – on a waitlist	2500 (74.9%)	315 (82.9%)	1731 (75.9%)	454 (67.2%)	75 (45.2%)	1944 (92.4%)
Lack of trained Professionals	1617 (48.4%)	137 (36.1%)	1124 (49.3%)	356 (52.7%)	79 (47.6%)	1179 (56%)
Not able to access services because diagnosis does not qualify them for services	691 (20.7%)	49 (12.9%)	469 (20.6%)	173 (25.6%)	44 (26.5%)	950 (45.2%)
Being too young to receive services that are needed	477 (14.3%)	128 (33.7%)	320 (14%)	29 (4.3%)	7 (4.2%)	361 (17.2%)
Being too old to receive services that are needed	1069 (32%)	18 (4.7%)	709 (31.1%)	342 (50.6%)	68 (41%)	995 (47.3%)
Services are too far	780 (23.3%)	53 (13.9%)	533 (24.2%)	174 (25.7%)	34 (20.5%)	724 (34.4%)
Services are not available in the right language	84 (2.5%)	13 (3.4%)	63 (2.8%)	8 (1.2%)	1 (.6%)	467 (22.2%)
They are deemed ineligible even if they have a diagnosis that should qualify them	864 (25.9%)	43 (11.3%)	513 (22.5%)	210 (31.1%)	45 (27.1%)	370 (17.6%)
Other barriers	766 (22.9%)	76 (20%)	595 (26.1%)	193 (28.6%)	43 (25.9%)	555 (26.4%)

FINANCIAL SUPPORT

Caregivers and Self-advocates were asked about any financial support they had received to help access services for their child or for themselves (see Table 15). Although over half of Caregivers across all age groups (60%) indicated that they had received support from their province/territory, only one quarter of this group of Caregivers (27%) indicated that it was sufficient to access the services they needed.

Among Self-advocates, 36% reported that they had received financial support to access services, and of these, only 21% indicated that it was sufficient to access supports. Approximately 50% of Caregivers indicated that they could afford services but struggled, and another 32% noted not being able to afford services. Approximately 31% of Self-advocates reported bring able to afford services but struggled, and another 45% reported they were not able to afford services.

TABLE 15: FINANCIAL SUPPORT FOR SERVICES

	TOTAL CAREGIVERS N = 3338	CAREGIVERS OF PRESCHOOLERS (UP TO 4 YEARS) N = 380	CAREGIVERS OF SCHOOL AGE CHILDREN (5-17 YEARS) N = 2282	CAREGIVERS OF ADULTS (18+ YEARS) N = 676	SELF-ADVOCATES N = 166
Received financial support from province / territory to help access services?	1984 (59.9%)	189 (50%)	1364 (60.3%)	431 (64.1%)	59 (35.5%)
Was the financial support sufficient to access the services?	526 (26.6%)	65 (34.4%)	340 (25%)	121 (28.1%)	35 (21.1%)
CAN YOU OR YOUR CHILD AFFORD TO PAY FOR SERVICES					
Yes, easily	499 (14.9%)	55 (14.6%)	306 (13.5%)	138 (20.8%)	39 (23.5%)
Yes, but struggle	1745 (52.2%)	202 (53.4%)	1219 (54%)	324 (48.8%)	51 (30.7%)
No, cannot afford services	1057 (31.6%)	121 (32%)	734 (32.5%)	202 (30.4%)	75 (45.2%)

I. COMMENTS SECTIONS SUMMARY

A number of questions in the survey had sections that permitted comments, elaborations or other answers. Careful review of these comments was undertaken, as this was the one area where respondents were able to move away from selecting from a list or set of choices and use their own words to describe their opinions. At times, the comments provided further context to the survey questions. Still other comments were intended to provide insight and perspectives that were not covered in the survey per se.

CAREGIVERS' COMMENTS

A review of the comments from Caregivers provided 6 predominant themes regarding services. The themes identified below were evident across the three categories of survey questions - services needed, services used, and barriers to receiving services – and across the age groups of their children. The themes are presented here in order of importance, as determined by frequency of comment:

1. Social skills support
2. Services for adults
3. Speech and OT services
4. System navigation/coordination
5. Financial assistance
6. Educational supports

There was a particular emphasis on supports for adults and financial assistance to access programs.

> *"We recognize we are part of the fortunate few who could pay for private services for our son. Most people we meet are not in this position and they wait too long for help. Our family struggled mentally with all the issues we faced in the early days. I can't imagine adding financial strain on top of that. We need to do more to help families in dire financial situations."*

Responses to questions regarding barriers to service illustrated an increased frequency of concern regarding services for adults and specific concerns about limited availability of services for individuals with high functioning Autism or Asperger syndrome. Related to this latter issue was the identification of the need for mental health services for those individuals on the more able end of the spectrum.

> *"We want him to participate in life; not a program; people not therapists; the ability to have a support person to participate fully and a school system that will include him in regular classroom in community school!"*

A recurrent theme throughout all comments sections for Caregivers was the need for family assistance, especially with respect to system navigation.

> *"…the help we have received since the diagnosis has been awesome , they come to our house, everyone is amazing with our son, we have speech therapy and early intervention we are on the waiting list for intensive early intervention, I must say I am very happy with all the help we have received."*

> *"Services should not be geared to making their autism appear to 'go away', but rather helping them be supported and successful in the world as they are….They deserve to be given the tools they need to be meaningful contributors to our society."*

SELF-ADVOCATES' COMMENTS

The comments section for Self-advocates were completed by individuals predominantly on the more able end of the spectrum. Much of the commentary reflected issues linked to having Asperger syndrome[18] or high functioning Autism. As a result, their comments present important feedback from a constituent group that previously has not had a chance to have their voices heard. Many were very articulate about their frustrations with having received their diagnosis very late, after having experienced extended periods without appropriate assistance. Their comments were both poignant and direct.

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[18] *Asperger syndrome is referenced in this section as most of the respondents were diagnosed prior to DSM-V, and self-identify as having Asperger syndrome.*

> *"It seems to be assumed that when we become adults, we vanish off this planet. There are VERY few services for adults, especially older ones. Many of us have difficulties with anxiety/depression and loneliness due to no help or concern at all when we were children. We either survived or we didn't; there was NO help whatsoever. We deserve some help now. ADULTS ARE IMPORTANT TOO!!"*

While their responses cannot necessarily be extrapolated to include others on the autism spectrum, they nevertheless provide a loud and powerful message about a large portion of people with ASD.

> *"Support and services for Autistic adults such as myself are pathetically lacking as is support for our voices or even acknowledgement that we are here. This survey and most services/programs are child oriented. It's distressing and leaves so many of us Autistic Adults out here by ourselves with nowhere to turn."*

The feedback from the Self-advocates provided five (5) compelling themes, presented here in order of importance, as determined by frequency of comment:

1. Employment
2. Social skills support
3. Challenges with getting a diagnosis when on the high end of the spectrum
4. Mental health supports
5. System navigation/coordination

Employment related issues focused on the need for support to get and keep a job. Meaningful employment that allows for accommodation to their unique social and sensory needs while tapping into their areas of skill and strength was a recurrent message. Like most Canadians seeking employment, they want the respect and independence that accompanies employment. A lack of adequate support and of allowances for their idiosyncrasies were identified as barriers to their success.

> *"I am 46. I have some very good skills and during very little of my life have I been able to use them as there is no proper support so you wind up completely marginalized. The work I do is for a foreign company as the attitudes in North America about people like me are not good. Consistently even medical professionals will assume I am mentally handicapped if I am not able to speak or speak slowly. That a person could have significant challenges with some areas of their life but have the potential to be productive in other areas is just completely outside of the average Canadian's grasp it seems. It's frustrating."*

Considerable commentary focused on the realities of living with Asperger syndrome. The respondents demonstrated an especially clear understanding of their need for social skills training, mentoring and support. Social difficulties were identified as the most significant barriers to their integration into successful adult living situations.

A significant number of respondents identified that getting a late diagnosis had posed very real challenges to their understanding of themselves and to their active and successful participation in their communities. In addition, it was clear from the feedback that they felt that most of the ASD services were not designed for them, leaving them poorly served in the ASD sector in particular and more generally in other support sectors, such as the mental health or health sector. Further, many identified the need for access to trained mental health practitioners who understood ASD, especially Asperger syndrome.

> *"Treat us with respect. I know myself and I know what I can and can't do. I am capable of making informed decisions about myself. Never assume you know me better than I know myself. And when I'm obviously in distress, show some sympathy instead of treating me like a manipulative child!"*

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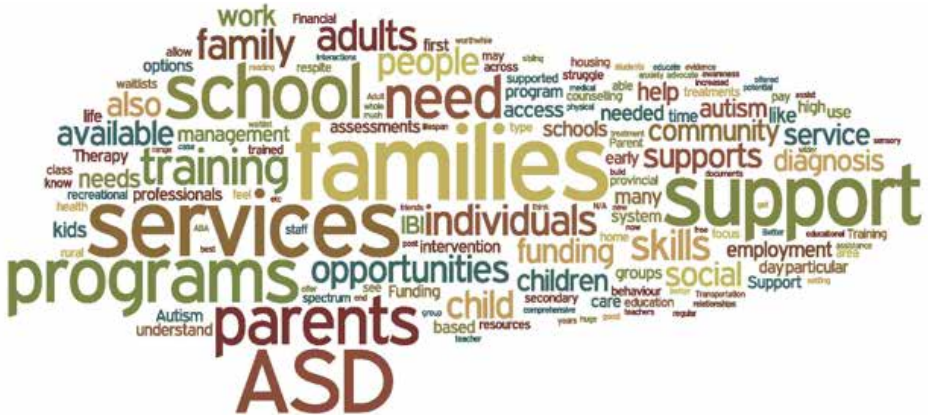
18. Asperger syndrome is referenced in this section as most of the respondents were diagnosed prior to DSM-V, and self-identify as having Asperger syndrome.

PROFESSIONALS' COMMENTS



The responses from Professionals highlighted many of the same issues identified by Caregivers and individuals with ASD. Namely, services for adults, transition planning and support, employment readiness and opportunities and a pervasive shortage of appropriate services.

> *"Families are often so busy coping that they can't research what is available. M. would be great if they could have a case manager that guides them through the maze and gets them on waiting lists early."*

However, two topics were presented with very strong frequency and which, interestingly, were referenced more in passing by either of the two other respondent groups. Professionals expressed a very significant concern about the lack of supports and services for families. This serves as a powerful reminder of the inclination of Caregivers to put the needs of their family member with ASD well ahead of their own needs.

> *"The majority of our families really struggle with respite. They have difficulty finding and keeping qualified individuals that can support their child. They also struggle with not having enough funding to allow for respite especially the high needs individuals. Then as they get older the parents struggle with lack of supports for adults on the spectrum and worry about what will happen when they are not available to look after their child with a disability."*

The professional respondents' focus on parents and family members was the most prominent of all their comments. Their comments are presented here in order of importance, as determined by frequency of comment:

1. Parent support,
2. Accessibility to service, including the availability and cost of such services, extensive waitlists and the limited options available in certain communities,
3. Poor autism awareness within the professional, educational and community sectors, leading to increased isolation and stress for families,
4. Respite opportunities for all family members,
5. System navigation, ensuring that families did not have to bear the burden of sorting through systemic challenges.

Also presented by the Professionals, but not represented in the comments of either the Caregivers' or individuals with ASD's, were the challenges associated with linguistic and cultural diversity. This issue merits further exploration in light of the relatively low level of diversity identified among the Caregiver respondents.

DISCUSSION OF NATIONAL PERSPECTIVE

A response rate of over 5600 to this national needs assessment is admirable on its own merit, providing a wealth of information that can be used to enhance evidence-based planning. Closer examination, however, illustrates the need for a more comprehensive outreach strategy to ensure a broader representation by Canadians at all levels of socio-economic standing and across all provinces and territories. Of particular concern is the limited response received from Yukon, Northwest Territories and Nunavut. A more targeted outreach strategy is required to gain a fuller picture of the service terrain in those communities.

The demographic profile of the participants of this study was primarily White/Caucasian, with a large majority having achieved university or college education. The lack of evident linguistic and cultural diversity presents a significant gap in the range of respondents. As such, the sample does not adequately provide a true representation of the population of Canada, or of the full range of Canadians facing the challenges associated with ASD.

These factors also limit some of the conclusions that can be drawn with respect to gaining access to services and being able to afford services. The respondents in the study frequently indicated that they faced financial pressures or were not able to afford the services they required. The sample largely represents Canadians who are not facing language or cultural barriers to accessing services, which leaves the question of whether those not represented in the study may face even more challenges than those reported by the respondents in the study.

Across all age groups the presence of mental health issues was significant, with anxiety and depression reported as levels that are high enough to be of real concern when planning for services and looking at what further role the health sector has to play in the ASD service network.

The study received a significant number of responses from adults who have ASD and completed the survey independently. Most indicated they had a diagnosis of Asperger syndrome. This is a group looking to be heard. They provided considerable insight into the challenges of being diagnosed later in life and being ‘able enough’ that most service options were not open to them. The level of mental health problems they reported was significant. Their identification of issues related to anxiety, depression and ADHD provided insight into the need for more mental health support services. Transition planning services are needed also for this group of individuals with ASD. These issues were also highly relevant to Caregivers of adults with ASD, reflecting a high level of need across the spectrum.

The data collected with respect to diagnostic processes provided some evidence of improvements in earlier identification. The average age of diagnosis declined, with the adults being diagnosed latest, school aged children next and preschoolers earliest. This provides some evidence of success for the investments that have been made in earlier identification and intervention.

While service use showed some variability, often based on what was available in a specific community, there was clear evidence that regardless of which services were received, more service was required. When looking at barriers to service, the largest single barrier identified was a lack of resources, followed by difficulty affording services. The financial burden experienced across all age groups was significant. Most Caregivers and Self-advocates reported some level of struggling to afford services.

NEXT STEPS

The primary objective identified by CASDA in developing this survey was to gather data from across the country that could be used to guide evidence-based priority setting. The presentation of data to affect decision-making and policy making, based on evidence, drove the process.

CASDA’s intent with this needs assessment survey project includes providing PHAC with data which can be used to fill critical knowledge gaps and contribute to advancing a strong evidence base to help improve the lives of Canadians affected by ASD. The data also may have value to PHAC in relation to its work on the determinants of health, particularly in the areas of immigrants, ethnic diversity, marginalized citizens and Canadians of lower socio-economic standing.

Priorities arising from this report’s data and its analysis include the following:

- Increased early and timely access to diagnosis, intensive behavioural intervention, parent support, and other forms of evidence-based early intervention
- Targeted outreach to address the unique issues of Canada’s northern communities
- The development of accessible mental health services for youth and adults with ASD that meet their level of need, which includes the involvement of the health, education, and community service sectors
- More outreach to reach Self-advocates, a large group of Canadians, many of whom are living on the periphery of their communities and often outside of the network of services
- Comprehensive planning for adulthood, including transition support services
- A plan to address the housing needs of adults with ASD
- Targeted outreach to linguistically and culturally diverse communities, facilitating understanding of their service needs and improving their access to service

The data in this report may also be useful in the dialogue between federal and provincial/territorial leaders. It presents an overview of the current state of ASD services, gaps and needs across the country. The reports in the appendix also present differences across jurisdictions which may be helpful in establishing guidance and standardization of practice. These synopses of the data and analysis for each province and the north can provide a useful context for such discussions.

Questions for further research which arise from this study include:

- Service needs in northern communities,
- Experiences of individuals with ASD in school systems,
- Mental health interventions for youth and adults with ASD,
- Financial vulnerability among individuals with ASD,
- Evaluation of what services and supports exist across Canada as measured against recognized best practices.

APPENDIX A

SURVEY DATA & ANALYSIS OF PROVINCES, NORTH & INDIVIDUALS WITHOUT A DIAGNOSIS

BRITISH COLUMBIA PARTICIPANTS' RESPONSES

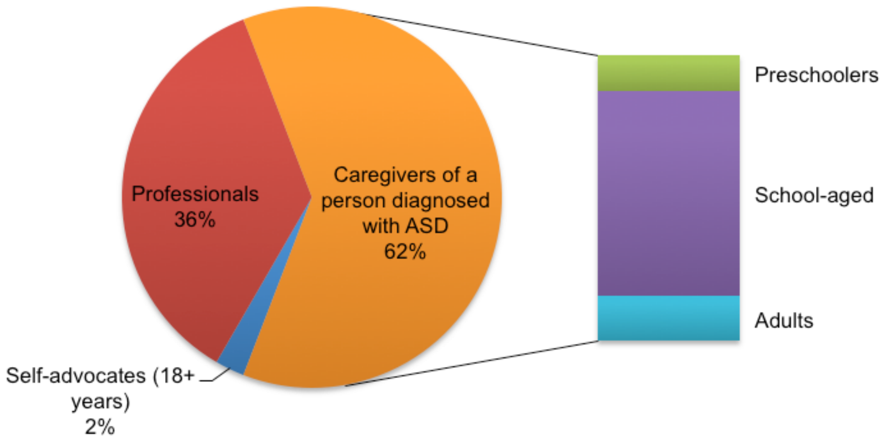
RESPONDENTS REPRESENTATION

As shown Figure 1, respondents from British Columbia (N = 841) consisted of 508 Caregivers, reporting on 519 individuals with ASD, 301 Professionals, and 21 Self-advocates. None of the BC respondents completed the French version of the survey.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 72% (n = 371) school age youth, aged 5-17
- 15% adults (n = 81), 18 years of age and over
- 13% (n = 67) preschool age children, 4 years of age and younger

Figure 1. Respondents from British Columbia

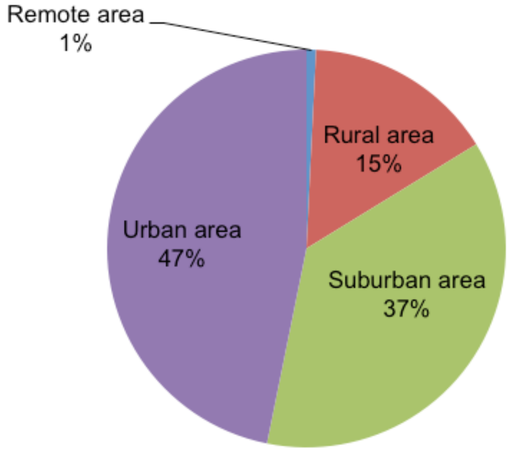


RESPONDENTS' DEMOGRAPHICS

Caregivers' Demographics

Most Caregiver respondents were mothers (85%), followed by fathers (10%). The average Caregiver age was 45.2 years (SD = 8.9 years), ranging from 24 to 72 years. Most Caregivers described themselves as White/Caucasian (77%). A majority of respondents achieved at least a college or university degree (87%). Eighty-six percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, respondents were mostly split between urban and suburban areas of BC. Approximately 24% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (84%) and their average age was 12 years (SD = 7.1 years).

- The average age, by age group is as follow:
    - The preschool age group was 4.1 Years (sd = .9 Years, ranging from 2 to 4.9 Years),
    - The school age group was 10.8 Years (sd = 3.7 Years, ranging from 5 to 17.9 Years), and
    - The adult age group was 24.2 Years (sd = 7.6 Years, ranging from 19 to 56 years).
- 94% of individuals with ASD lived at home with the Caregiver respondents. Preschoolers and school age youth were more likely to be living at home (>98%), compared to adults with ASD (73%).
- Most individuals with ASD were born in Canada (93%).
- 47% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 14% Asperger syndrome, 18% PDD-NOS, and 21% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Self-advocates' Demographics

Of the 21 Self-advocates, over half of the respondents were male (52%), 33% were female, and 14% were transgendered. On average, Self-advocates were 35.9 years of age (SD = 12.6 years), ranging from 18 to 57 years of age. The majority of Self-advocates described themselves as White/Caucasian (91%). 67% of Self-advocates reported receiving an Asperger syndrome diagnosis.

Eighty-one percent of the Self-advocates were born in Canada or had been living in Canada for at least 20 years. Fifty-seven percent of Self-advocates reported living in an urban area of British Columbia. Reported residency of Self-advocates was evenly split between 48% living with a family, and 48% living in their own home or apartment.

Nineteen percent of respondents reported that they had completed at least a college education, and another 19% attained a trades' apprenticeship or certificate, diploma, or another non-university certificate.

Over half (57%) of Self-advocates were currently employed; 85% in part-time employment. Of the Self-advocates who were currently enrolled in school (29%), over 80% were in post-secondary education. One quarter of Self-advocates indicated that they were not currently employed or in school. Approximately 28% of Self-advocates reported that they had some financial difficulties or were in deep financial trouble.

Professionals' Demographics

There was a wide age range of professional respondents, from 21 to 73 years of age (M = 42.6 years, SD = 11.7 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 40 years (M = 13 years, SD = 8.9 years).

- 93% had worked with school age children
- 62% had worked with preschool age children
- 31% had worked with adults
- 17% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents currently living in British Columbia, the average age of diagnosis for individuals with ASD was 5.7 years (SD = 4.5 years, ranging from 1 to 49 years).[19] The following is the breakdown of age of diagnosis by age category of the individual with ASD:

- Preschool age children (4 years of age or younger): M = 2.97, SD = .7, ranging from 1 to 4 years,
- School age children (5 -17 years of age): M = 5.3, SD = 3.2, ranging from 1 to 17 years,
- Adults (18 years or older): M = 9.5, SD = 7.8, ranging from 2 to 49 years.

Overall, Caregivers identified psychologists (36%) as the most frequent health Professionals providing their child's ASD diagnosis, followed by psychiatrists (27%), and pediatricians (20%). Similar trends were evident for the younger age groups, with psychologists providing the ASD diagnosis most frequently for preschoolers (40%) and school age children (36%).

In adults, the most frequent diagnosticians reported were psychiatrists (46%), followed by psychologists (28%). Almost half of Self-advocates reported that psychiatrists (48%) had provided their ASD diagnosis.

HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers and Self-advocates reported that health care providers had identified a number of physical and mental health diagnoses with reference to the person with ASD. As shown in Figure 4, the following health issues were reported.[20]

- Reports of anxiety and depression increased steadily with age group. Caregivers of adults and self-advocates reported the highest rates of anxiety and depression,
- Intellectual disability/developmental disability (id/dd), and behaviour problems were more common among all three caregiver groups than among self-advocates,
- Depression, diabetes, asthma, and bone/joint/muscle problems were more common among self-advocates than caregiver groups
- Anxiety and gastro-intestinal (gi) problems increased across the three caregiver age groups,
- Sleep problems were a common problem in all respondents, ranging from 22% (preschoolers) to 40% (adults).

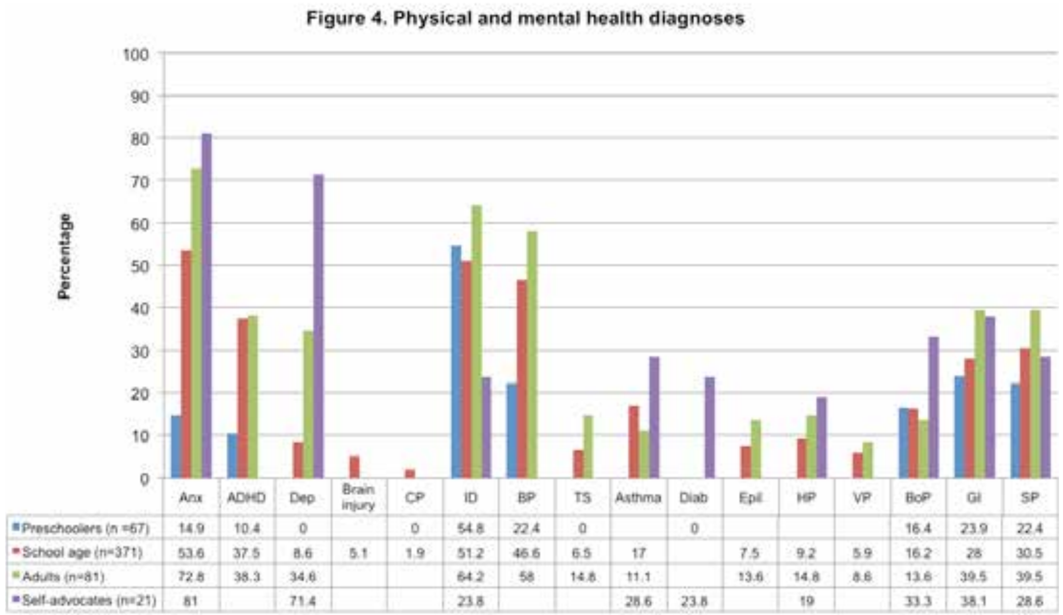


Figure 4. Physical and mental health diagnoses

	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
■ Preschoolers (n =67)	14.9	10.4	0		0	54.8	22.4	0		0				16.4	23.9	22.4
■ School age (n=371)	53.6	37.5	8.6	5.1	1.9	51.2	46.6	6.5	17		7.5	9.2	5.9	16.2	28	30.5
■ Adults (n=81)	72.8	38.3	34.6			64.2	58	14.8	11.1		13.6	14.8	8.6	13.6	39.5	39.5
■ Self-advocates (n=21)	81		71.4			23.8			28.6	23.8		19		33.3	38.1	28.6

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

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19. Age of diagnosis was not available for the Self-advocates.

20. When sample sizes have less than 5 participants, data is not presented (left blank).

Caregivers and Self-advocates also reported on any formal psychiatric diagnoses ever provided (Table 1). These diagnoses were uncommon for preschool age children, and rose steadily through other age categories. For example, anxiety rose to 25% of school age children, 51% of adults, and 43% of Self-advocates. Similarly, a diagnosis of depression was uncommon in school age children (6%), but rose to 32% in adults and 57% in Self-advocates.

TABLE 1: FORMAL PSYCHIATRIC DIAGNOSES RECEIVED

	SCHOOL AGE CHILDREN (5-17 YEARS) N = 371	ADULTS (18+ YEARS) N = 81	SELF-ADVOCATES (18+ YEARS) N = 21
PSYCHIATRIC DIAGNOSES (EVER)			
Anxiety	92 (25%)	41 (51%)	9 (43%)
Depression	21 (6%)	26 (32%)	12 (57%)
Psychosis/ Schizophrenia	<5	<5	<5
Obsessive-Compulsive Disorder	36 (10%)	24 (30%)	<5
Other	52 (14%)	18 (22%)	6 (29%)

Health Service Use

Caregivers and Self-advocates reported on their health service use in the last 12 months, as shown in Figure 5.[21]

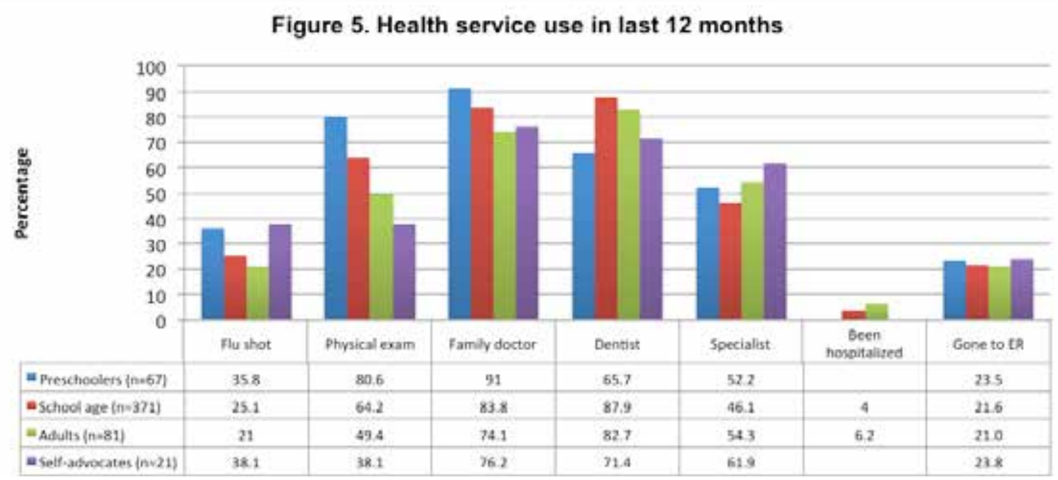
Figure 5. Health service use in last 12 months

	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Been hospitalized	Gone to ER
🟦 Preschoolers (n=67)	35.8	80.6	91	65.7	52.2		23.5
🟥 School age (n=371)	25.1	64.2	83.8	87.9	46.1	4	21.6
🟩 Adults (n=81)	21	49.4	74.1	82.7	54.3	6.2	21.0
🟪 Self-advocates (n=21)	38.1	38.1	76.2	71.4	61.9		23.8

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers and Self-advocates indicated which services they had used in the past 6 months. These were noted as recent service use.

Caregivers reported that the most recently received services for preschoolers were:

- Non-IBI forms of early intervention (81%),
- Daycare or preschool programs (57%),
- Early IBI (64%),
- Behavioural intervention for behaviour management (43%),
- Recreation programs (40%),
- Activity-based programs (40%).

The most commonly used recent services for school age children were:

- Activity-based programs (54%),
- Recreation / leisure programs (46%),
- Behavioural intervention for behaviour management (41%),
- Social skills programs (39%),
- Respite care (30%).

For Caregivers of adults with ASD, the most common recently used services were:

- Post-secondary educations programs (31%),
- Respite care (31%),
- Life skills programs (28%),
- Employment programs (28%),
- Mental health treatment (27%).

Self-advocates were most likely to have recently used mental health treatment, with all other services being used less in fewer than 20% of participants.

The total number of recently used services reported by Caregivers and Self-advocates was examined. The following is a breakdown by age category and respondent type:

- Preschool age children (4 years of age or younger): M = 4.0, SD = 2, ranging from 0 to 8 services,
- School age youth (5 -17 years of age): M = 3.7, SD = 2.5, ranging from 0 to 12 services,
- Adults (18 years or older): M = 2.9, SD = 3, ranging from 0 to 14 services,
- Self-advocates (18 years or older): M = 1.1, SD = 1.4, ranging from 0 to 5 services.

Current Service Needs

Caregivers and Self-advocates identified their top 5 current service needs, selecting from a list provided.

According to Caregivers, the most commonly reported top 5 service needs of preschoolers were:

- Non-IBI forms of early intervention (66%),
- Social skills programs (66%),
- Early IBI (64%),
- Daycare/preschool programs (54%),
- Activity-based programs (48%).

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[21] *When sample sizes have less than 5 participants, data is not presented (left blank).*

For school age children, the top 5 needs were:

- Social skills programs (76%),
- Activity-based programs (50%),
- Recreation programs (49%),
- Specialized summer programs (41%),
- Behavioural intervention programs (37%).

For adults with ASD, the most common top 5 needs were:

- Employment or day programs (61%),
- Life skills training (52%),
- Social skills programs (48%),
- Post-secondary educational programs (47%),
- Housing/residential programs (43%).

For Self-advocates, the top 5 needs were:

- Mental health treatment (48%),
- Post-secondary education (43%),
- Employment services (38%),
- Other programs (38%),
- Social skills programs (29%) and recreational programs (29%).

Professionals reported that the top 5 needs for persons diagnosed with ASD were:

- Early detection of ASD (60%),
- Social skills programs (57%),
- Early intensive behavioural intervention (54%),
- Non-IBI early treatment (48%),
- Behaviour intervention for behaviour management (41%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers that they have experienced when accessing services. By age group, the most common barriers were identified as follows:

Caregivers of preschoolers most commonly identified the following barriers:

- Lack of resources (73%),
- Difficulty affording services (54%)
- Being too young to access services (43%).

Caregivers of school age children commonly identified the following barriers:

- Lack of resources (72%)
- Difficulty affording services (52%)
- Lack of trained professionals (49%).

Caregivers of adults identified:

- Lack of services (61%),
- Lack of trained health professionals (59%),
- Being too old to access service (51%),
- Difficulty affording services (44%).

Self-advocates most commonly noted the following barriers:

- Not being able to afford services (67%),
- Negative experiences with professionals in the past (52%),
- Lack of trained professionals (52%).

Professionals identified the following barriers:

- Lack of resources (89%),
- Difficulty affording services (74%),
- Lack of trained health professionals (64%).
- Being too old to receive services (46%),
- Diagnosis does not qualify them for services (42%).

ALBERTA PARTICIPANTS' RESPONSES

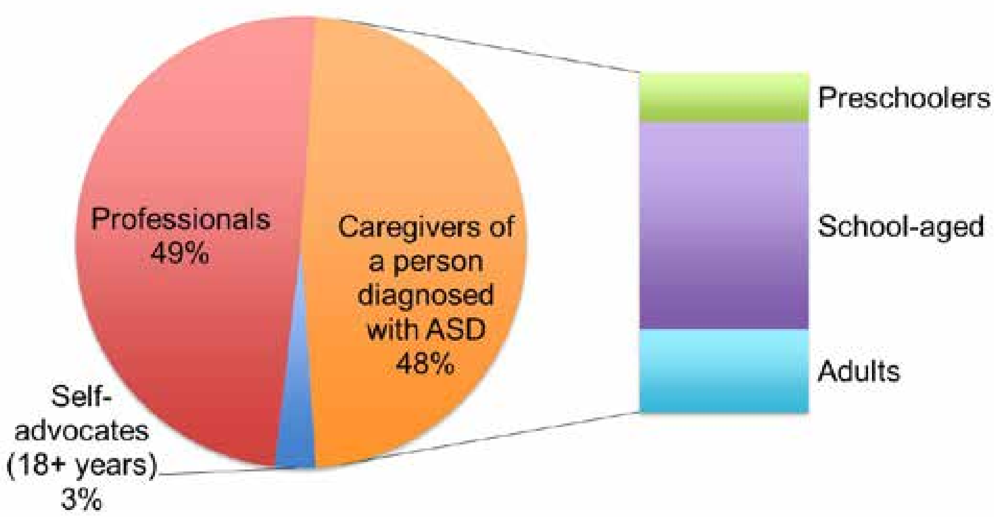
RESPONDENTS REPRESENTATION

As shown in Figure 1, respondents from Alberta (N = 474) consisted of 224 Caregivers reporting on 227 individuals with ASD, 233 Professionals, and 14 Self-advocates.[22] Less than one percent of Alberta respondents completed the French version of the survey.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 61% school age children, aged 5-17 (n = 139)
- 24% adults, 18 years of age and over (n = 55)
- 16% preschool age children (n = 33)

Figure 1. Respondents from Alberta



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[22] We are unable to report on the health and service experiences of any groups with less than 20 respondents. In the case of Alberta, this refers to the Self-advocates.

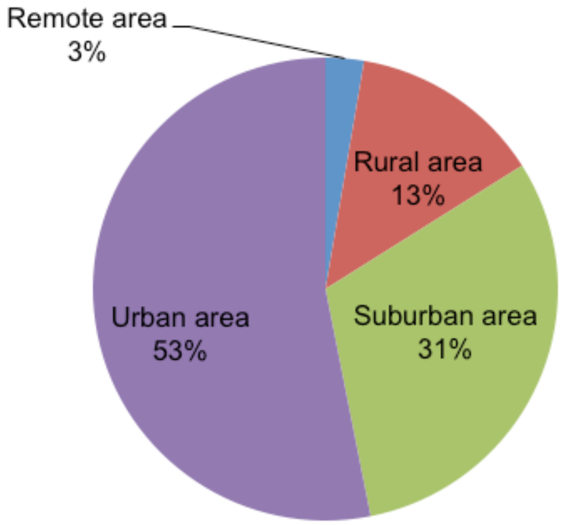
RESPONDENTS' DEMOGRAPHICS

Caregivers' Sample Demographics

Most Caregiver respondents were mothers (83%), followed by fathers (14%). The average Caregiver age was 45.1 years (SD = 9.6 years), ranging from 20 to 72 years. Most Caregivers described themselves as White/Caucasian (83%). A majority of respondents achieved at least a college or university degree (85%). Approximately 17% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Eighty-nine percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, the majority of respondents (53%) reported living in an urban area of Alberta.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

- The majority of individuals with ASD were male (83%) and their average age was 13.5 years (SD = 8.3 years, ranging from 3 to 53 years). The average age, by age group, is as follows:
  - The preschool age group was 4.5 years (SD = .7, ranging from 3 to 4.9 years),
  - The school age group was 11.1 years (SD = 4.1, ranging from 5 to 17.9 years), and
  - The adult age group 24.7 years (SD = 7.3, ranging from 18 to 53 years).
- Ninety percent of individuals with ASD lived at home with the Caregiver respondents. The majority of preschoolers and school age children were living at home (>97%), whereas only 69% of adults lived at home.
- Most individuals with ASD were born in Canada (91%).
- 49% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 16% Asperger Syndrome, 8% PDD-NOS, and 26% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

SELF-ADVOCATES' DEMOGRAPHICS

Of the 17 Self-advocates, the majority of respondents were male (71%). On average, Self-advocates were 31.5 years of age (SD = 10.9 years), ranging from 19 to 57 years of age. The majority of Self-advocates described themselves as White/Caucasian (93%). 72% of Self-advocates reported receiving an Asperger syndrome diagnosis.

All Self-advocates were born in Canada. Just over half reported that they lived with a family member (57%), while 43% indicated that they live in their own home or apartment.

Approximately 21% of respondents completed at least a college education, and another 29% attained a trades' apprenticeship or certificate, diploma, or another non-university certificate. 21% of Self-advocates reported being currently enrolled in school.

Forty-three percent of Self-advocates were currently employed; of these, half in full-time employment and half in part-time. Approximately 14% indicated that they were not currently employed and not in school.

Professionals' Demographics

There was a wide age range of professional respondents, from 19 to 66 years of age (M = 34.3 years, SD = 11.5 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 35 years (M = 8.2 years, SD = 7.2).

- 95% had worked with school age children
- 66% had worked with preschool age children
- 39% had worked with adults
- 25% had worked with all 3 age groups

Perspectives on Diagnostic Process

Of the Caregiver respondents, the average age of diagnosis for individuals with ASD was 5.2 years (SD = 5.7 years, ranging from 1 to 53 years).[23] The following is the breakdown of age of diagnosis by age category of the individual with ASD:

- Preschool age children (4 years of age or younger): M = 2.8 years, SD = 1.0, ranging from 1 to 4.9 years
- School age children (5 -17 years of age): M = 4.3 years, SD = 2.4, ranging from 2 to 13 years
- Adults (18 years or older): M = 8.8 years, SD = 10.0, ranging from 1 to 53 years

From Caregivers' responses, pediatricians (41%) were the most frequently noted health Professionals providing their child's ASD diagnosis, followed by psychologists (24%), and psychiatrists (16%). Similar trends were evident for the younger age groups, with pediatricians providing the ASD diagnosis most frequently for preschoolers (49%) and school age children (44%). In adults, the most frequent diagnosticians reported were psychologists (29%), followed closely by pediatricians (27%).

HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers reported that health care providers had identified a number of physical and mental health diagnoses with reference to the person with ASD. As shown in Figure 3, the following health issues were reported[24]:

- Anxiety and sleep problems, which increased steadily with age and with the highest levels reported by Caregivers of adults,
- ADHD was far more common in school age children and adults than in preschoolers
- Intellectual disability and behaviour problems were common among all three Caregiver groups,
- Epilepsy and hearing problems were also far more common among Caregivers of adults than the other groups,
- Gastro-intestinal problems were present in approximately 30% of Caregiver reports.

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23. Age of diagnosis was not available for the Self-advocates

24. When sample sizes have less than 5 participants, data is not presented (left blank).

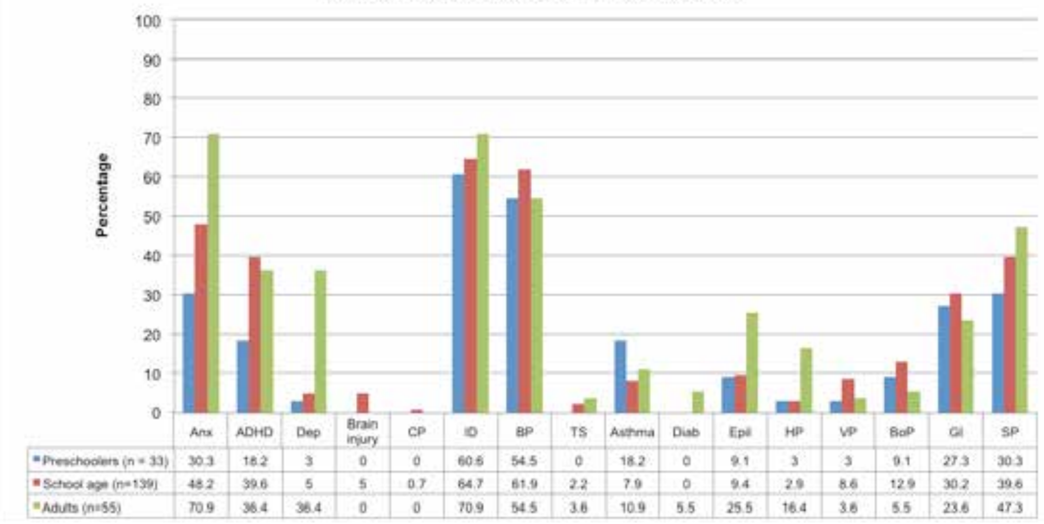


Figure 3. Physical and mental health diagnoses

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers also reported on any formal psychiatric diagnoses ever provided (Table 1). These diagnoses were uncommon for preschool age children, and rose steadily through other age categories. For example, depression was rarely diagnosed in preschool age children, but rose to 4.3% of school age children, and 31% of adults. Similarly, a diagnosis of anxiety was highest in adults, at 38%.

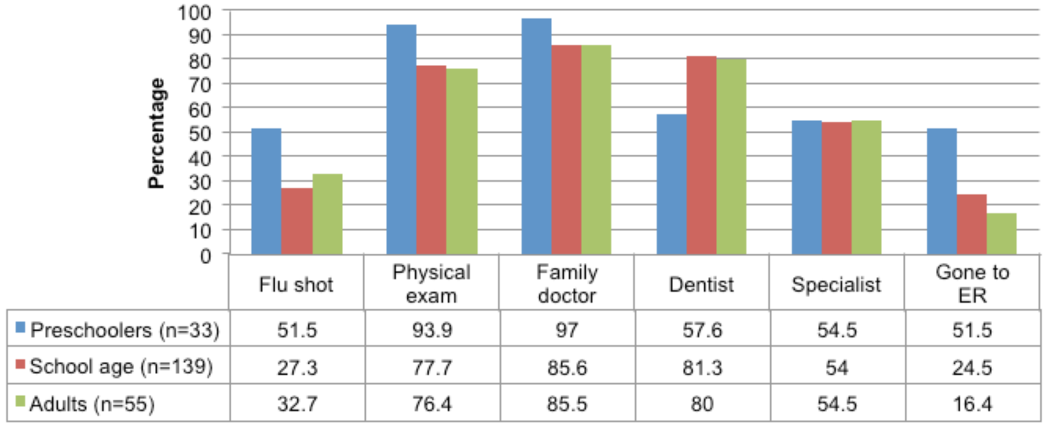
TABLE 1: FORMAL PSYCHIATRIC DIAGNOSES RECEIVED

	SCHOOL AGE CHILDREN (5-17 YEARS) N = 139	ADULTS (18+ YEARS) N = 55
PSYCHIATRIC DIAGNOSES (EVER)		
Anxiety	21 (15.1%)	21 (38.2%)
Depression	6 (4.3%)	17 (32%)
Psychosis/Schizophrenia	<5	<5
Obsessive-Compulsive Disorder	12 (8.6%)	13 (23.6%)
Other	13 (9.4%)	14 (25.5%)

Health Service Use

Caregivers and Self-advocates reported on their health service use in the last 12 months, as shown in Figure 4.[25]

Figure 4. Health service use in last 12 months



DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers were asked to indicate which services they had used in the past 6 months. These were noted as recent service use.

Caregivers reported that the most recently received services for preschoolers were:

- Non-IBI early intervention (82%),
- Daycare or preschool programs (73%),
- Respite care (61%),
- Activity-based programs (49%),
- Diagnostic or developmental assessment services (49%).

The most commonly used recent services for school age children were:

- Respite care (57%),
- Activity-based programs (48%),
- Behaviour management (33%),
- Recreation / leisure programs (33%),
- Life skills programs (29%).

For Caregivers of adults with ASD, the most common recent services were:

- Mental health treatment (46%),
- Activity-based programs (35%),
- Recreation programs (33%),
- Social skills programs (33%),
- Specialized transportation (33%),
- Employment or adult day programs (33%).

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[25] When sample sizes have less than 5 participants, data is not presented (left blank). In this case, that included being hospitalized in the last 12 months for all age groups.

The total number of recently used services reported by Caregivers and Self-advocates provided the following breakdown by age category and respondent type:

- Preschool age children (4 years of age or younger): M = 5.2, SD = 2.7, ranging from 0 to 12 services,
- School age children (5 -17 years of age): M = 3.8, SD = 2.9, ranging from 0 to 12 services,
- Adults (18 years or older): M = 3.7, SD = 2.7, ranging from 0 to 11 services,
- Self-advocates (18 years or older): M = 1.4, SD = 1.7, ranging from 0 to 5 services.

Current Needs

Caregivers identified the **top 5** current service needs, selecting from a list provided.

The most common top 5 current service needs of preschoolers were:

- Activity-based programs (67%),
- Social skills (64%),
- Non-IBI early intervention (55%),
- Recreation programs (55%),
- Early IBI (46%).

For school age children, the top 5 current service needs were:

- Activity-based programs (61%),
- Recreation programs (56%),
- Specialized summer programs (49%),
- Life skills training (43%),
- Respite care (33%).

For adults with ASD, the most common top 5 current service needs were:

- Employment or day programs (71%),
- Life skills training (53%),
- Social skills programs (51%),
- Housing/residential options (49%),
- Post-secondary educational programs (36%).

Professionals reported that the top 5 current service needs for individuals with ASD were:

- Early detection of ASD (54%),
- Early IBI (46%),
- Non-IBI early intervention (45%),
- Social skills programs (41%),
- Parent/training programs (34%).

Barriers to Service

All respondents were asked to identify the barriers that they have experienced when accessing services. By age group, the most commonly identified barriers were as follows:

The majority of Caregivers of preschoolers most commonly reported the following barriers:

- Lack of resources (70%),
- Being too young to access services (52%),
- Lack of trained professionals (42%).

Caregivers of school age children most commonly identified the following barriers:

- Lack of resources (60%),
- Lack of trained professionals (57%),
- Difficulty affording services (50%).

Caregivers of adults commonly identified:

- Lack of trained health professionals (62%),
- Lack of services (60%),
- Being too old to access service (53%).

Professionals most commonly noted the following barriers for individuals with ASD:

- Lack of resources (90%),
- Difficulty affording services (76%),
- Lack of trained health professionals (54%).

SASKATCHEWAN PARTICIPANTS' RESPONSES

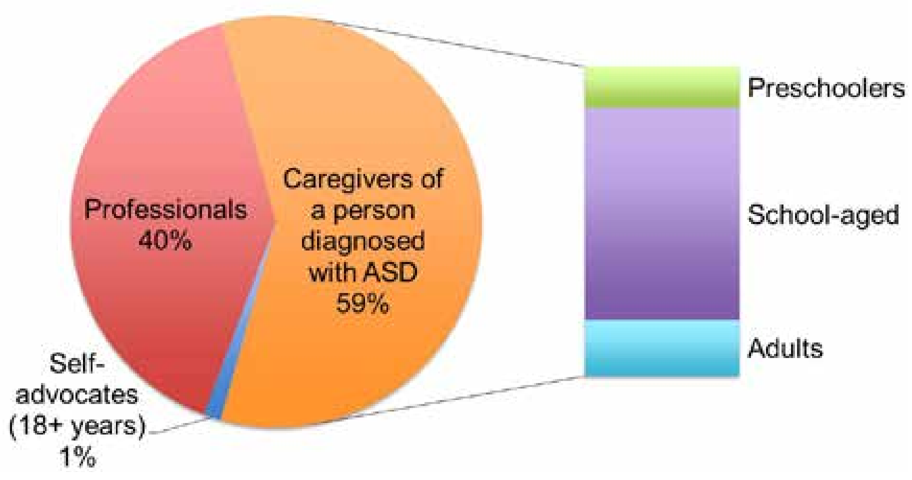
RESPONDENTS REPRESENTATION

As shown Figure 1, respondents from Saskatchewan (N = 218) consisted of 125 Caregivers reporting on 128 individuals with ASD, 87 Professionals, and 3 Self-advocates.[26] Less than one percent of Saskatchewan respondents completed the French version of the survey.

Within the Caregiver respondent group, the following is the breakdown by age of child:

- 69% school age children, aged 5-17 (n = 88)
- 18% adults, 18 years of age and over (n = 23)
- 13% preschool age children (n = 17)

Figure 1. Respondents from Saskatchewan



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[26] *We are unable to report on the health and service experiences specifically of any groups with less than 20 respondents. In the case of Saskatchewan, this refers to Caregivers of preschool age children and Self-advocates.*

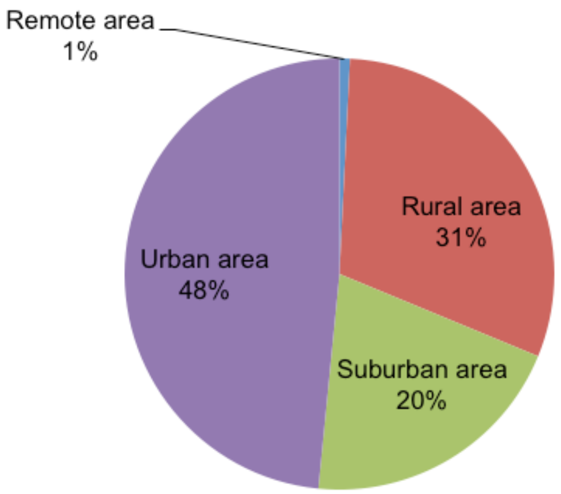
RESPONDENTS' DEMOGRAPHICS[27]

Caregivers' Demographics

Most Caregiver respondents were mothers (90%), followed by fathers (7%). The average Caregiver age was 43.4 years (SD = 8.1 years), ranging from 26 to 68 years. Most Caregivers described themselves as White / Caucasian (91%). A majority of respondents achieved at least a college or university degree (82%). Approximately, 17.5% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Ninety-four percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, 48% of Caregivers reported living in an urban area of Saskatchewan, closely followed by living in a rural area (31%).

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (84%), and the average age was 12.6 years (SD = 6.5 years, ranging from 3 to 40 years).

- The average age, by age group, is as follows:
  - The preschool age group was 4.4 years (SD = .7 years, ranging from 3 to 4.9 years),
  - The school age children was 11.6 years (SD = 3.6 years, ranging from 5 to 17.9 years),
  - Adults was 22.7 years (SD = 5.2, ranging from 18 to 40 years),
- Ninety-seven percent of individuals with ASD lived at home with the Caregiver respondents.
- All Caregivers of preschoolers and school age children reported that their child was living at home with family.
- Eighty-three percent of adults reported living at home with family.
- Most individuals with ASD were born in Canada (95%).
- 37% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 24% Asperger syndrome, 21% PDD-NOS, and 19% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Professionals' Demographics

There was a wide age range of professional respondents, from 23 to 65 years of age (M = 41 years, SD = 11.1 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 33 years (M = 10.3 years, SD = 7.5 years).

- 92% had worked with school age children
- 40% had worked with pre-school age children
- 40% had worked with adults
- 23% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 5.8 years (SD = 3.2 years, ranging from 1 to 18 years). The average age of diagnosis for school age children was 5.9 (SD = 2.9 years) and age of diagnosis for adults was 7.2 (SD = 4.5 year).

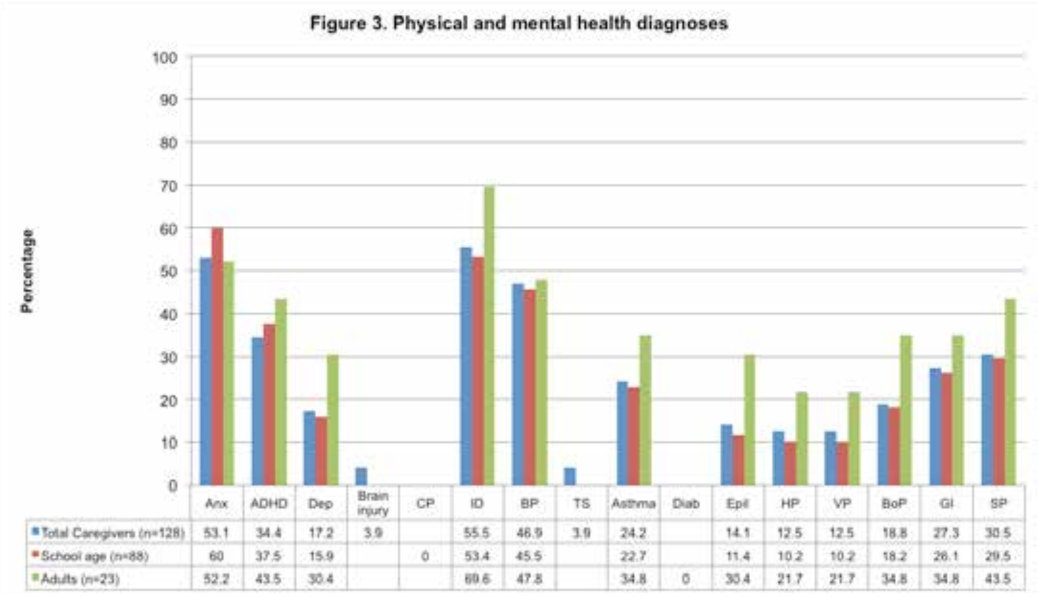
From Caregivers' responses, psychologists (39%) were the most frequently noted health professionals providing their child's ASD diagnosis, followed by pediatricians (23%) and psychiatrists (23%). Similar trends were found for school age children and adults, with psychologists the most frequently noted diagnostician (38%, 30%, respectively), followed by psychiatrists (26% for both) and pediatricians (25, 17% respectively).

HEALTH STATUS AND SERVICE USE

Health Concerns

As shown in Figure 3,[28] Caregivers reported that health care providers had identified a number of physical and mental health diagnoses with reference to the person with ASD.

Figure 3. Physical and mental health diagnoses



	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
■ Total Caregivers (n=128)	53.1	34.4	17.2	3.9		55.5	46.9	3.9	24.2		14.1	12.5	12.5	18.8	27.3	30.5
■ School age (n=88)	60	37.5	15.9		0	53.4	45.5		22.7		11.4	10.2	10.2	18.2	26.1	29.5
■ Adults (n=23)	52.2	43.5	30.4			69.6	47.8		34.8	0	30.4	21.7	21.7	34.8	34.8	43.5

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers across all three age groups reported that individuals with ASD received a number of formal psychiatric diagnoses (see Table 1 for age breakdown):

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[27] *Self-advocate demographics are not included as the number of respondents was less than 5.*

[28] *When sample sizes have less than 5 participants, data is not presented (left blank).*

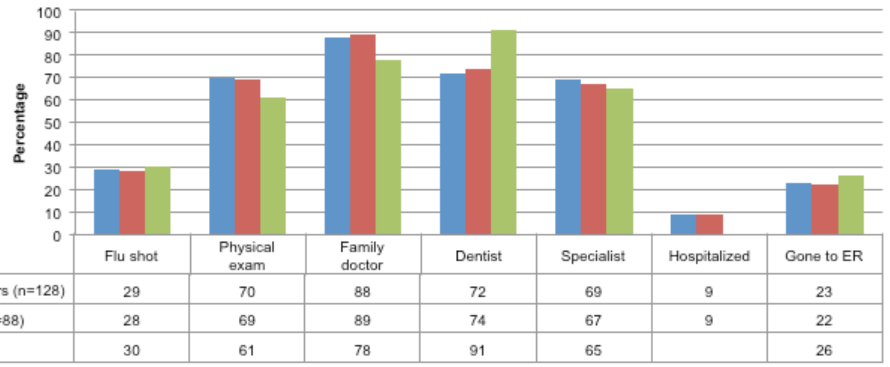
TABLE 1: FORMAL PSYCHIATRIC DIAGNOSES RECEIVED

	SCHOOL AGE CHILDREN (5-17 YEARS) N = 139	ADULTS (18+ YEARS) N = 55
PSYCHIATRIC DIAGNOSES (EVER)		
Anxiety	20 (22.7%)	7 (30.4%)
Depression	9 (10.2%)	6 (26.2%)
Psychosis/Schizophrenia	<5	<5
Obsessive-Compulsive Disorder	12 (8.6%)	13 (23.6%)
Other	9 (10.2%)	<5

Health Service Use

Caregivers reported on their health service use in the past 12 months. As shown in Figure 4,[29] Caregivers across all age groups, school age children, and adults were reported to have used the following health services.

Figure 4. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Hospitalized	Gone to ER
🟦 Total Caregivers (n=128)	29	70	88	72	69	9	23
🟥 School age (n=88)	28	69	89	74	67	9	22
🟩 Adults (n=23)	30	61	78	91	65		26

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers were asked to indicate which services they had used in the past 6 months. These were noted as recent service use.

Caregivers, across age groups, reported that the most recently received services were:

- Activity-based programs (48%),
- Recreation programs (40%),
- Social skills programs (38%),
- Non-IBI early intervention (22%),
- Daycare programs (20%),
- Mental health treatment (20%).

The most commonly used recent services for school age children were:

- Activity-based programs (58%),
- Social skills programs (47%),
- Recreation / leisure programs (46%),
- Mental health treatment (21%),
- Respite care (18%).

The most commonly used recent services for adults were:

- Activity-based programs (30%),
- Mental health treatment (30%),
- Life skills (30%),
- Respite care (26%),
- Recreation / leisure programs (22%),
- Specialized transportation (22%),
- Employment or adult day programs (22%).

Caregivers reported on the total number of recently used services.

- Across all age groups, Caregivers reported that on average their child had recently received 3.2 services (SD = 2.4, ranging from 0 to 13 services),
- Caregivers of school age children reported that on average their child had recently received 3.1 services (SD = 2.2, ranging from 0 to 8 services) and for adults 2.7 services (SD = 2.6, ranging from 0 to 10 services).

Current Service Needs

Caregivers identified their top 5 current service needs, selecting from a list provided.

Caregivers, across age groups, reported that their top 5 current service needs were:

- Social skills programs (72%),
- Recreation programs (53%),
- Activity-based programs (45%),
- Life skills programs (43%),
- Specialized summer camps (33%).

For school age children, the top 5 current service needs were:

- Social skills programs (78%),
- Recreation programs (56%),
- Activity-based programs (49%),
- Life skills programs (48%),
- Specialized summer camps (39%).

For adults, the top 5 current service needs were:

- Social skills programs (57%),
- Employment or adult day programs (52%),
- Life skills programs (48%),
- Recreation programs (44%),
- Post-secondary education (35%).

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[29] *When sample sizes have less than 5 participants, data is not presented (left blank).*

Professionals reported that the top 5 current service needs for individuals with ASD were:

- Non-IBI early intervention (56%),
- Early detection of ASD (55%),
- Social skills programs (43%),
- Behaviour management (38%),
- Respite care (32%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have experienced when accessing services. By age group, the barriers were identified as follows:

Caregivers, across age groups, most commonly reported the following as major barriers:

- Lack of resources (67%),
- Lack of trained professionals (65%),
- Being too old to access services (40%),
- Difficulty affording services (42%).

Caregivers of school age children commonly identified the following barriers:

- Lack of resources (73%),
- Lack of trained professionals (68%),
- Difficulty affording services (42%),
- Too old to receive services (40%).

Most commonly, Caregivers of adults identified the following barriers:

- Too old to receive services (61%),
- Lack of trained professionals (57%),
- Lack of resources (48%),
- Difficulty affording services (39%).

Professionals most commonly identified the following barriers:

- Lack of resources (90%),
- Lack of trained professionals (79%),
- Difficulty affording services (70%),
- Too old to receive services (45%),
- Negative experiences with professionals in the past (37%).

MANITOBA PARTICIPANTS' RESPONSES

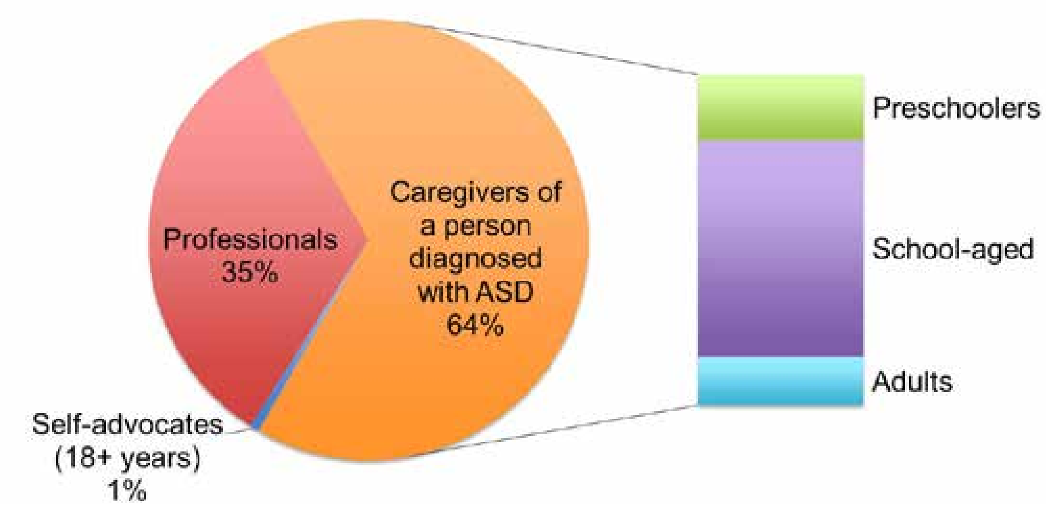
RESPONDENT REPRESENTATION

As shown in Figure 1, respondents from Manitoba (N = 134) consisted of 85 Caregivers reporting on 86 individuals with ASD, 47 Professionals, and 1 Self-advocate.[30] None of Manitoba respondents completed the French version of the survey.

Within the Caregiver respondent group, the following is the breakdown by age of child:

- 73% school age children, aged 5-17 (n = 63)
- 16% adults, 18 years of age and over (n = 14)
- 11% preschool age children (n = 9)

Figure 1. Respondents from Manitoba



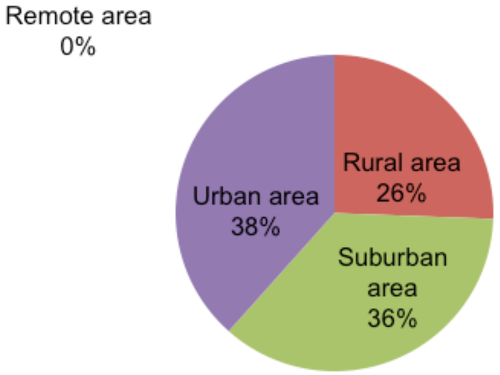
RESPONDENTS' DEMOGRAPHICS[31]

Caregivers' Demographics

Most Caregiver respondents were mothers (94%), followed by fathers (6%). The average Caregiver age was 42.9 years (SD = 6.7 years), ranging from 30 to 67 years. Most Caregivers described themselves as White/Caucasian (90%). A majority of respondents achieved at least a college or university degree (84%). Ninety-two percent lived in Canada all their lives or for at least 20 years. Approximately 18% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

As shown in Figure 2, 38% of Caregivers reported living in an urban area of Manitoba.

Figure 2. Reported Size of Community



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[30] We are unable to report on the health and service experiences specifically of any groups with less than 20 respondents. In the case of Manitoba, this refers to Caregivers of preschool age children, of adults, and the Self-advocates.

[31] Self-advocates' demographics were not included as the number of respondents was less than 5.

Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (81%), and the average age was 12.2 years (SD = 6 years, ranging from 3 to 31 years).

- The average age, by age group is as follows:
  - The preschool age group was 3.8 years (SD = .9 years, ranging from 3 to 4.9 years)
  - The school age group was 11.1 years (SD = 3.6 years, ranging from 5 to 17.9 years),
- All but one individual with ASD (an adult) was living with at home with their family,
- Most individuals with ASD were born in Canada (97%),
- 43% of individuals with ASD had a diagnosis of Autism/Autistic Disorder, 20% Asperger syndrome, 13% PDD-NOS, and 24% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Professionals' Demographics

There was a wide age range of professional respondents, from 21 to 59 years of age (M = 36.4 years, SD = 9.9 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 30 years (M = 9.7 years, SD = 7.2 years).

- 89% had worked with school age children
- 45% had worked with preschool age children
- 30% had worked with adults
- 15% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 4.7 years (SD = 3.6 years, ranging from 1 to 18 years). The average age of diagnosis for school age children was 4.2 (SD = 2.6 years, ranging from 1 to 12 years).

Overall, psychiatrists (35%) were the most frequent noted health professionals providing their child's ASD diagnosis, followed by pediatricians (28%) and psychologists (17%). Similar trends were found for school age children, with psychiatrists (32%), followed by pediatrician (27%), and psychologists (19%).

HEALTH STATUS AND SERVICE USE

Health Concerns

As shown in Figure 3,[32] Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD.

Caregivers across the three age groups reported that individuals with ASD received a number of formal psychiatric diagnoses, including:

- Anxiety Disorders (35%),
- Obsessive Compulsive Disorder (11%),
- Depression (11%).

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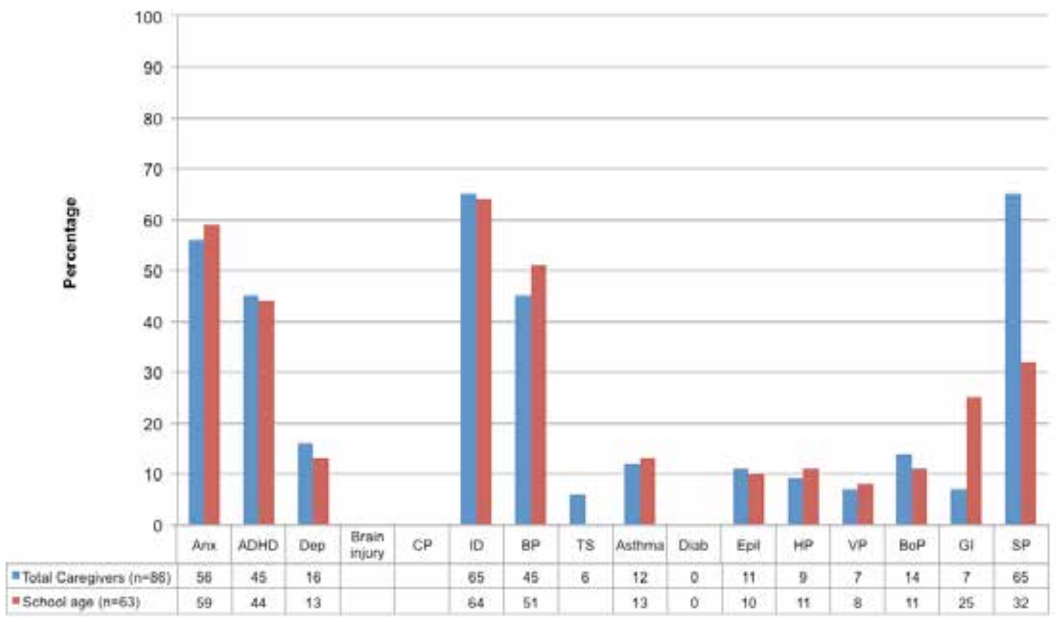
32. When sample sizes have less than 5 participants, data is not presented (left blank).

Figure 3. Physical and mental health diagnoses



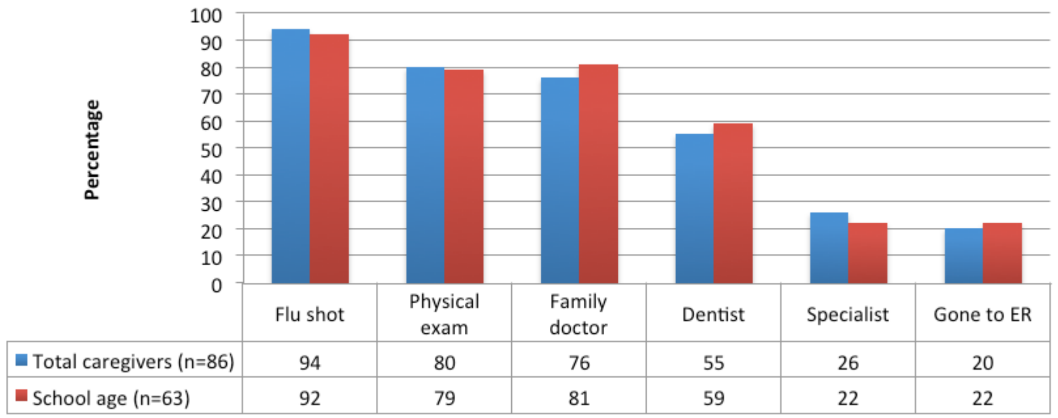
	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
■ Total Caregivers (n=86)	56	45	16			65	45	6	12	0	11	9	7	14	7	65
■ School age (n=63)	59	44	13			64	51		13	0	10	11	8	11	25	32

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Health Service Use

Caregivers reported on the health service use by individuals with ASD in the past 12 months, as shown in Figure 4.[33]

Figure 4. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Gone to ER
■ Total caregivers (n=86)	94	80	76	55	26	20
■ School age (n=63)	92	79	81	59	22	22

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers indicated which services they had used in the past 6 months. These were noted as recent service use.

Caregivers, across age groups, reported that the most recently received services were:

- Respite care (49%),
- Activity-based programs (38%),
- Non-IBI early intervention (29%).

32. When sample sizes have less than 5 participants, data is not presented (left blank).

The most commonly used recent services for school age children were:

- Respite care (60%),
- Activity-based programs (43%),
- Recreation / leisure programs (25%),
- Non-IBI early intervention (29%),
- Recreation (22%).

The total number of recently used services was reported by Caregivers. Caregivers, across age groups, reported that on average their child had recently used 2.9 services (SD = 2, ranging from 0 to 9 services). Similarly, Caregivers of school age children reported that on average their child had recently or was currently receiving 3.2 services (SD = 2.1, within the same range).

Current Service Needs

Caregivers identified their top 5 current service needs, selecting from a list provided.

Caregivers, across age groups, reported that their top 5 current service needs were:

- Social skills programs (70%),
- Recreation programs (44%),
- Specialized summer camps (42%),
- Activity-based programs (41%),
- Life skills programs (37%).

For school age children, the top 5 current service needs were:

- Social skills (75%),
- Specialized summer programs (54%),
- Recreation programs (48%),
- Activity-based (46%),
- After-school programs (37%),
- Life skills programs (37%).

Professionals reported that the top 5 needs for persons diagnosed with ASD were:

- Early detection of ASD (53%),
- Early intensive behavioural intervention (49%),
- Social skills (49%),
- Behaviour intervention for behaviour management (47%),
- Life skills (45%),
- Non-IBI early intervention (34%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services. The barriers were identified as follows:

Caregivers, across age groups, most commonly reported the following as major barriers:

- Lack of resources (69%),
- Lack of trained professionals (54%),
- Being too old to access services (40%),
- Difficulty affording services (38%).

Caregivers of school age children commonly identified the following barriers:

- Lack of resources (73%),
- Lack of trained professionals (59%),
- Too old to receive services (43%),
- Difficulty affording services (43%).

A majority of Professionals identified:

- Lack of resources (96%),
- Difficulty affording services (68%),
- Diagnosis does not qualify them for services (64%),
- Lack of trained professionals (62%),
- Being too old to receive the service (53%),
- Services are too far (53%).

ONTARIO PARTICIPANTS' RESPONSES

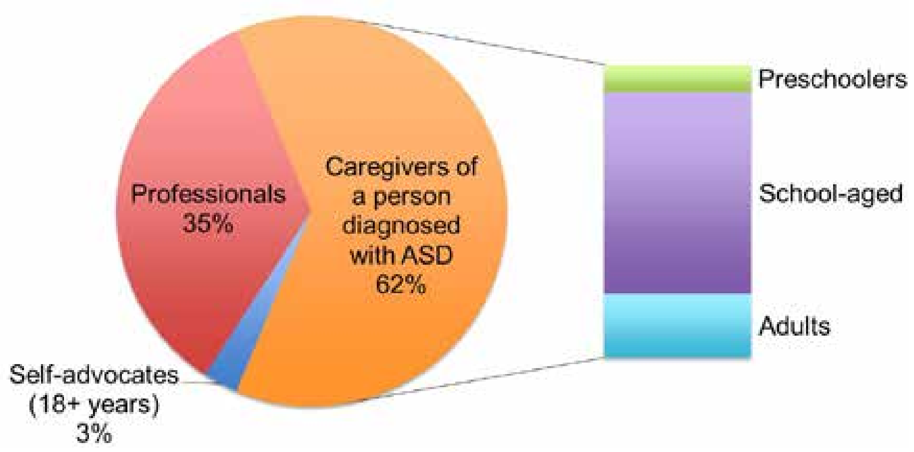
RESPONDENTS REPRESENTATION

As shown in Figure 1, respondents from Ontario (N = 2,823) consisted of 1,730 Caregivers reporting on 1,767 individuals with ASD, 974 Professionals, and 82 Self-advocates. Less than one percent of Ontario respondents completed the French version of the survey.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 69% school age children, aged 5-17 (n = 1,215)
- 22% adults, 18 years of age and over (n = 386)
- 9% preschool age children (n = 166)

Figure 1. Respondents from Ontario



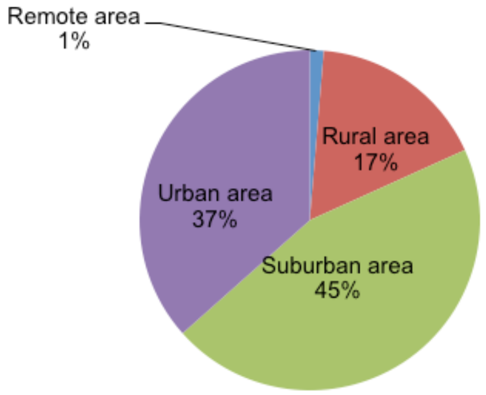
RESPONDENTS' DEMOGRAPHICS

Caregivers' Demographics

Most Caregiver respondents were mothers (85%), followed by fathers (11%). The average Caregiver age was 45.7 years (SD = 8.8 years), ranging from 22 to 82 years. Most Caregivers described themselves as White/Caucasian (83%). A majority achieved at least a college or university degree (86%). Approximately 26% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Ninety-two percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, majority of respondents (45%) reported living in a suburban area of Ontario.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (81%) and their average age was 13.2 years (SD = 7.7 years, ranging from 2 to 61 years).

- The average age, by age group is as follows:,
    - The preschool age group was 4.1 years (SD = .8 years, ranging from 2 to 4.9 years),
    - The school age group was 10.9 years (SD = 3.7 years, ranging from 5 to 17.9),
    - The adult age group 24.3 years (SD = 7.1 years, ranging from 18 to 61 years),
- Ninety-five percent of individuals with ASD lived at home with the Caregiver respondents. Preschoolers and school age children were more likely to be living at home (>98%), compared to adults with ASD (80%),
- Most individuals with ASD were born in Canada (95%),
- 40% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 24% Asperger syndrome, 13% PDD-NOS, and 23% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Self-advocates' Demographics

Over half of the respondents were female (52%), 42% were male, and 6.1% were transgendered. On average, Self-advocates were 36.7 years of age (SD = 10.7 years), ranging from 19 to 64 years of age. The majority of Self-advocates described themselves as White/Caucasian (90%). 84% of Self-advocates reported receiving an Asperger syndrome diagnosis.

Almost all Self-advocates were born in Canada or had been living here for at least 20 years. Forty-eight percent of Self-advocates reported living in an urban area of Ontario, closely followed by living in a suburban area (37%). Most Self-advocates reported that they lived in their own home or apartment (61%), followed by living with a family member (31%).

Approximately 30% of respondents had received at least a college education, and another 40% attained a trades' apprenticeship or certificate, diploma, or another non-university certificate. Of the Self-advocates who were currently enrolled in school (26%), three quarters were in post-secondary education.

Over half (51%) of Self-advocates were currently employed; of these, 40% in full-time employment and the rest in part-time. Approximately 38% indicated that they were not currently employed and not in school. Approximately 35% of Self-advocates reported that they had some financial difficulties or were in deep financial trouble.

Professionals' Demographics

There was a wide age range of professional respondents, from 20 to 70 years of age (M = 41.8 years, SD = 11.2 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 41 years (M = 12 years, SD = 7.9).

- 89% had worked with school age children
- 61% had worked with pre-school age children
- 47% had worked with adults
- 27% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for individuals with ASD was 5.5 years (SD = 4 years, ranging from 1 to 44 years). The following is the breakdown of age of diagnosis by age category:

- Preschool age children (4 years of age or younger): M = 2.9, SD = 1.1, ranging from 1 to 4.9 years,
- School age children (5 -17 years of age): M = 5.22, SD = 3.2, ranging from 1 to 17 years,
- Adults (18 years or older): M = 7.6, SD = 6.5, ranging from 1 to 44 years.

Overall, Caregivers identified pediatricians (39%) as the most frequent health professionals providing their child's ASD diagnosis, followed by psychologists (32%), and psychiatrists (19%). Similar trends were evident for the younger age groups, with pediatricians providing the ASD diagnosis most frequently for preschoolers (52%) and school age children (41%).

In adults, the most frequent diagnosticians reported were psychiatrists (34%), followed by psychologists (27%). A large number of Self-advocates also reported that psychiatrists (41%) had provided their ASD diagnosis.

HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers and Self-advocates reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD. As shown in Figure 3,[35] the following health issues were reported:

- Anxiety and sleep problems, which increased steadily with age and with the highest levels of anxiety and sleep problems reported by Caregivers of adults and Self-advocates,
- Depression was identified as a serious problem for many Self-advocates,
- Intellectual disability and behaviour problems were far more commonly reported among all three age groups by Caregiver respondents compared to Self-advocates,
- Bone, joint, and muscle problems were far more common among Self-advocates than other groups,
- Gastro-intestinal problems were present in approximately one third of Caregiver reports, and half of Self-advocate reports.

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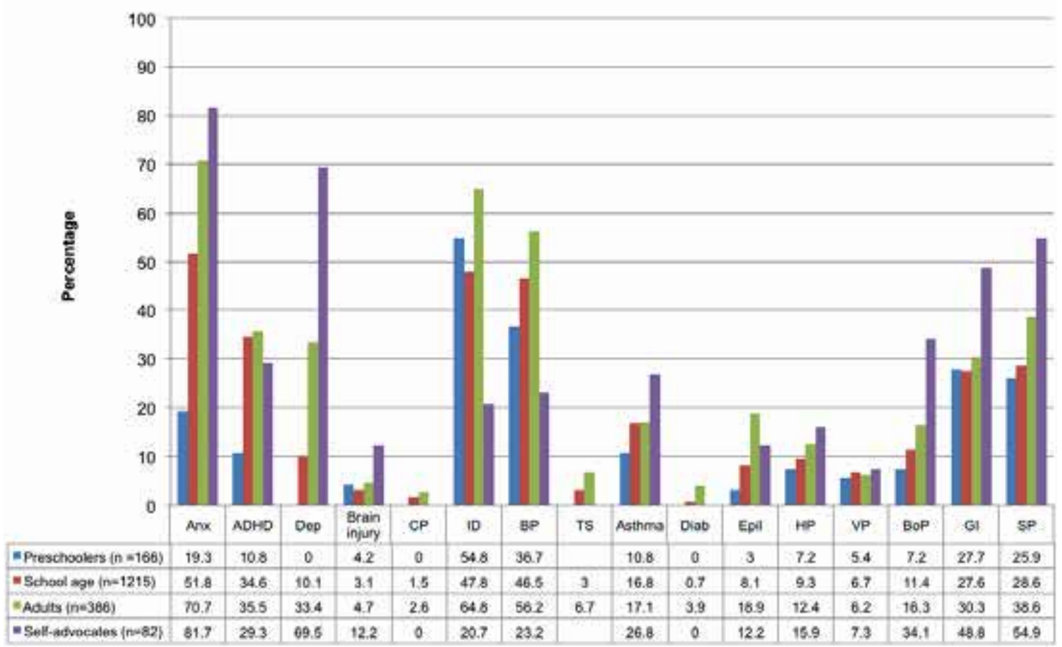
[35] *When sample sizes have less than 5 participants, data is not presented (left blank).*

Figure 3. Physical and mental health diagnoses



Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers and Self-advocates also reported on any formal psychiatric diagnoses ever provided (Table 1). These diagnoses were uncommon for preschool age children, and rose steadily through other age categories. For example, anxiety rose to 21% of school age children, 43% of adults, and 62% of Self-advocates. Similarly, a diagnosis of depression was uncommon in school age children (6%), but rose to 25% in adults and 54% in Self-advocates.

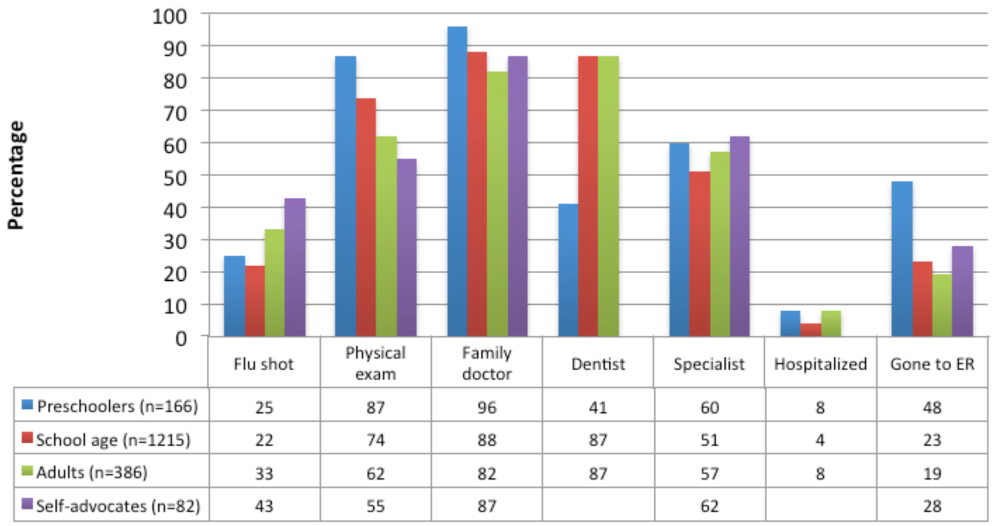
TABLE 1: FORMAL PSYCHIATRIC DIAGNOSES RECEIVED

	SCHOOL AGE CHILDREN (5-17 YEARS) N = 1215	**ADULTS** (18+ YEARS) N = 386	**SELF-ADVOCATES** (18+ YEARS) N = 82
PSYCHIATRIC DIAGNOSES (EVER)			
Anxiety	257 (21%)	164 (43%)	51 (62%)
Depression	73 (6%)	96 (25%)	44 (54%)
Psychosis/ Schizophrenia	16 (1%)	14 (4%)	5 (6%)
Obsessive-Compulsive Disorder	101 (8%)	102 (26%)	14 (17%)
Other	116 (10%)	57 (15%)	20 (24%)

Health Service Use

Caregivers and Self-advocates reported on their health service use in the last 12 months. As shown in Figure 4,[36] considering all age groups and respondent types, school age children had accessed the most health services in the last 12 months, with Self-advocates accessing the least number of different health services. [37]

Figure 4. Health service use in last 12 months



DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers and Self-advocates indicated which services they had used in the past 6 months. These were noted as recent service use.

Caregivers reported that the most recently received services for preschoolers were:

- Non-IBI early intervention (76%),
- Daycare or preschool programs (64%),
- Recreation programs (40%),
- Diagnostic or developmental assessment services (37%).

The most commonly used recent services for school age children were:

- Activity-based programs (46%)
- Recreation / leisure programs (43%),
- Social skills programs (33%),
- Respite care (26%),
- Behaviour therapy for behaviour management (19%).

For Caregivers of adults with ASD, the most common services used were:

- Mental health treatment (28%),
- Respite care (25%),
- Activity-based programs (23%),
- Life skills programs (22%),
- Recreation programs (21%).

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[36] When sample sizes have less than 5 participants, data is not presented (left blank).

[37] Gone to the ER only includes English speaking Caregivers

Self-advocates were most likely to have recently used:

- Mental health treatment (43%),
- Post-secondary education programs (20%),
- Employment supports (12%), specialized transportation (11%), and
- Recreation programs (10%).

The total number recently used services reported by Caregivers and Self-advocates provided the following breakdown by age category and respondent type:

- Preschool age children (4 years of age or younger): M = 3.6, SD = 1.9, ranging from 0 to 9 services,
- School age children (5 -17 years of age): M = 3.1, SD = 2.4, ranging from 0 to 13 services,
- Adults (18 years or older): M = 2.5, SD = 2.4, ranging from 0 to 12 services,
- Self-advocates (18 years or older): M = 1.3, SD = 1.5, ranging from 0 to 8 services.

Current Service Needs

Caregivers and Self-advocates identified their top 5 current service needs, selecting from a list provided.

THE TOP 5 SERVICE NEEDS IDENTIFIED BY CAREGIVERS OF PRESCHOOLERS WERE:

- Non-IBI early intervention (74%),
- Early intensive behavioural intervention (69%),
- Social skills programs (65%),
- Activity-based programs (55%),
- Daycare/preschool programs (42%).

For school age children, the most common top 5 were:

- Social skills programs (74%),
- Activity-based programs (50%),
- Recreation programs (46%),
- Specialized summer programs (45%),
- Life skills training (40%)

For adults with ASD, the most common top 5 service needs were:

- Employment or day programs (60%),
- Social skills programs (49%),
- Life skills training (48%),
- Recreation programs (37%),
- Post-secondary educational programs (34%).

For Self-advocates, the top 5 needs were:

- Mental health treatment (55%),
- Employment services (40%),
- Post-secondary education (38%),
- Social skills (37%),
- Activity-based programs (31%),
- Housing/residential options (31%).

Professionals reported that the top 5 needs for persons diagnosed with ASD were:

- Early detection of ASD (49%),
- Early IBI (46%),
- Social skills programs (43%),
- Behaviour intervention for behaviour management (39%),
- Mental health treatment (32%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services. By age group, the most commonly identified barriers were as follows:

The majority of Caregivers of preschoolers most commonly reported the following barriers:

Lack of resources (91%),

Difficulty affording services (63%),

Being too young to access services (31%).

Caregivers of school age children most commonly identified the following barriers:

- Lack of resources (80%),
- Difficulty affording services (62%),
- Lack of trained professionals (42%).

Caregivers of adults also most commonly identified:

- Lack of services (73%),
- Being too old to access service (50%).
- Lack of trained health professionals (49%),
- Difficulty affording services (45%).

Self-advocates most commonly noted the following barriers:

- Not being able to afford services (50%),
- Negative experiences with Professionals (46%).
- Lack of trained professionals (44%),
- Being too old to receive services (44%).

A majority of Professionals identified:

- Lack of resources (95%),
- Difficulty affording services (86%),
- Diagnosis does not qualify them for services (52%),
- Lack of trained health professionals (46%).

QUEBEC PARTICIPANTS' RESPONSES

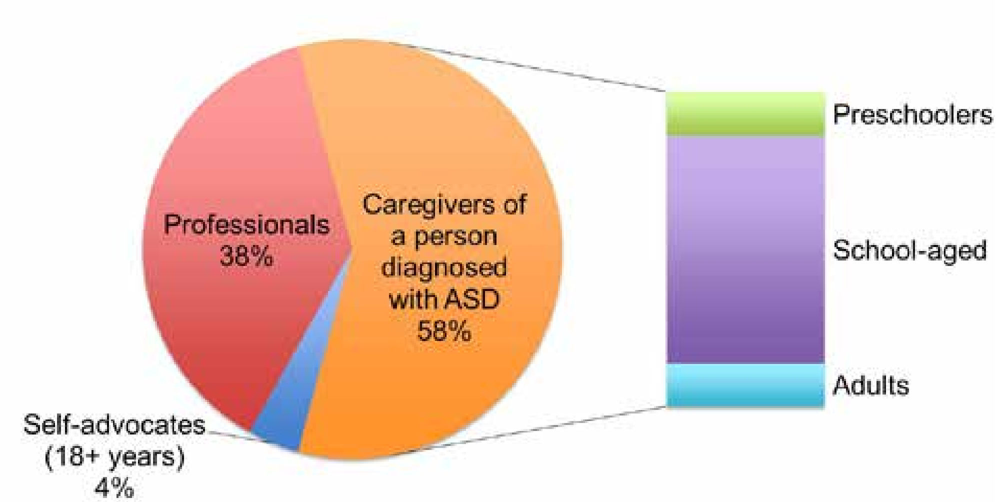
RESPONDENTS REPRESENTATION

As shown in Figure 1, respondents from Quebec (N = 401) consisted of 230 Caregivers reporting on 234 individuals with ASD, 151 Professionals, and 16 Self-advocates.[38] Sixty-one percent of respondents completed the French version of the survey.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 72% school age youth, aged 5-17 (n = 169)
- 14% adults, 18 years of age and over (n = 32)
- 14% preschool age children (n = 33)

Figure 1. Respondents from Quebec



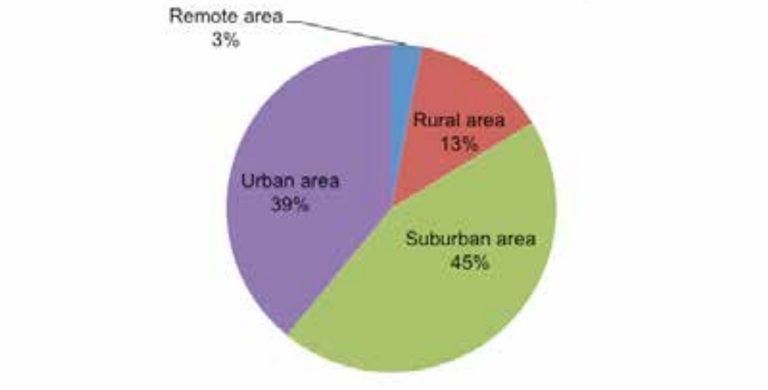
RESPONDENTS' DEMOGRAPHICS

Caregivers' Demographics

Most Caregiver respondents were mothers (90%), followed by fathers (7%). The average Caregiver age was 42.9 years (SD = 8 years), ranging from 23 to 76 years. Most Caregivers described themselves as White/Caucasian (90%). A majority of respondents achieved at least a college or university degree (86%). Approximately 20% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Ninety-two percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, 45% of Caregivers reported living in a suburban area, followed by 39% who indicated they lived in an urban area of Quebec.

Figure 2. Reported Size of Community



Profile of individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (88%). The average age of individuals with ASD, as reported by Caregivers, was 11.1 years (SD = 6.2 years).

- The average age, by age groups is as follows:
  - The preschool age group was 4.4 years (SD = .7 years, ranging from 3 to 4.9 years),
  - The school age group was 10.1 years (SD = 3.3 years, ranging from 5 to 17.9 years),
  - The adult age group 23.5 years (SD = 4.4 years, ranging from 18 to 37 years),
- Ninety-seven percent of individuals with ASD lived at home with their Caregiver respondents. All preschoolers and all but one school age child were living at home (>99%), whereas 84% of adults lived at home,
- Most individuals with ASD were born in Canada (97%),
- 33% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 11% Asperger Syndrome, 24% PDD-NOS, and 32% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Self-advocates' Demographics

The majority of respondents were male (69%), and 31% were female. On average, Self-advocates were 34.9 years of age (SD = 12.2 years), ranging from 20 to 50 years of age. The majority of Self-advocates described themselves as White/Caucasian (81%). Approximately 62% of Self-advocates reported receiving an Asperger syndrome diagnosis. One quarter (25%) of the Self-advocates indicated that someone had helped them complete the survey, whether it be a friend, professional, or parent.

Three quarters of Self-advocates were born in Canada. Sixty-three percent of the Self-advocates reported that they lived in their own home, and 31% reported living in a family member's home.

Approximately 25% of respondents completed at least a college education. Thirty-one percent of Self-advocates reported being currently enrolled in school, with the 80% in post-secondary education.

Sixty-three percent of Self-advocates were currently employed; of these, 60% in full-time employment and the rest in part-time. Approximately 25% of the Self-advocates indicated that they were not currently employed and not in school.

Professionals' Demographics

There was a wide age range of professional respondents, from 22 to 62 years of age (M = 40 years, SD = 10.3 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 41 years (M = 11.3 years, SD = 7.7 years).

- 93% had worked with school age children
- 56% had worked with pre-school age children
- 48% had worked with adults
- 30% had worked with all 3 age groups

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38. We are unable to report on the health and service experiences specifically of any groups with less than 20 respondents. In the case of Quebec, this refers to Self-advocates.

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for individuals with ASD was 5.2 years (SD = 3.5 years, ranging from 2 to 25 years).[39] The following is the breakdown of age of diagnosis by age category:

- Preschool age children (4 years of age or younger): M = 3.3, SD = .9, ranging from 2 to 4.9 years,
- School age youth (5 -17 years of age): M = 5.1, SD = 2.7, ranging from 2 to 15 years,
- Adults (18 years or older): M = 8.0, SD = 6.2, ranging from2 to 25 years.

From Caregivers' responses, psychiatrists (50%) were the most frequently noted health Professionals providing their child's ASD diagnosis, followed by psychologists (26%) and pediatricians (10%). Psychologists (39%) were the most frequently reported diagnosticians by Caregivers of preschoolers (39%), followed closely by psychiatrists (36%). For school age children and adults, psychiatrists were the most frequently reported diagnosticians (50%, 63%, respectively), followed by psychologists (27%, 9% respectively).

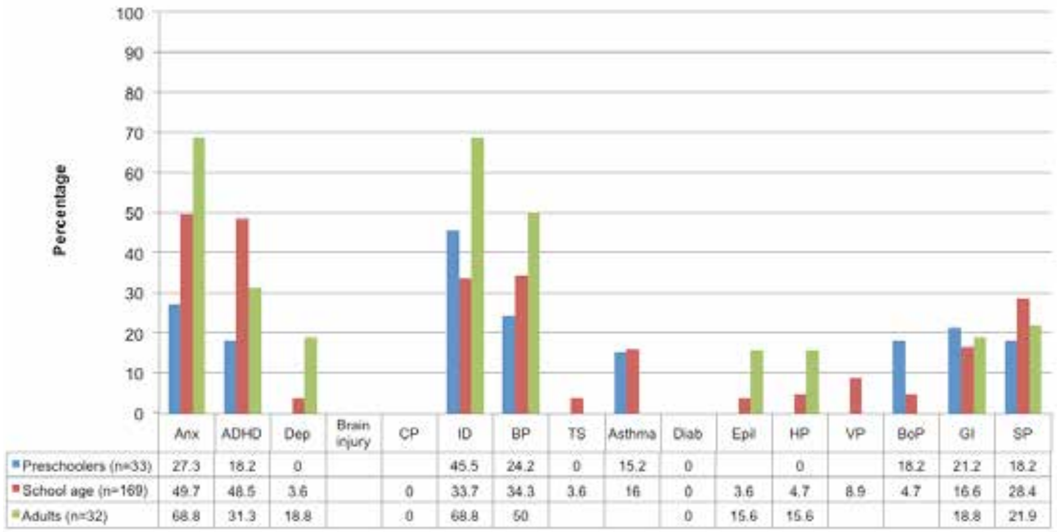
HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD. As shown in Figure 3,[40] the following health issues were reported:

- Anxiety, depression, and behaviour problems increased steadily with age, with the highest levels reported by Caregivers of adults,
- Gastrointestinal problems and sleep problems were common in all three age groups,
- ADHD was far more common in school age youth than preschoolers and adults,
- Intellectual disability was fairly common among all three Caregiver groups, with the adults reporting the highest levels.

Figure 3. Physical and mental health diagnoses



	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
■ Preschoolers (n=33)	27.3	18.2	0			45.5	24.2	0	15.2	0		0		18.2	21.2	18.2
■ School age (n=169)	49.7	48.5	3.6		0	33.7	34.3	3.6	16	0	3.6	4.7	8.9	4.7	16.6	28.4
■ Adults (n=32)	68.8	31.3	18.8		0	68.8	50			0	15.6	15.6			18.8	21.9

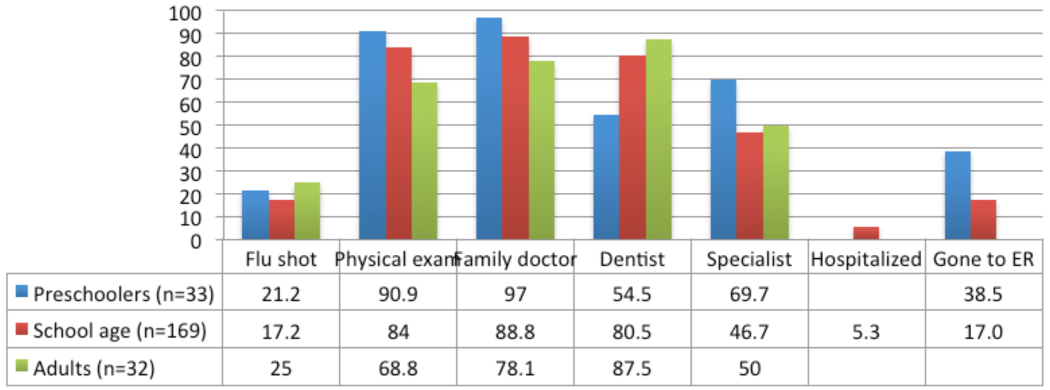
Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers also reported on any formal psychiatric diagnoses ever provided. These diagnoses were not prevalent in preschool age children, but rose steadily through the other age categories. For example, anxiety rose to 11% of school age children, and 34% of adults. Similarly, a diagnosis of depression did not occur in preschoolers, but rose to 13% in adults. Similar trends were seen in Obsessive Compulsive Disorder.

Health Service Use

Caregivers reported on their health service use in the last 12 months, as shown in Figure 4[41].[42]

Figure 4. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Hospitalized	Gone to ER
■ Preschoolers (n=33)	21.2	90.9	97	54.5	69.7		38.5
■ School age (n=169)	17.2	84	88.8	80.5	46.7	5.3	17.0
■ Adults (n=32)	25	68.8	78.1	87.5	50		

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers were asked to indicate which services they had used in the past 6 months. These were noted as recent service use.

Caregivers reported that the most common recently received services for preschoolers were:

- Non-IBI early intervention (67%),
- Early intensive behaviour intervention (36%),
- Daycare or preschool programs (36%),
- Early detection of ASD (33%),
- Diagnostic or developmental assessment services (33%).

The most commonly used recent services for school age youth were:

- Activity-based programs (42%),
- Non-IBI early intervention (31%),
- Recreation programs (28%),
- Behaviour management (27%),
- Social skills (23%).

For Caregivers of adults with ASD, the most commonly used services were:

- Life skills (34%),
- Post-secondary education programs (28%),
- Employment or adult day programs (28%),
- Recreation programs (25%),
- Specialized transportation (25%).

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39. Age of diagnosis was not available for the Self-advocates

40. When sample sizes have less than 5 participants, data is not presented (left blank).

41. Gone to the ER only includes English speaking Caregivers.

42. When sample sizes have less than 5 participants, data is not presented (left blank).

The total number of recently used services reported by Caregivers and Self-advocates provided the following breakdown by age category and respondent type:

- Preschool age children (4 years of age or younger): M = 3.3, SD = 2.5, ranging from 0 to 10 services,
- School age youth (5 -17 years of age): M = 2.8, SD = 2.2, ranging from 0 to 12 services,
- Adults (18 years or older): M = 2.9, SD = 3, ranging from 0 to 13 services,
- Self-advocates (18 years or older): M = 1.8, SD = 2, ranging from 0 to 6 services.

Current Service Needs

Caregivers and Self-advocates identified their top 5 current service needs, selecting from a list provided.

The most common top 5 service needs of preschoolers were:

- Non-IBI early intervention (67%),
- Early IBI (36%),
- Daycare programs (36%),
- Early detection of ASD (33%),
- Diagnostic or developmental assessment services (33%).

For school age children, the most common top 5 current service needs identified by Caregivers included:

- Activity-based programs (42%),
- Non-IBI early intervention (31%),
- Behaviour management programs (27%),
- Social skills programs (23%),
- Recreation programs (18%).

For adults with ASD, the most common top 5 service needs were:

- Life skills training (34%),
- Employment or day programs (28%),
- Post-secondary education programs (28%),
- Recreation programs (25%),
- Specialized transportation (25%).

Professionals reported that the top 5 needs for individuals with ASD were:

- Early detection of ASD (65%),
- Early IBI (54%),
- Non-IBI early intervention (54%),
- Social skills programs (40%),
- Diagnostic or developmental assessment services (33%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services. By age group, the most common barriers were identified as follows:

The majority of Caregivers of preschoolers identified the following barriers:

- Lack of resources (91%),
- Difficulty affording services (46%).

Caregivers of school age children most commonly identified the following barriers:

- Lack of resources (86%)
- Lack of trained professionals (62%),
- Difficulty affording services (41%).

Caregivers of adults also identified:

- Lack of services (81%),
- Lack of trained health professionals (72%),
- Being too old to access service (38%).

Professionals most commonly identified the following barriers:

- Lack of resources (95%),
- Difficulty affording services (85%),
- Lack of trained professionals (67%).

NEW BRUNSWICK PARTICIPANTS' RESPONSES

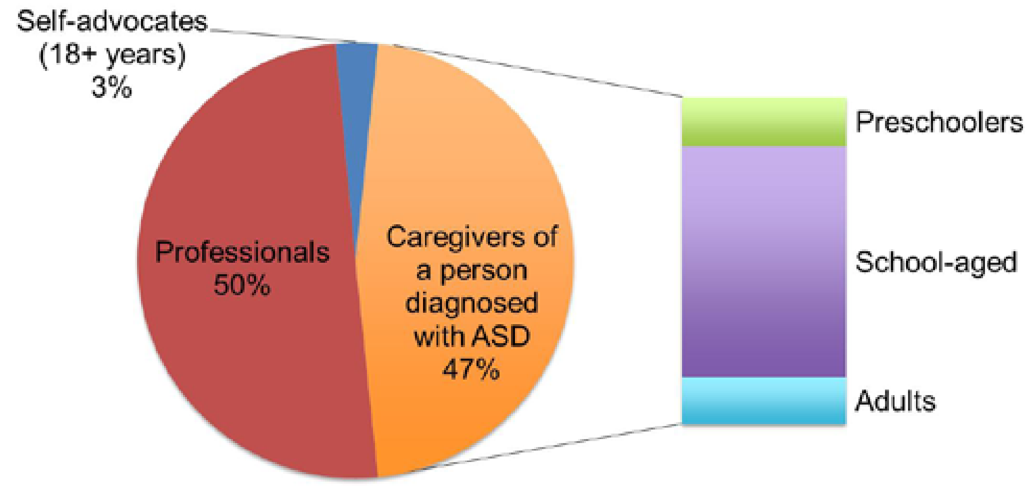
RESPONDENT REPRESENTATION

As shown in Figure 1, respondents from New Brunswick (N = 257) consisted of 120 Caregivers reporting on 120 individuals with ASD, 129 Professionals, and 8 Self-advocates.[43] Twenty-five percent of New Brunswick respondents completed the French version of the survey.

Within the Caregiver respondent group, the following is the breakdown by age of child:

- 72% school age children, aged 5-17 (n = 85)
- 15% preschool age children (n = 18)
- 14% adults, 18 years of age and over (n = 17)

Figure 1. Respondents from New Brunswick



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[43] We are unable to report on the health and service experiences specifically of any groups with less than 20 respondents. In the case of New Brunswick, this refers to Caregivers of preschool age children, adults, and Self-advocates.

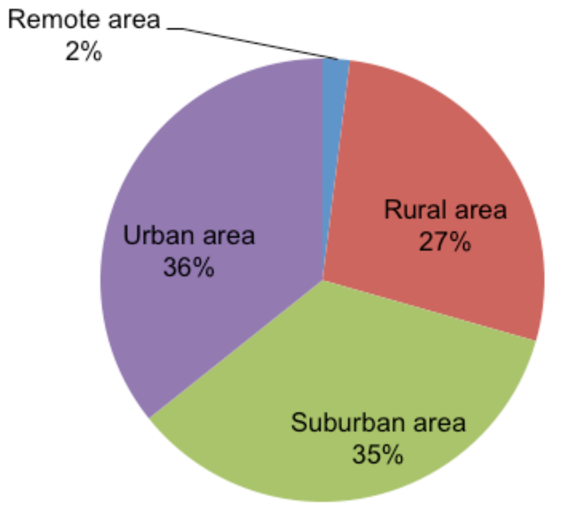
RESPONDENTS' DEMOGRAPHICS

Caregivers' Demographics

Most Caregiver respondents were mothers (84%), followed by fathers (10%). The average Caregiver age was 43.7 years (SD = 8.4 years), ranging from 27 to 73 years. Most Caregivers described themselves as White/Caucasian (93%). A majority of respondents achieved at least a college or university degree (89%). Approximately, 25% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Ninety-six percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, 36% of Caregivers reported living in an urban area of New Brunswick, closely followed by living in a suburban area (35%).

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (79%), and the average age was 11.8 years (SD = 5.9 years).

- The average age, by age group, is as follows:
  - For the preschool age group was 4.2 years (SD = .6 years, ranging from 3 to 4.9 years),
  - The school age children was 11.4 years (SD = 3.7 years, ranging from 5 to 17.9 years),
  - Adults was 21.9 (SD = 3.3, ranging from 18 to 30 years),
- Almost all individuals (>99%) with ASD lived at home with the Caregiver respondents,
- Most individuals with ASD were born in Canada (98%),

35% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 27% Asperger Syndrome, 15% PDD-NOS, 23% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Self-advocates' Demographics

Five respondents were male and 3 were female. On average, Self-advocates were 28.4 years of age (SD = 8 years), ranging from 20 to 44 years of age. The majority of Self-advocates described themselves as White/Caucasian (n = 7). Six Self-advocates reported receiving an Asperger syndrome diagnosis. Five Self-advocates reported living in an urban area of New Brunswick. All Self-advocates were born in Canada. Seven Self-advocates were currently employed; of these, 5 were employed full-time.

Professionals' Demographics

There was a wide age range of professional respondents, from 21 to 74 years of age (M = 39 years, SD = 11.1 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 38 years (M = 9.9 years, SD = 7.8 years).

- 75% had worked with school age children
- 47% had worked with pre-school age children
- 23% had worked with adults.
- 10% had worked with all 3 age groups

Perspectives on Diagnostic Process

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 5.6 years (SD = 4.2 years, ranging from 1 to 18 years). The average age of diagnosis for school age children was 5.5 (SD = 3.4 years, ranging from 1 to 14 years) and age of diagnosis for adults was 9.3 (SD = 6.3 years, ranging from 2 to 18 years).

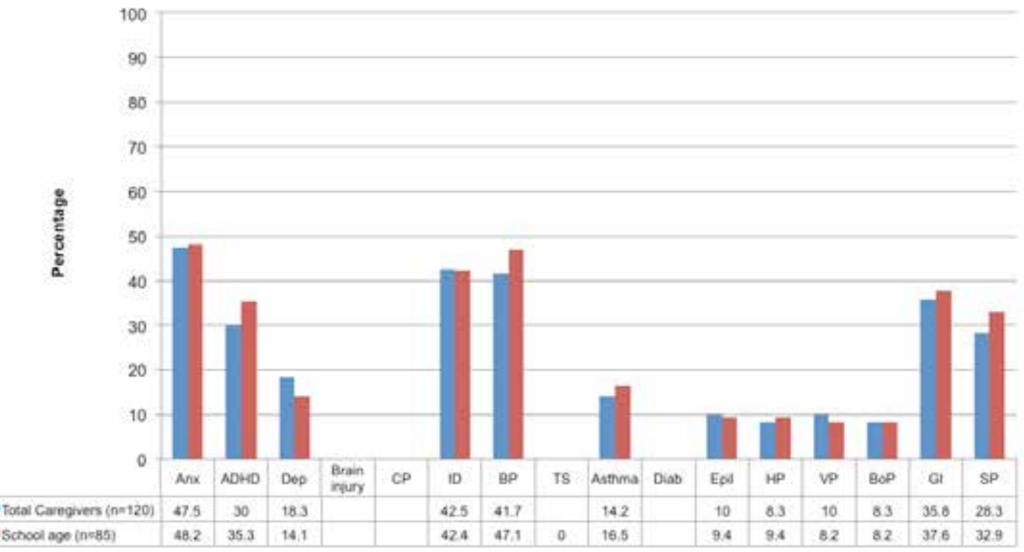
Overall, Caregivers identified psychologists and pediatricians as the most frequently noted health Professionals providing their child's ASD diagnosis, both at 32%, followed by psychiatrists (13%). For school age children, psychologists were the most frequent noted diagnosticians at (35%) followed by pediatricians (28%) and psychiatrists (12%).

HEALTH STATUS AND SERVICE USE

Health Concerns

As shown in Figure 3,[44] Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD.

Figure 3. Physical and mental health diagnoses



	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
Total Caregivers (n=120)	47.5	30	18.3			42.5	41.7		14.2		10	8.3	10	8.3	35.8	28.3
School age (n=85)	48.2	35.3	14.1			42.4	47.1	0	16.5		9.4	9.4	8.2	8.2	37.6	32.9

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

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[44] *When sample sizes have less than 5 participants, data is not presented (left blank).*

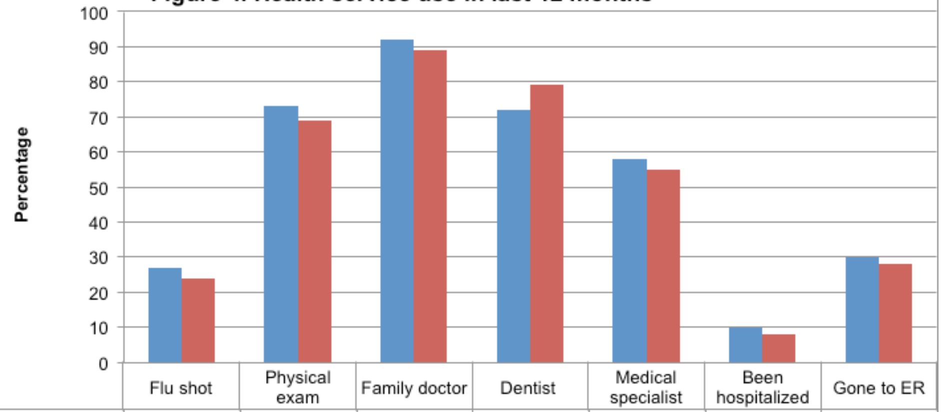
Caregivers across three age groups also reported that individuals with ASD received a number of formal psychiatric diagnoses, including:

- Anxiety Disorders (20%),
- Obsessive Compulsive Disorder (8%),
- Depression (8%).

Health Service Use

Caregivers reported on the use of health services in the last 12 month, as shown in Figure 4.

Figure 4. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Medical specialist	Been hospitalized	Gone to ER
🟦 Total Caregivers (n=120)	27	73	92	72	58	10	30.0
🟥 School age (n=85)	24	69	89	79	55	8	28.0

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers and Self-advocates indicated which services they had used in the past 6 months. These were noted as recent service use.

Caregivers, across age groups, reported that the most recently received services were:

- Activity-based programs (42%),
- Recreation / leisure programs (27%),
- Non-IBI early intervention (21%),
- Behaviour therapy for behaviour management (20%),
- Social skills programs (20%).

The most commonly used recent services for school age children were:

- Activity-based programs (45%),
- Recreation programs (27%),
- Social skills programs (21%),
- Mental health treatment programs (20%),
- Behaviour therapy for behaviour management (19%).

Caregivers also reported on the total number of recently used services. Caregivers, across all age groups, reported that on average their child had recently received 2.6 services (SD = 2.1, ranging from 0 to 9 services). Similarly, Caregivers of school age children reported that on average their child had recently used 2.4 services (SD = 2.1, ranging from 0 to 9 services).

Current Service Needs

Caregivers and Professionals identified the top 5 current service needs, selecting from a list provided.

Caregivers, across age groups, reported that their top 5 current service needs were:

- Social skills programs (64%),
- Activity-based programs (49%),
- Recreation programs (41%),
- Specialized summer camps (40%),
- Life skills programs (40%).

For school age children, the top 5 current service needs were:

- Social skills programs (69%),
- Activity-based programs (48%),
- Specialized summer camps (47%),
- Life skills programs (44%),
- Recreation programs (37%).

Professionals identified the following top 5 current service needs for individuals with ASD:

- Early IBI (68%),
- Early detection of ASD (67%),
- Social skills programs (48%),
- Behaviour therapy for behaviour management (45%),
- Non-IBI early intervention programs (41%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they had faced when accessing services. By age group, the barriers were identified as follows.

Caregivers, across age groups, reported the following as major barriers:

- Lack of resources (62%),
- Lack of trained professionals (60%),
- Difficulty affording services (52%),
- Being too old to receive services (31%).

Caregivers of school age children most commonly identified the following barriers:

- Lack of resources (60%),
- Difficulty affording services (52%),
- Lack of trained professionals (58%),
- Too old to receive services (32%).

Professionals most commonly identified the following barriers:

- Lack of resources (83%),
- Difficulty affording services (78%),
- Lack of trained professionals (70%),
- Too old to receive services (42%),
- Services too far (42%).

PRINCE EDWARD ISLAND PARTICIPANTS' RESPONSES

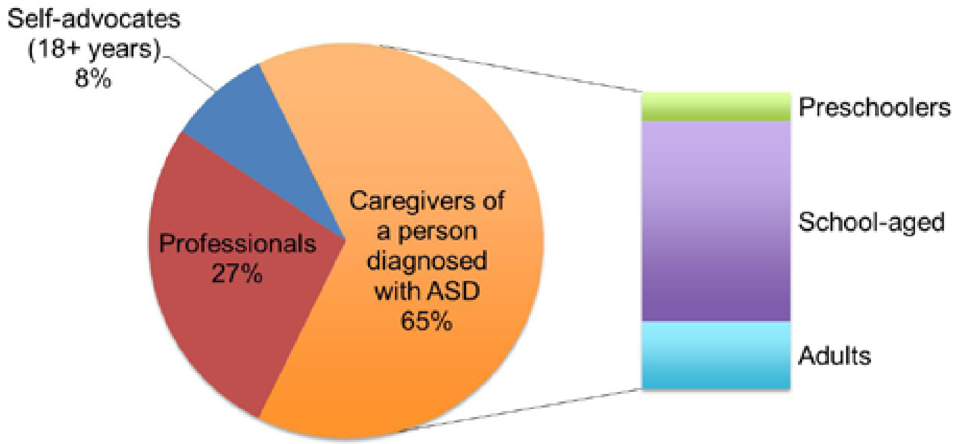
RESPONDENTS REPRESENTATION

As shown in Figure 1, respondents from Prince Edward Island (N = 48) consisted of 30 Caregivers reporting on 31 individuals with ASD, 13 Professionals, and 4 Self-advocates.[45] Four percent of Prince Edward Island respondents completed the French version of the survey.

Within the Caregiver respondent group, the following is the breakdown by age of child:

- 68% school age children, aged 5-17 (n = 21)
- 23% adults, 18 years of age and over (n = 7)
- 10% preschool age children (n = 3)

Figure 1. Respondents from Prince Edward Island



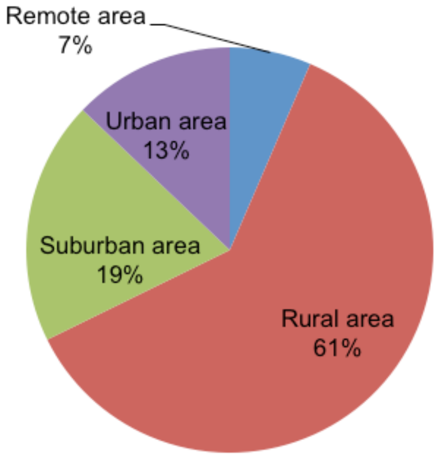
RESPONDENTS' DEMOGRAPHICS[46]

Caregivers' Demographics

Most Caregiver respondents were mothers (97%), followed by grandparents (3%). The average Caregiver age was 43.8 years (SD = 10.3 years), ranging from 26 to 74 years. Most Caregivers described themselves as White/Caucasian (90%). A majority of respondents achieved at least a college or university degree (90%). Approximately, 13% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Majority of Caregivers (83%) noted that they had lived in Canada all their lives or for at least 20 years. As shown in Figure 2, majority of Caregivers reported living in a rural area of Prince Edward Island.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

Seventy-five percent of individuals with ASD were male (77%) and the average age was 13.1 years (SD = 6.5 years), ranging from 4 to 29 years of age.

- The average age, by age group, is as follows:
  - For school age children was 10.9 years (SD = 3.7 years, ranging from 5 to 17.9 years),
  - Adults was 22.4 (SD = 3.1 years, ranging from 19to 29 years),
- Most individuals with ASD lived at home with the Caregiver respondents (94%),
- All Caregivers of preschool and school age children noted that the child was living at home with family and 78% Caregivers of adults noted that they lived at home with family,
- A majority of individuals with ASD were born in Canada (94%),
- 45% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 32% Asperger Syndrome, 7% PDD-NOS, and 16% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Professionals' Demographics

There was a wide age range of professional respondents, from 25 to 56 years of age (M = 41.9 years, SD = 11.4 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working (2 years) for up to 20 years (M = 9.9 years, SD = 6.1 years).

- 85% had worked with school age children
- 46% had worked with pre-school age children
- 54% had worked with adults.
- 23% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 5.5 years (SD = 3.7), ranging from 2 to 15 years. For school age children, the average age of diagnosis was 6.2 years of age (SD = 4.3), with the same age range.

Across age groups, Caregivers reported that psychologists (36%) most frequently provided their child's ASD diagnosis, followed by psychiatrists (32%), and pediatricians (23%). A similar trend was found for school age children, with psychologists, at 48%, noted as the most frequent diagnosticians, followed by psychiatrists (29%) and pediatricians (19%).

HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD, as shown in Figure 3.[47]

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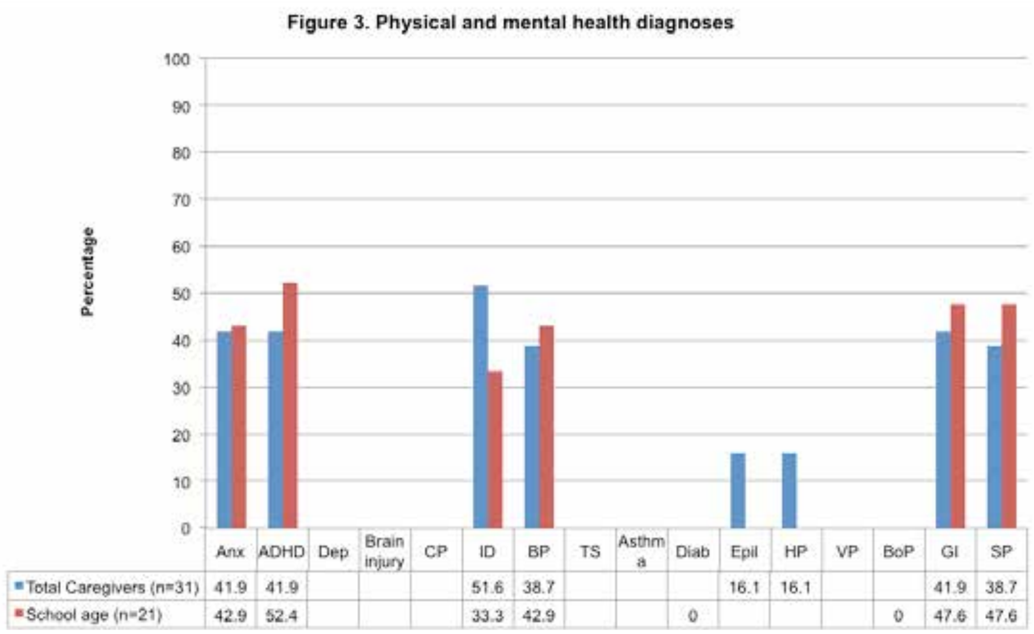
[45] We are unable to report on their health and service experiences specifically of any groups with less than 20 respondents. In the case of Prince Edward Island this refers to Caregivers of preschool age children, adults, Self-advocates, and Professionals.

[46] We are unable to report on the Self-advocates' demographics as the number of respondents is less than 5.

[47] When sample sizes have less than 5 participants, data is not presented (left blank).

Figure 3. Physical and mental health diagnoses



	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
🟦 Total Caregivers (n=31)	41.9	41.9				51.6	38.7				16.1	16.1			41.9	38.7
🟥 School age (n=21)	42.9	52.4				33.3	42.9			0				0	47.6	47.6

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers across the three age groups also reported that individuals with ASD received a number of formal psychiatric diagnoses, including:

- Anxiety Disorders (13%),
- Obsessive Compulsive Disorder (10%),
- Depression (10%),
- Psychotic disorder (3%).

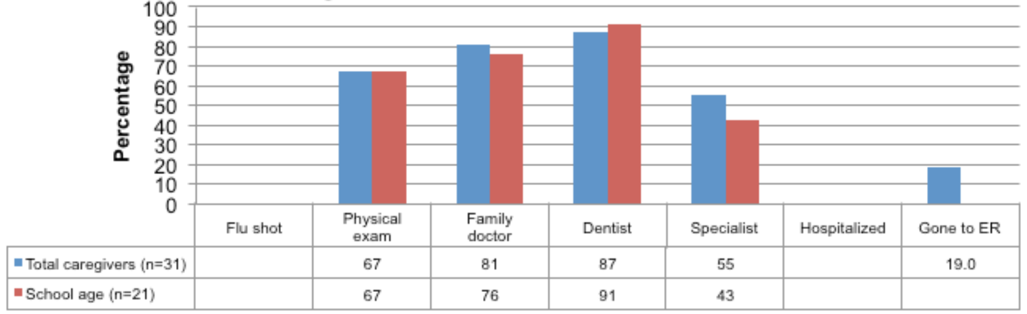
Caregivers of school age children reported that individuals with ASD received of the following formal psychiatric diagnoses:

- Anxiety Disorders (19%),
- Obsessive Compulsive Disorder (14%),
- Depression (14%).

HEALTH SERVICE USE

Caregivers reported on the use of health services in the last 12 months as shown in Figure 4.[48]

Figure 4. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Hospitalized	Gone to ER
🟦 Total caregivers (n=31)		67	81	87	55		19.0
🟥 School age (n=21)		67	76	91	43		

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers, across the age groups, indicated which services they had used in the past 6 months. These were noted as recent service use.

Caregivers, across age groups, reported that the most recently received services were:

- Recreation programs (29%),
- Activity-based programs (26%),
- Respite care programs (39%),
- Life skills training (36%),
- After-school programs (26%).

Caregivers of school age children reported that the most recently received services were:

- After-school programs (33%),
- Social skills programs (24%),
- Respite care programs (33%),
- Life skills programs (24%),
- Behaviour management programs (24%).

Caregivers, across age groups, reported that on average their child had recently received or was currently receiving 3.1 services (SD = 2.4), ranging from 0 to 13 services.

Current Service Needs

Caregivers identified their top 5 current service needs, selecting from a list provided.

Caregivers, across age groups, reported that their top 5 current service needs were:

- Social skills programs (81%),
- Recreation programs (58%),
- Activity-based programs (52%),
- Life skills programs (48%),
- Specialized summer camps (36%).

Caregivers of school age children reported that their top 5 current service needs were:

- Social skills programs (86%),
- Life skills programs (57%),
- Activity-based programs (52%),
- Recreation programs (48%),
- Specialized summer camps (48%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services.

Caregivers, across age groups, reported the following as major barriers:

- Lack of trained professionals (58%),
- Difficulty affording services (48%),
- Lack of resources (48%).

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[48] When sample sizes have less than 5 participants, data is not presented (left blank).

Caregivers of school age children most commonly identified the following barriers:

- Lack of trained professionals (57%),
- Difficulty affording services (52%),
- Lack of resources (52%).

NOVA SCOTIA PARTICIPANTS' RESPONSES

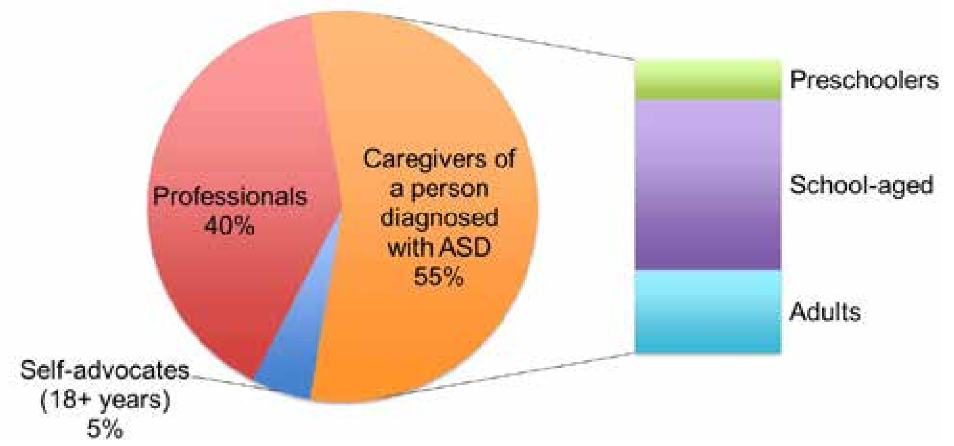
RESPONDENTS REPRESENTATION

As shown Figure 1, respondents from Nova Scotia (N = 325) consisted of 176 Caregivers reporting on 180 individuals with ASD, 129 Professionals, and 16 Self-advocates.[49] Less than one percent of Nova Scotia respondents completed the French version of the survey.

Within the Caregiver respondent group (the largest respondent group overall), the following is the breakdown by age of child:

- 58% school age children, aged 5-17 (n = 105)
- 28% adults, 18 years of age and over (n = 51)
- 13% preschool age children (n = 24)

Figure 1. Respondents from Nova Scotia



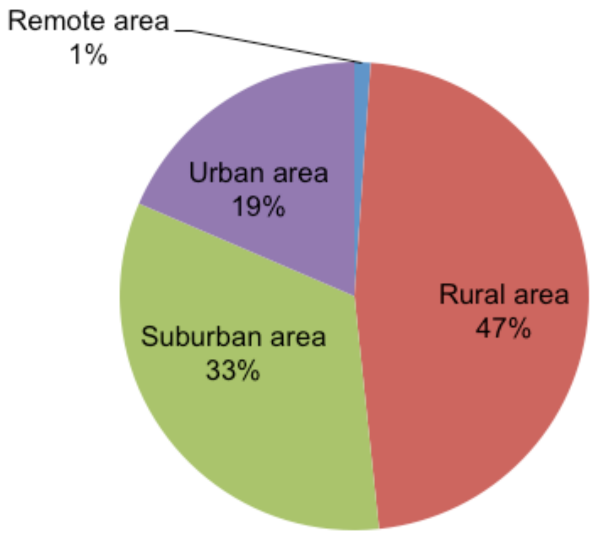
RESPONDENTS' DEMOGRAPHICS

CAREGIVERS' SAMPLE DEMOGRAPHICS

Most Caregiver respondents were mothers (84%), followed by fathers (11%). The average Caregiver age was 45.4 years (SD = 10.2 years), ranging from 23 to 78 years. Most Caregivers described themselves as White/Caucasian (93%). A majority of respondents achieved at least a college or university degree (84%). Approximately 19% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

Ninety-seven percent lived in Canada all their lives or for at least 20 years. As shown in Figure 2, 47% of Caregivers reported living in a rural area of Nova Scotia, followed by 33% reported living in a suburban area in Nova Scotia.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (80%), and their average age was 13.8 years (SD = 7.8 years).

- The average age, by age group, is as follows:
  - For the preschool age group was 4 years (SD = .7 years, ranging from 3 to 4.9 years),
  - The school age group was 11.2 years (SD = 3.7 years, ranging from 5 to 17.9 years),
  - The adult age group 23.6 years (SD = 5.8 years, ranging from 18 to 43 years),
- Ninety-three percent of individuals with ASD lived at home with the Caregiver respondents. Majority of preschoolers and school age children were living at home (>96%), whereas 84% of adults lived at home,
- Most individuals with ASD were born in Canada (97%),
- 50% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 20% Asperger Syndrome, 11% PDD-NOS, and 17% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

SELF-ADVOCATES' DEMOGRAPHICS

The majority of respondents were male (80%). On average, Self-advocates were 36.9 years of age (SD = 12 years), ranging from 23 to 59 years of age. The majority of Self-advocates described themselves as White/Caucasian (88%). As shown in Figure 3, approximately one third of Self-advocates reported receiving an Asperger syndrome diagnosis and one third reported a diagnosis of ASD/PDD. One quarter of the Self-advocates indicated that someone had helped them complete the survey, whether it be a friend, professional, or parent.

Ninety-four percent of Self-advocates were born in Canada. Just over half (56%) of the Self-advocates reported that they lived in their own home, and 44% reported living in a family member's home.

Approximately 25% of respondents completed at least a college education, and another 38% attained a trades' apprenticeship or certificate, diploma, or another non-university certificate.

Forty-four percent of Self-advocates were currently employed; of these, 43% in full-time employment and the rest in part-time. Approximately 44% of Self-advocates were not currently employed and not in school.

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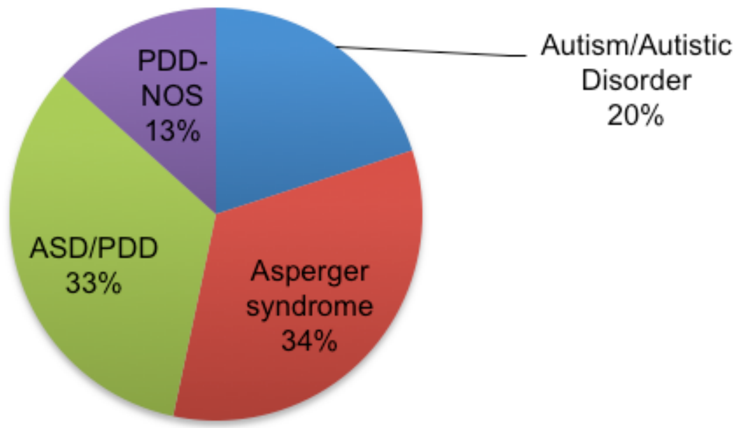
49. We are unable to report on the health and service experiences specifically of any groups with less than 20 respondents. In the case of Nova Scotia, this refers to the Self-advocates.

Figure 3. Self-advocates reported ASD diagnosis



Professionals' Demographics

There was a wide age range of professional respondents, from 22 to 67 years of age (M = 40.4 years, SD = 10.6 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working for up to 42 years (M = 10.9 years, SD = 8.1 years).

- 85% had worked with school age children
- 59% had worked with pre-school age children
- 43% had worked with adults.
- 26% had worked with all 3 age groups

Perspectives on Diagnostic Process

Of the Caregiver respondents, the average age of diagnosis for individuals with ASD was 5.5 years (SD = 5.1 years, ranging from 1 to 40 years).[50] The following is the breakdown of age of diagnosis by age category of the individual with ASD:

- Preschool age children (4 years of age or younger): M = 3.0, SD = .7, ranging from 2 to 4 years,
- School age children (5 -17 years of age): M = 4.6, SD = 2.9, ranging from 1 to 14 years,
- Adults (18 years or older): M = 8.7, SD = 7.8, ranging from 1 to 40 years.

Overall, psychologists (53%) were the most frequently noted health Professionals providing their child's ASD diagnosis, followed by psychiatrists (20%) and pediatricians (15%). Similar trends were evident for all the Caregiver age groups, with psychologists providing the ASD diagnosis most frequently for preschoolers (67%), school age children (55%), and adults (41%).

HEALTH STATUS AND SERVICE USE

Health Concerns

Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD. As shown in Figure 4,[51] the following health issues were reported:

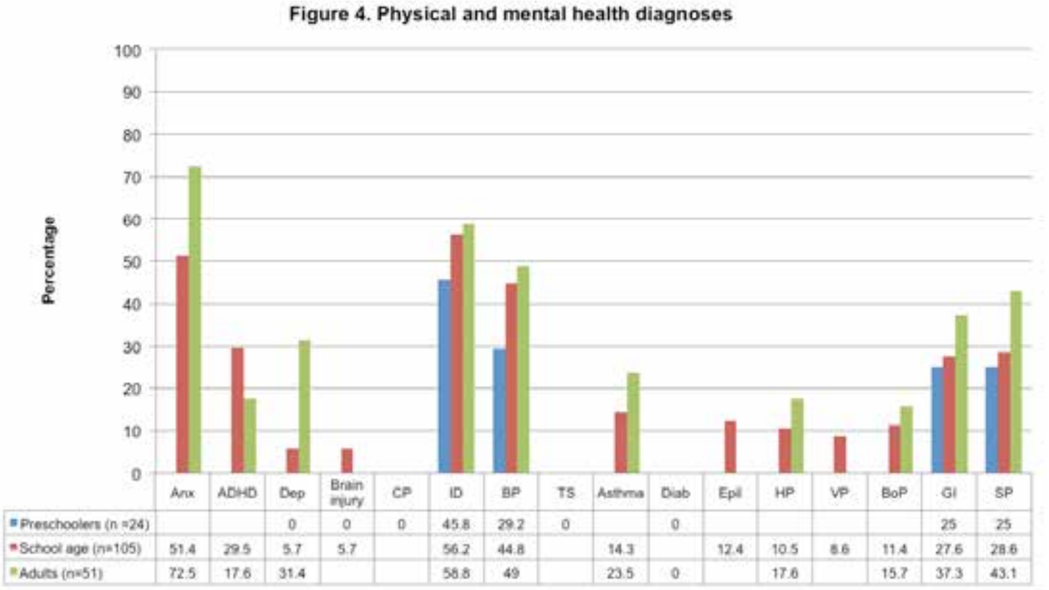
- The number of physical and mental health diagnoses increased steadily with age groups, including anxiety, IDD/DD, Depression, gastrointestinal problems, behaviour problems, asthma, bone and joint problems, and sleep problems, with the highest levels reported by Caregivers of adults,
- Affective disorders, such as anxiety and depression, were serious problems noted by Caregivers of adults,
- ADHD was more common in school age children and adults than preschoolers,
- Intellectual disability was fairly common among all three Caregiver groups.

Caregivers also reported on any formal psychiatric diagnoses ever provided (Table 1). These diagnoses were not common in preschool age children, and rose steadily through other age categories. For example, anxiety rose to 17% of school age children, and 37% of adults. Similarly, a diagnosis of depression did not occur in preschoolers, and rose to 31% in adults.

TABLE 1: FORMAL PSYCHIATRIC DIAGNOSES RECEIVED

	SCHOOL AGE CHILDREN (5-17 YEARS) N = 105	ADULTS (18+ YEARS) N = 51
PSYCHIATRIC DIAGNOSES (EVER)		
Anxiety	18 (17%)	19 (37%)
Depression	<5	16 (31%)
Psychosis/ Schizophrenia	<5	<5
Obsessive-Compulsive Disorder	5 (5%)	7 (14%)
Other	6 (6%)	7 (14%)

Figure 4. Physical and mental health diagnoses



	Anx	ADHD	Dep	Brain injury	CP	ID	BP	TS	Asthma	Diab	Epil	HP	VP	BoP	GI	SP
Preschoolers (n =24)			0	0	0	45.8	29.2	0		0					25	25
School age (n=105)	51.4	29.5	5.7	5.7		56.2	44.8		14.3		12.4	10.5	8.6	11.4	27.6	28.6
Adults (n=51)	72.5	17.6	31.4			58.8	49		23.5	0		17.6		15.7	37.3	43.1

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

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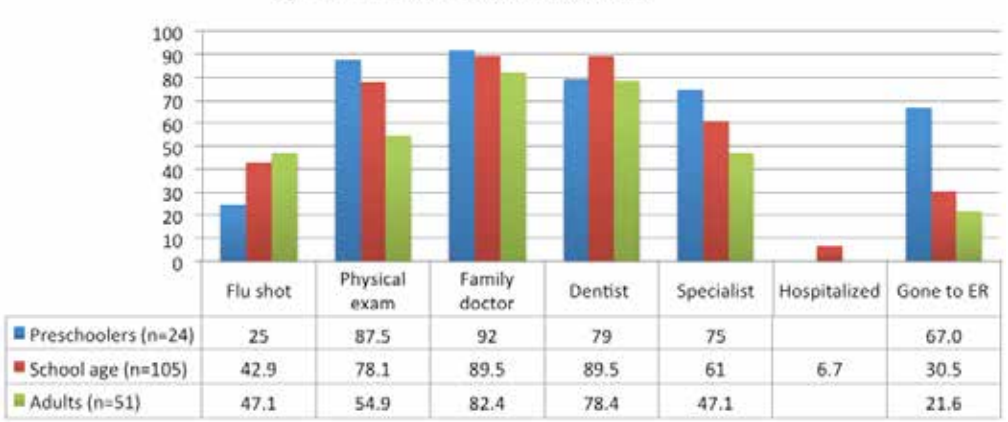
[50] Age of diagnosis was not available for the Self-advocates

[51] When sample sizes have less than 5 participants, data is not presented (left blank).

Health Service Use

Caregivers reported on their health service use in the last 12 months, as shown in Figure 5.[52]

Figure 5. Health service use in last 12 months



	Flu shot	Physical exam	Family doctor	Dentist	Specialist	Hospitalized	Gone to ER
🟦 Preschoolers (n=24)	25	87.5	92	79	75		67.0
🟥 School age (n=105)	42.9	78.1	89.5	89.5	61	6.7	30.5
🟩 Adults (n=51)	47.1	54.9	82.4	78.4	47.1		21.6

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers were asked to indicate which services they had used in the past 6 months. These we noted as recent service use.

Caregivers reported that the most recently received services for preschoolers were:

- Non-IBI early intervention (100%),
- Daycare or preschool programs (58%),
- Activity-based programs (46%),
- Diagnostic or developmental assessment services (38%),
- Recreational programs (38%).

The most commonly used recent services for school age children were:

- Activity-based programs (49%),
- Recreation programs (41%),
- Social skills programs (28%),
- Respite care (21%).

For Caregivers of adults with ASD, the most commonly used services were:

- Respite care (33%),
- Recreation programs (29%),
- Activity-based programs (28%),
- Social skills programs (24%),
- Employment or adult day programs (20%).

The total combined number of recently used services reported by Caregivers and Self-advocates provided the following breakdown by age category and respondent type:

- Preschool age children (4 years of age or younger): M = 3.5, SD = 1.6, ranging from 0 to 6 services,
- School age children (5 -17 years of age): M = 3.0 SD = 2.4, ranging from 0 to 11 services,
- Adults (18 years or older): M = 2.3, SD = 2.2, ranging from 0 to 10 services,
- Self-advocates (18 years or older): M = 2.6, SD = 2.3, ranging from 0 to 7 services.

Current Needs

Caregivers identified their top 5 current service needs, selecting from a list provided.

The top 5 current service needs of preschoolers were:

- Early IBI (83%),
- Non-IBI early intervention (67%),
- Social skills programs (58%),
- Activity-based programs (54%).

For school age children, the top 5 current service needs were:

- Social skills programs (76%),
- Recreation programs (59%),
- Activity-based programs (55%),
- Specialized summer programs (43%),
- Life skills training (38%).

For adults with ASD, the most common top 5 current service needs were:

- Social skills programs (63%),
- Employment or day programs (61%),
- Housing/residential options (51%),
- Life skills training (49%),
- Recreation programs (43%).

Professionals reported that the top 5 current service needs for individuals with ASD were:

- Early IBI (64%),
- Early detection of ASD (52%),
- Social skills (44%),
- Behaviour management (36%),
- Non-IBI early intervention (35%).

BARRIERS TO SERVICE

All respondents were asked to identify what barriers they have faced when accessing services.

The majority of Caregivers of preschoolers most commonly reported the following barriers:

- Lack of resources (79%),
- Being too young to access services (50%),
- Lack of trained professionals (50%).

Caregivers of school age children most commonly identified the following barriers:

- Lack of resources (70%),
- Lack of trained professionals (57%),
- Difficulty affording services (41%).

Most commonly, Caregivers of adults also reported:

- Lack of services (65%),
- Being too old to access service (51%),
- Lack of trained health professionals (43%).

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52. Gone to the ER only includes English speaking Caregivers.

Professionals most commonly identified the following barriers:

- Lack of services (96%),
- Difficulty affording services (74%),
- Lack of trained professionals (63%).

NEWFOUNDLAND & LABRADOR PARTICIPANTS' RESPONSES

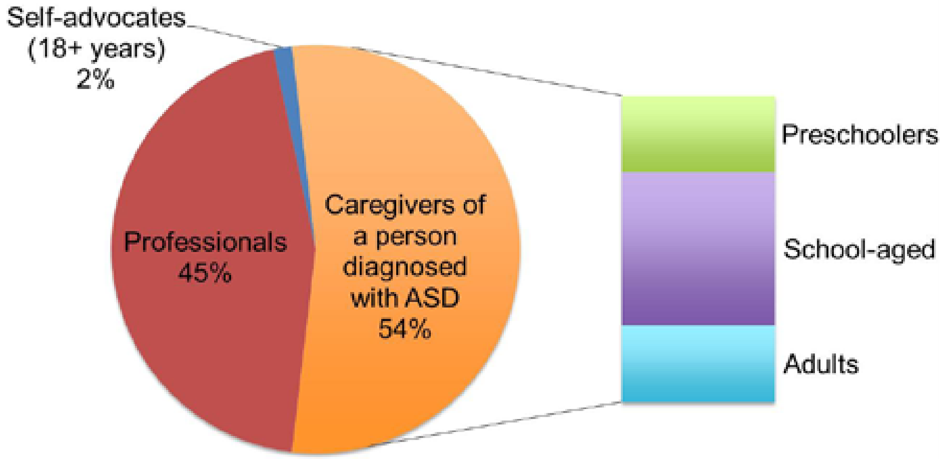
RESPONDENT REPRESENTATION

As shown Figure 1, respondents from Newfoundland and Labrador (N = 67) consisted of 34 Caregivers reporting on 36 individuals with ASD, 30 Professionals, and 1 Self-advocate.[53] Less than one percent of Newfoundland and Labrador respondents completed the French version of the survey.

Within the Caregiver respondent group, the following is the breakdown by age of child:

- 25% preschool age children (n = 9)
- 50% school age children, aged 5-17 (n = 18)
- 25% adults, 18 years of age and over (n = 9)

Figure 1. Respondents from Newfoundland & Labrador



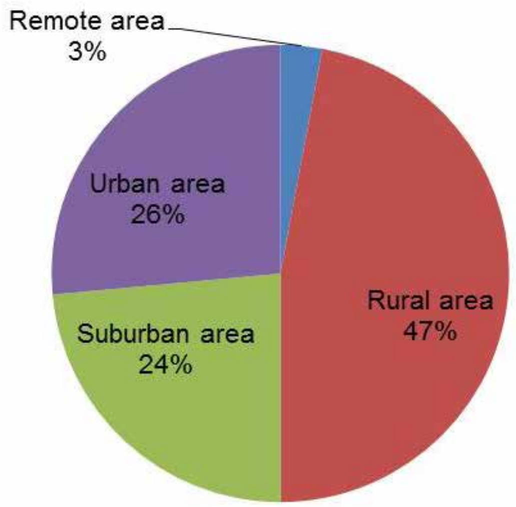
RESPONDENTS' DEMOGRAPHICS[54]

Caregivers' Demographics

Most Caregiver respondents were mothers (91%), followed by fathers (9%). The average Caregiver age was 44.5 years (SD = 10.4 years), ranging from 25 to 69 years. Most Caregivers described themselves as White/Caucasian (97%). A majority of respondents achieved at least a college or university degree (92%). Approximately 15% of Caregivers reported that they had some financial difficulties or were in deep financial trouble.

All Caregivers noted that they had lived in Canada all their lives or for at least 20 years. As shown in Figure 2, 50% of Caregivers reported living in a remote or rural area of the province.

Figure 2. Reported Size of Community



Profile of Individuals with ASD, as reported by Caregivers

Seventy-five percent of individuals with ASD were male, and the average age was 12.8 years (SD = 9.1 years) and ranged from 3 to 38 years.

- The average age, by age group, is as follows:
    - The preschool age group was 3.7 years (SD = .7 years, ranging from 3 to 4.9 years),
    - The school age group was 10.6 years (SD = 2.7, ranging from 6 to 17 years),
    - The adult group was 26.3 (SD = 6, ranging from 18 to 38 years),
- Most individuals with ASD lived at home with the Caregiver respondents (94%),
- All Caregivers of preschoolers and school age children reported that their child was living at home with family and 78% of adults lived at home with family,
- All individuals with ASD were born in Canada,
- 56% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 22% Asperger syndrome, 8% PDD-NOS, and 14% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Professionals' Demographics

There was a wide age range of professional respondents, from 25 to 57 years of age (M = 38.5 years, SD = 9.6 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals just beginning their careers to those who had been working (2 years) for up to 30 years (M = 10.7 years, SD = 7.4 years).

- 100% had worked with school age children
- 70% had worked with pre-school age children
- 50% had worked with adults.
- 50% had worked with all 3 age groups

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 5.5 years (SD = 6.4 years, ranging from 1 to 36 years). Overall, pediatricians (72%) were the most frequently noted health professionals providing their child's ASD diagnosis, followed by psychiatrist (8%).

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[53] We are unable to report on their health and service experiences specifically of any groups with less than 20 respondents. In the case Newfoundland and Labrador, this refers to any of the specific age groupings.

[54] We are unable to report on the Self-advocate demographics as the number of respondents was less than 5.

HEALTH STATUS AND SERVICE USE

Health Concerns

As shown in Figure 3,[55] Caregivers reported that health care providers had identified a number of physical and mental health diagnoses about the person with ASD.

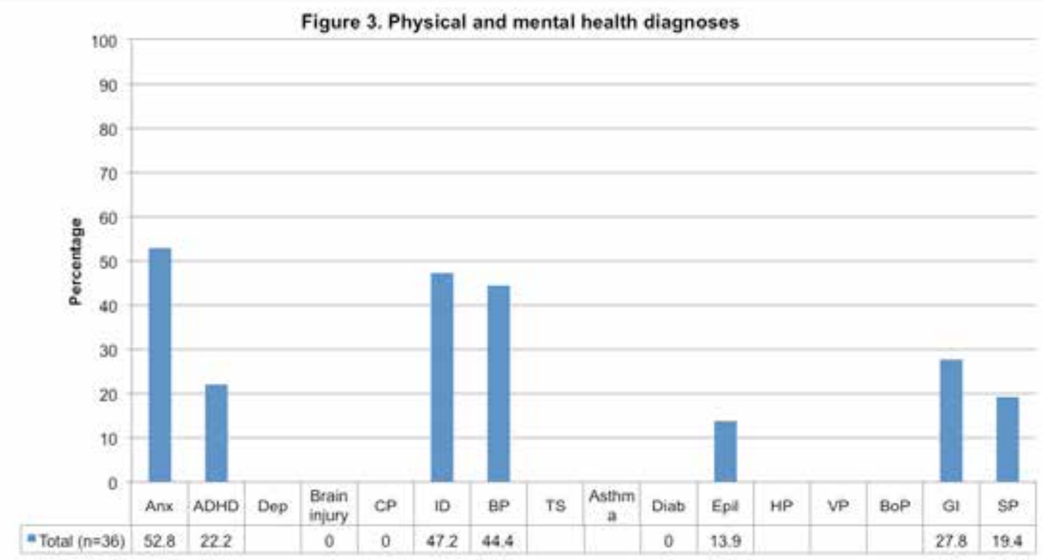
Figure 3. Physical and mental health diagnoses

Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

Caregivers across three age groups also reported that individuals with ASD received a number of formal psychiatric diagnoses, including:

- Anxiety Disorders (25%),
- Obsessive Compulsive Disorder (17%),
- Depression (8%).

Health Service Use

Caregivers and Self-advocates reported on their health service use in the last 12 months, as shown in Figure 4.[56]

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Service Use – Recent (last 6 months)

Caregivers indicated the services they had used in the past 6 months.

Across age groups, the most commonly used services were:

- Recreation programs (44%),
- Activity-based programs (42%),
- Social skills (33%),
- Non-IBI early intervention (28%),
- Specialized transportation (25%),
- Early IBI (25%).

On average, the total number of recently used services reported by Caregivers, across age groups, was 3.4 services (SD = 2.2, ranging from 0 to 7 services).

Current Service Needs

Caregivers and Self-advocates identified their top 5 current service needs, selecting from a list provided. The most common top 5 current service needs were:

- Social skills programs (56%),
- Activity-based programs (53%),
- Recreation programs (39%),
- Life skills programs (33%),
- Specialized summer camps (28%),
- Mental health treatment (25%).

BARRIERS TO SERVICE

Caregivers were asked to identify the barriers they have faced when accessing services. We also asked Professionals to note the barriers that they felt individuals with ASD and their families faced.

Caregivers, across age groups, reported the following as major barriers:

- Lack of resources (58%),
- Lack of trained professionals (44%),
- Services too far (31%),
- Being too old to receive services (31%).

Professionals identified the following barriers:

- Lack of resources (97%),
- Lack of trained professionals (73%),
- Services too far (73%),
- Difficulty affording services (70%),
- Not able to access services because diagnosis does not qualify them for services (47%),
- Being too old for services (47%.

YUKON, NORTHWEST TERRITORIES, AND NUNAVUT PARTICIPANTS' RESPONSES

RESPONDENTS REPRESENTATION

Respondents from Yukon, Northwest Territories, and Nunavut (N = 19) consisted of 9 Caregivers reporting on 9 individuals with ASD, 10 Professionals, and no Self-advocates.[57] Five percent of respondents from the Yukon, Northwest Territories, and Nunavut completed the French version of the survey. Seven of the Caregivers reported on school age children aged 5-17 years.

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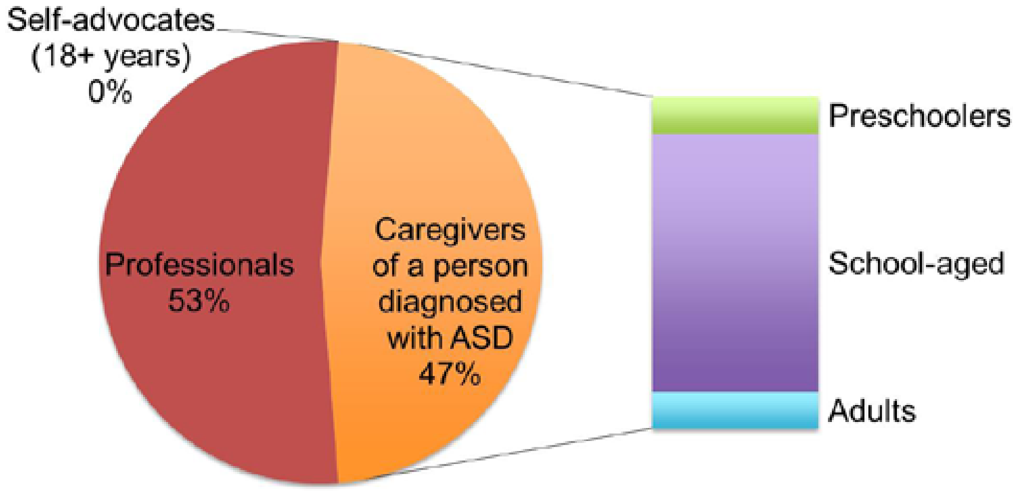
56. When sample sizes have less than 5 participants, data is not presented (left blank).

57. We are unable to report on their health and service experiences specifically of any groups with less than 20 respondents. In the case of Yukon, Northwest Territories, and Nunavut, we are unable to report on their specific experiences as a result. We do report in general terms, but with a small group of respondents, caution should be taken when interpreting the results.

Figure 1. Respondents from Yukon, Northwest Territories, and Nunavut



RESPONDENTS' DEMOGRAPHICS

Caregivers' Demographics

Most Caregiver respondents were mothers (89%), followed by fathers (11%). The average Caregiver age was 44.1 years (SD = 9.2 years), ranging from 32 to 54 years. Five (56%) Caregivers described themselves as White/Caucasian. All respondents achieved at least a college or university degree. All Caregivers reported that they had lived in Canada all their lives or for at least 20 years. Six out of the 9 Caregivers reported living in a remote area of Yukon, Northwest Territories, or Nunavut.

Profile of Individuals with ASD, as reported by Caregivers

The majority of individuals with ASD were male (67%), and the average age was 12.2 years (SD = 6.8 years).

- All Caregivers reported that the individuals with ASD lived at home with family and were born in Canada,
- 22% of individuals with ASD had a diagnosis of Autism / Autistic Disorder, 11% Asperger Syndrome, 11% PDD-NOS, and 56% as Autism Spectrum Disorder or Pervasive Developmental Disorder.

Professionals' Demographics

There was a wide age range of professional respondents, from 34 to 62 years of age (M = 46.4 years, SD = 11.4 years). Professional respondents ranged in the number of years that they had been working with the ASD population, from individuals in the beginning of their careers (3 years) to those who had been working for up to 35 years (M = 10.5 years, SD = 10.6 years).

- 7 had worked with school age children
- 6 had worked with preschool age children
- 6 had worked with adults.

PERSPECTIVES ON DIAGNOSTIC PROCESS

Of the Caregiver respondents, the average age of diagnosis for all the individuals with ASD was 4.6 years (SD = 3 years, ranging from 2 to 11 years). Across all age groups, Caregivers identified pediatricians (50%) as the most frequently noted health Professionals providing their child's ASD diagnosis.

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Current Service Needs

Caregivers identified their top 5 current service needs, selecting from a list provided.

Across age groups, the top current service needs were:

- Respite care (67%),
- Social skills programs (55%),
- Activity-based programs (33%),
- Behaviour therapy for behaviour management (33%),
- Life skills programs (33%),
- Post-secondary education programs (33%).

BARRIERS TO SERVICE

All respondents were asked to identify the barriers they have faced when accessing services.

Caregivers across age groups most commonly reported the following as major barriers:

- Services too far (89%),
- Lack of resources (78%),
- Lack of trained professionals (78%),
- Difficulty affording services (56%),

Professionals identified the following barriers:

- Lack of resources (100%),
- Difficulty affording services (90%),
- Lack of trained professionals (90%),
- Services too far (60%),
- Diagnosis does not qualify them for services (50%).

SELF-ADVOCATES WITHOUT FORMAL DIAGNOSIS PARTICIPANTS' RESPONSES

The results for Self-advocates who reported that they had not received an official diagnosis from a health professional (n = 13; 62%) or were unsure if they had (n = 8; 38%) are shown here. The data for this group of respondents has not been included in any of the other data reports and analyses. Although the respondents were excluded from the other reports that focused on the service experiences of individuals diagnosed with ASD, we felt it appropriate to include their data as a separate report, as they identify themselves as being part of this community.

RESPONDENT REPRESENTATION

Those who had not received an official diagnosis were from the following provinces:

British Columbia, Alberta, Ontario, Quebec, Nova Scotia and Newfoundland and Labrador.

Fourteen percent of Self-advocates without a formal diagnosis completed the French version of the survey.

RESPONDENTS' DEMOGRAPHICS

The majority of respondents were female (52%) and 38% were male. On average, Self-advocates were 42.1 years of age (SD = 12 years), ranging from 23 to 65 years. The majority of Self-advocates described themselves as White/Caucasian (91%). None of the Self-advocates indicated that someone had helped them complete the survey.

Ninety-one percent of Self-advocates were born in Canada. Sixty-seven percent of the Self-advocates reported that they lived in their own home, and 29% reported living in a family member's home.

Twenty-nine percent of respondents completed at least a college education, and another 24% attained a trades' apprenticeship or certificate, diploma, or another non-university certificate.

Approximately 43% of Self-advocates were not currently employed and not in school. Forty-eight percent of Self-advocates were currently employed; of these, 80% in full-time employment and the rest in part-time.

HEALTH STATUS AND SERVICE USE

Health Concerns

Self-advocates reported that health care providers had identified a number of physical and mental health diagnoses. As shown in Figure 1,[58] below, the following health issues were reported:

- Anxiety and depression are prevalent in over half of the Self-advocates,
- ADHD and behaviour problems also seem to be common in Self-advocates less than 30% had a diagnosis of an intellectual disability,
- Gastro-intestinal problems are common in one third of the Self-advocates.

Self-advocates reported on any formal psychiatric diagnoses ever provided by a health professional. Forty-eight percent were reported to have a diagnosed Anxiety Disorder (48%) and 48% reported a diagnosis of depression.

Health Service Use

Self-advocates reported on their health service use in the past 12 months. They reported the following health service use patterns:

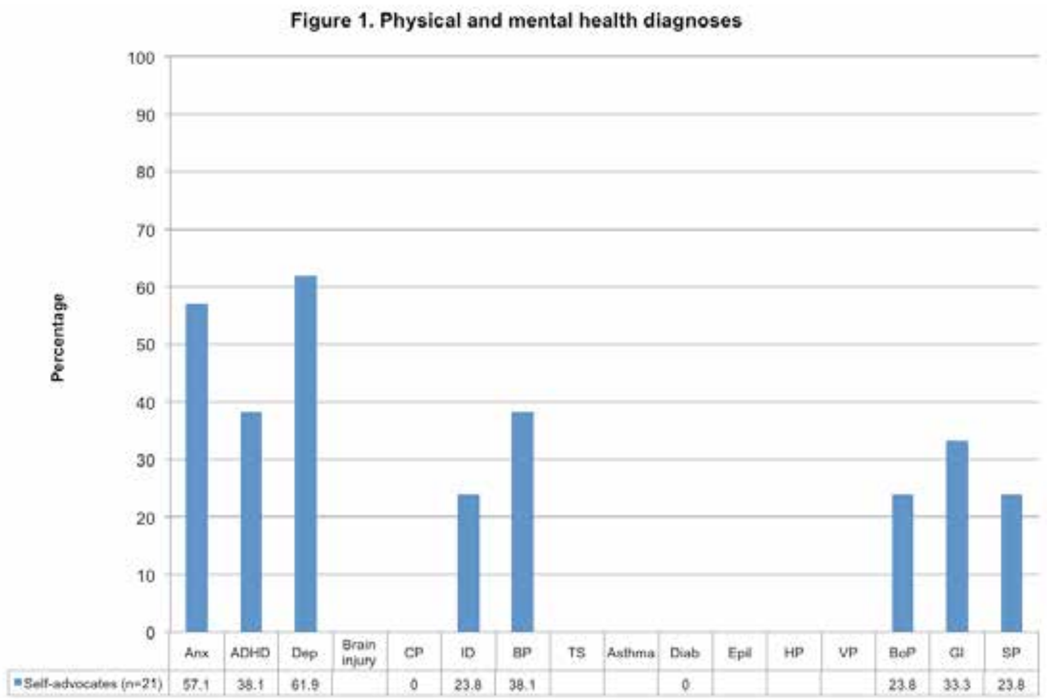
- Family doctor (76%),
- Physical exam (62%),
- Medical specialist (52%),
- Dentist appointment (48%),
- Flu shot (29%),
- Gone to the ER (24%),

DEVELOPMENTAL AND COMMUNITY SERVICE USE

Current Needs

Self-advocates identified their top 5 current service needs. The most common top 5 current service needs noted by Self-advocates without a formal diagnosis were:

- Social skills programs (71%),
- Diagnostic or assessment services (43%),
- Mental health treatment programs (33%),
- Activity-based programs (29%),
- Housing/residential options (29%),
- Life skills programs (29%),
- Employment or adult day programs (29%).



Anx: Anxiety; Dep: Depression; CP: Cerebral Palsy; ID: Intellectual Disability; BP: Behaviour Problems; HP: Hearing Problems; TS: Tourette syndrome; Diab: Diabetes; Epil: Epilepsy/Seizure Disorder; HP: Hearing Problems; VP: Vision Problems; BoP: Bone, joint or muscle problems; GI: Gastrointestinal problems; SP: Sleep problems

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58. When sample sizes have less than 5 participants, data is not presented (left blank).