CAHS
ACSS

Assessment on Autism

Findings from Pan-Canadian Opinion Surveys and Web-Based Focus Groups
2021

ENVIRONICS
RESEARCH

Contents

Introduction to Full Report

Methodology

Environics, an independent research firm, conducted pan-Canadian opinion surveys and hosted online focus groups. Their market research included the following:

- Online survey and web-based focus groups in English and French, across Canada,
- Recruitment and data processing activities, and
- Extensive data cleaning process to remove questionable responses.

Recruitment

Targeted pre-determined quotas for region, age, gender, and ethnicity were determined based on total Canadian population estimates. The process allowed us to oversample certain populations, such as Indigenous populations. Recruitment started with an existing database of Canadians.

Environics panel database was used largely to recruit the general public group, with spill over into other groups. To supplement this, Environics developed a page on its website to invite participants to the survey. This page was posted on various Facebook groups for autism and was also disseminated by organizations (that provide services, tools, and resources to Autistic people) as part of their newsletters.

General Limitations

There is no pan-Canadian database of Autistic adults, family members, or service providers that could be used to set recruitment quotas. Thus, there was no clear mechanism to establish a ‘representative sample’ of Autistic adults, family members, or service providers.

Market Research Limitations

Sample excludes individuals not on social media forums/pages and Environics’ database.

Sample excludes individuals who have limited access to online networks/internet/technology; during the COVID-19 pandemic, an online approach is the only feasible method of doing market research.

Sample excludes those with limited time and resources to complete the survey as well as those who have limited trust and sense of value in public consultations and the institutions behind them. These individuals typically experience other systemic issues that act as barriers to participating in market research activities.

Sample also excluded people who may require support completing online surveys (e.g., such us supports with reading and written communication).

Overall, caution should be exercised in generalizing the findings of this survey.

Sample Limitations

We recognize that communities in Canada, such as Black, South Asian, and East Asian communities are diverse and heterogeneous groups of people and that the sample in this survey does not include the views of all these diverse groups of Canadians. Moreover, there is considerable diversity within these broad categories of ethnicity.

We also recognize that the Northern and Maritime provinces as well as Francophone and older populations have limited representation in this survey sample.

Pan-Canadian Opinion Survey – Part 1

The data presented in this report is from the first **Pan-Canadian Opinion Survey**, one part of a variety of engagement activities. The purpose of this **Pan-Canadian Opinion Survey** was to better understand the needs, experiences, and perceptions associated with autism from diverse stakeholder perspectives to guide the working groups in their ongoing review of the scientific literature.

The survey was live from March 10th to April 5th, 2021.

Where appropriate, data from all four groups is shown together. The four groups are:

- Autistic adults (n=329), referred to in this report as “Surveyed Autistic adults”,
- Family members of Autistic people (n=272), referred to in this report as “Surveyed family members”,
- Service providers (n=373), referred to in this report as “Surveyed service providers”, and
- General public who have no connection to autism (n=1,008), referred to in this report as “general public”.

Perspectives when answering the survey:

- Autistic adults were asked questions about themselves.
- Family members were asked questions about their Autistic family members; and not to answer as representatives of their children’s perspectives.
- Service providers were asked questions about their Autistic clients.
- The general public was asked questions about themselves.

Sample Description

- The sample participating in the first Pan-Canadian Opinion Survey consisted of 329 Autistic adults, 272 family members, 373 service providers, and 1008 individuals from the general public.
- Most of the Autistic adults, family members, and service provider participants (63 – 80%) were between the ages of 18 – 45, whereas 57% of the general public participants were over the age of 45.
- 55% of Autistic adults, 61% of family members identified as being “white only”, compared to 72 – 75% of the general public and service providers.
- 38% of family members and 44% of Autistic adults identified as either Indigenous or another minority group, compared to 25% of service providers and 25% of the general public.
- Most participants were from Ontario, Quebec, British Columbia, and Alberta. Participation from the Territories (0 – 1%), Prince Edward Island (0 – 1%), and Saskatchewan (0 – 3%) were limited.
- More than 60% of the Autistic adults and family member participants indicated having a household income of $60,000 or more, compared to 53% of the general public participants.

Surveyed Autistic Adults

- 89% of surveyed Autistic adults self-reported that they received a formal diagnosis and almost half of the participants received a diagnosis after the age of 18.
- Among surveyed Autistic adults, almost half identified as a woman and 8% identified as gender-fluid, non-binary two-spirit, and/or transgender.
- About half of surveyed Autistic adults live independently and almost a quarter live with family.
- Over half (55%) of the surveyed Autistic adults are married or living with a common-law spouse.
- More than half of surveyed Autistic adults have a university or post-graduate education.
- Among surveyed Autistic adults, 23% indicated they speak and don’t have selective mutism, suggesting that more than 75% of respondents use other forms of communication. 10% of participants indicated that they are non-speaking and use augmentative and alternative communication (AAC) devices to communicate.
- Approximately 1 in 3 surveyed Autistic adults indicated they experience some form of mental health concern. A similar percentage of participants indicated they have sleeping issues.

Surveyed Family Members

- Among surveyed family members, most identified as a woman. 60% of them are a parent of an Autistic child, while almost 20% are a sibling.
- 58% of surveyed family members have a university or post-graduate education.
- The majority of surveyed family members indicated they had one Autistic family member, with most of the Autistic family members being male and under the age of 18.
- 95% of surveyed family members indicated that their Autistic family member received a formal diagnosis.
- About 42% said that their Autistic family member received a diagnosis between ages 0 – 5, 32% indicated that it was between ages 6 – 12, 9% indicated it was between ages 13 – 17, and 8% indicated it was after the age of 18.
- About a third of them indicated that their Autistic family member is fully or partially non-speaking and uses augmentative and alternative communication (AAC) devices to communicate, while a third indicated that their family member speaks and does not have selective mutism, and a third indicated that their Autistic family member speaks, but with selective (situational) mutism.

Surveyed Service Providers

- 55% of surveyed service providers are healthcare providers, while the remaining participants either work or volunteer with Autistic people in different capacities.

- Of the surveyed healthcare providers, the majority were occupational therapists, instructor therapists/senior therapists, and psychologists. There was low representation among physicians.
- Other than surveyed healthcare providers, participants who indicated that they work with Autistic people were mostly social workers, educators, and educational assistants.
- 70% of surveyed service providers have been working with Autistic people for over 5 years.

Key Observations

Overall, there is extensive support for a national autism strategy with over 3 in 4 surveyed Autistic adults, family members, service providers, and the general public supporting it.

Findings

1. Social Inclusion

1.1 Stigma and Autism Acceptance

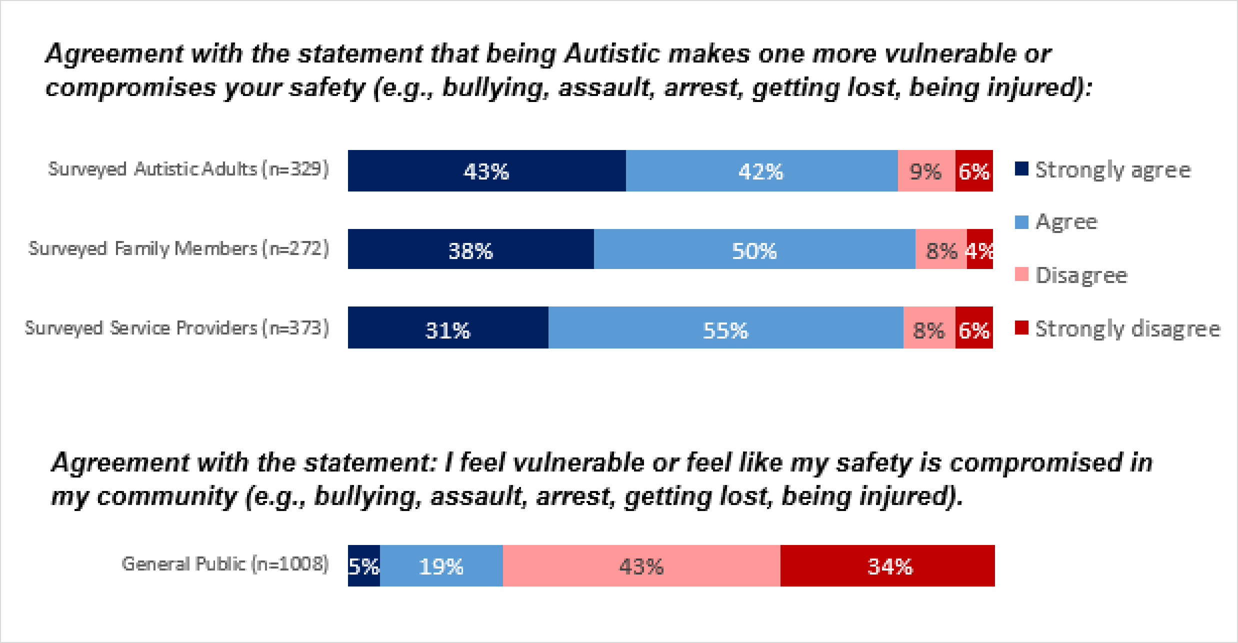
About 6 in 10 surveyed Autistic adults indicated they have a good quality of life, with surveyed family members and service providers being slightly more optimistic. In comparison, over 8 in 10 general public Canadians indicated they have a good quality of life.

1.2 Experiences of Discrimination Against Autistic People

Generally, surveyed Autistic adults, family members, and service providers reported that their rights have been violated more often when compared to the general public.

1.3 Human Rights, Public Safety, and Decision-Making

Almost all those surveyed with a connection to autism agreed that Autistic people were more likely to have their safety compromised, whereas just over 2 in 10 of the general public fear for their own safety (strongly agree + agree).



Agreement with the statement that being Autistic makes one more vulnerable or compromises your safety (e.g., bullying, assault, arrest, getting lost, being injured):

Agreement with the statement: I feel vulnerable or feel like my safety is compromised in my community (e.g., bullying, assault, arrest, getting lost, being injured).

1.4 Community Participation, Accessibility, and Education

The school system was rated by only a quarter of surveyed Autistic adults and their family members as meeting the needs of Autistic people.

1.5 Accessibility, Community Participation, Recreation, and Sports

While most surveyed Autistic adults expressed interest in participating in community-based activities, just over half would be comfortable participating.

While communities provided accommodations for Autistic people, lack of transportation was identified as a limitation for over half of those surveyed.

There was consensus among all surveyed groups that less than half of the general public is knowledgeable about autism.

2. Economic Inclusion

2.1 Economic Inclusion / Financial Stability

Approximately half of surveyed Autistic adults indicated that funded autism services are available and accessible to them.

A quarter of surveyed Autistic adults and family members spend $10,000 or more on autism-related needs, with a further 4 in 10 spending between $2,000 and $10,000 annually (out-of-pocket).

This leads to almost 7 in 10 surveyed Autistic adults, family members, and service providers indicating that the extra costs related to autism results in some financial hardships.

Overall, all surveyed groups indicated a higher need and acceptance for having healthcare related costs (such as diagnosis, counseling, therapy, medication, mental health support) being fully publicly-funded – including members of the general public.

2.2 Employment

Surveyed Autistic adults, family members, and service providers noted that workplace accommodations and education for employers/employees are most required for Autistic people to succeed in the workplace. Surveyed providers also noted that employment support/job coaching is required.

2.3 Models of Social Enterprise and Supportive Employment in Working Age Adults

Classroom accommodations, alternative approaches to learning, and mental health support would be the most helpful in achieving further education for surveyed Autistic adults as indicated by them, surveyed family members, and service providers.

2.4 Autism-Friendly Housing Options Across the Lifespan

A variety of challenges to accessing housing were indicated by surveyed Autistic adults including cost, which was identified as the biggest challenge, along with long waitlists for subsidizes housing, landlord discrimination, complicated requirements, and few options meeting their needs. Surveyed service providers agreed with these challenges, but believed cost was less of a challenge compared to other barriers.

3. Diagnosis, Supports, and Services

3.1 Adult and Child Diagnosis

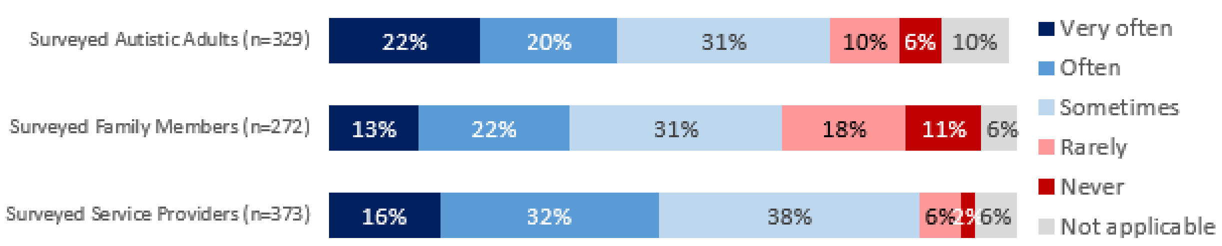
Most of those surveyed (over 75%) had to pay something out-of-pocket for their diagnosis by a healthcare professional, with a quarter having to pay $2,000 or more.

3.2 Adult and Child Supports and Services

Generally, needs and preferences were considered in service plans, as reported by all surveyed groups.

Access to information and education are the things families most need when supporting an Autistic person.

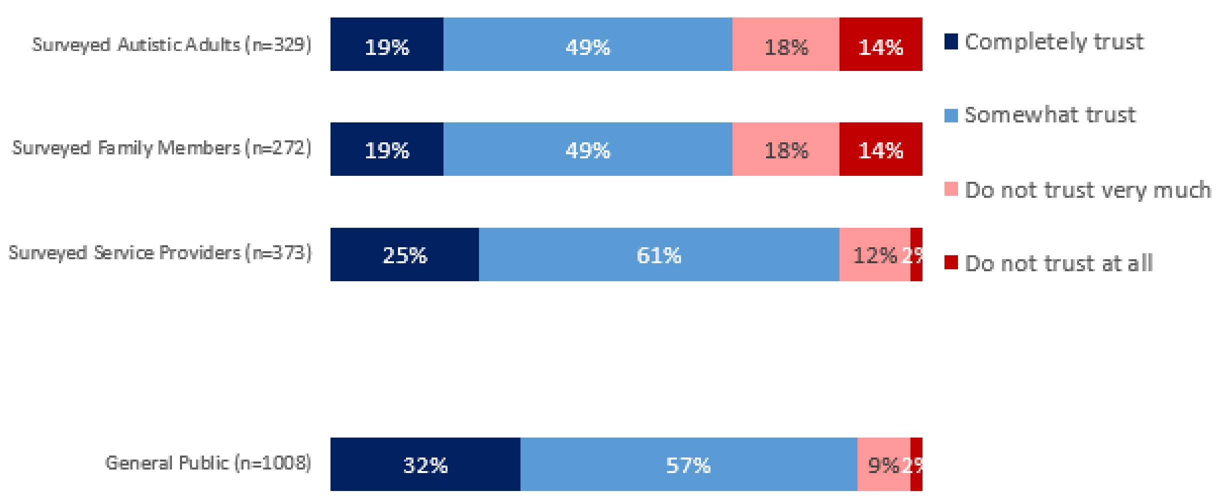
Almost 7 out of 10 surveyed Autistic adults and family members (and more according to surveyed service providers) indicated that cost restrictions have prevented them from accessing services. This compares to just over a quarter of general public Canadians who have sometimes gone without health/social services due to cost (very often + often + sometimes).


Frequency of going without autism-related services because of cost restrictions:


Frequency of going without necessary health or social services because of cost restrictions:

3.3 Health Systems

While many surveyed Autistic adults and family members reported that they trust the healthcare system to provide fair and equal treatment, a greater proportion of the general public are trusting of the system.


Trusting the healthcare system to treat one fairly and equally:

About half (or fewer) of surveyed Autistic adults indicated that the various service providers who work with Autistic people are knowledgeable about working with Autistic children and youth, with knowledge decreasing slightly when working with Autistic adults. Service providers themselves noted that their level of knowledge when working with Autistic adults is lacking in comparison to when they work with Autistic children.

Web-Based Focus Groups with Autistic Adults

Methodology

The target population audience for the qualitative online community consisted of Autistic adults, who have received a diagnosis by a healthcare professional or self-identify as autistic.

A total of 26 Autistic adults participated over a span of two days, from June 15 – 16, 2021. Participants were recruited as part of the Pan-Canadian Opinion Survey (Part 1) and asked to be part of this qualitative online discussion.

Sample details:

- 16 Autistic adults completed the exercise in English.
- 10 Autistic adults completed the exercise in French.

Separate English and French focus groups were run concurrently.

Efforts were made to recruit a diverse sample of participants across gender, region, urbanity, income, education, and other key demographic factors. Nevertheless, because the number of participants is low, we cannot draw conclusions about differences among these subgroups. That is the role of the quantitative phase of the research program.

The online community used the Recollective online bulletin board platform (programmed and hosted in Canada). This platform generated an asynchronous threaded discussion that developed as participants completed the research. The discussion guide for this research was developed by CAHS and Environics Research.

Purpose of Report

This report represents the findings from the focus group discussions conducted with 26 Autistic adults. It is meant to supplement other engagement methods conducted by CAHS and Environics Research. The stories and experiences outlined in this report reflect those of the participating Autistic adults.

Qualitative research involves collecting and analyzing non-numerical data (e.g., text, video, or audio) to understand concepts, opinions, or experiences. It is not meant to replace quantitative data analysis methods. To comply with industry standards, this report, like all qualitative research, avoids reporting percentages or other numbers in the observations because it would imply a statistical significance which is not possible with this sample of respondents.

The results provide an overview of participants’ views about the issues explored, but these findings cannot be generalized to all members of the general public or members of the targeted audience segments.

Key Observations

Regardless of background or profile, all Autistic adult participants expressed similar challenges, views, and struggles, suggesting that support and solutions can be universal.

Many of their challenges began at the healthcare professional level, particularly in cases where they were not assessed appropriately or their concerns were not taken seriously.

Currently, many face discrimination in society and at work mainly because people are not aware or understanding of autism. These experiences begin at school and continue into adult life.

Few supports and services are available to Autistic adults, either because of limited availability or lack of accessibility due to cost.

All participating Autistic adults feel that increasing autism awareness should be a large part of a national autism strategy, in addition to focusing on the services, funding, and supports that empower them.

Findings

1. Social Inclusion

1.1 Stigma and Autism Acceptance

The participating Autistic adults believe there is a need for greater acceptance and understanding among healthcare professionals, educators, and the general public, particularly around the diversity of needs and experiences of Autistic people.

They feel that increasing awareness should be a large part of a national autism strategy, in addition to focusing on the services, funding, and supports they need to reach their potential – ultimately removing the existing barriers that limit them.

It was also recommended that CAHS communicate, as part of the Assessment on Autism, how Autistic people (of all backgrounds) were included in the assessment process and are involved in driving the national autism strategy – this will garner further support from Autistic people.

1.2 Experiences of Discrimination Against Autistic People

Almost all have experienced some level of discrimination, many in the workplace, in social situations, and while trying to access healthcare.

Many do not feel comfortable disclosing their autism diagnosis as that often results in maltreatment, instead of more support.

1.3 Human Rights, Public Safety, and Decision-making

About half of the participants indicated that there have been moments when they have felt unsafe due to being misunderstood, being perceived as vulnerable, or not having high situational awareness. There were mentions of being bullied during school, and even as adults, as well as experiences of abuse.

Solutions:

There was no clear solution to supporting Autistic people to feel safe. Many Autistic adults indicated that they isolate themselves or limit interaction with the public to feel safer.

They did indicate that having people understand them and not judge them helps them feel safe and can reduce discrimination. Shifting the narrative away from one that positions autism as a problem or issue was also suggested.

Training on situational awareness and financial freedom can also help.

There is a need to adopt disability justice and neurodiversity paradigms and to adhere to the UNCRPD.

1.4 Community Participation, Accessibility, and Education

Generally, high school was difficult for most participants as they lacked the support and understanding they needed from teachers and peers. These feelings were exacerbated for many by being bullied or having no/few friends.

Secondary education was better for some due to a higher level of understanding and availability of services. However, there are others who continued to struggle with accessing services and accommodations. Some described the process of having to constantly “prove” their need for accommodations as being treated like they were trying to “cheat the system”.

Francophones generally seemed to have a harder time with schooling, with many feeling discouraged and dropping out due to the lack of support they received and social challenges. However, some mentioned that when appropriate supports were provided, they were able to excel in their studies.

Solutions:

The main solution offered for a better experience in high school is to have teachers specifically for Autistic students or those that specialize in the area. This would lead to a better understanding Autistic students’ needs and more tailored teaching.

1.5 Accessibility, Community Participation, Recreation, and Sports

All participating Autistic adults indicated that in order for them to have a sense of community belonging they need to be accepted without judgment and be active participants in the community – no different than anyone else.

Solutions:

Sports and other activities were seen as a way of bridging people together, as well as helping Autistic adults build friendships and relationships. Creating safe spaces online and in-person where Autistic adults can meet (to discuss mutual interests) was also appreciated, along with mentorship programs through different stages of life. Some participants talked about the benefits of meeting other Autistic people with whom they share similarities and can relate to.

2. Economic Inclusion

2.1 Economic Inclusion / Financial Stability

For many participants, their finances are barely enough to meet their basic needs, with COVID-19 making things worse. They have also received limited support to help manage their money/finances – some receive assistance from parents or do their own research.

Solutions:

Autistic adults offered up a few solutions to help improve their finances beginning at the employer level. Creating more opportunities for them allows them to be employed and earn an income; at which point financial literacy courses can help them manage their money and navigate the often-confusing world of banks, forms, etc.

Most also suggested Universal Basic Income or improved access to Disability Tax Credits, along with covering the cost of services they need to pay for themselves.

This is where they see the government having a role, realizing they are the authority that can implement change.

2.2 Employment

Half of the Autistic adult participants are currently looking for a job or not working. Of those who work, some work for themselves and only a few work in the area they trained in, but they enjoy being independent and working.

A wide variety of challenges have been experienced by Autistic adults when trying to find employment. This includes poor support from employment services, finding employment that meets their needs/expectations, and struggling with resume development, networking, and interviewing.

Many also reported that their workplaces have not made any accommodations for them and fear judgment by other employees. In particular, there is often a lack of understanding around sensory challenges.

Solutions:

Having better funded employment services for Autistic people would improve the services that they are able to receive. A general word of advice was disclosing a candidates’ autism diagnosis so Human Resources (HR) can take the necessary steps to accommodate them and their needs during the interview process. Having HR aware of their diagnosis can also help with workplace education.

Another proposed solution was having headhunters or mentors who specialize in jobs for neurodiverse people and can help them build resumes. Small business support and mentorships were also suggested for those who would like to be self-employed.

2.3 Models of Social Enterprise and Supportive Employment in Working Age Adults

Many report that their workplaces have not made any accommodations for them and fear judgment by other employees.

Solutions:

Thriving in the workplace mostly involves employers doing more to accommodate Autistic people (allowing headphones, work-from-home options, etc.) and employee education/training.

2.4 Autism-Friendly Housing Options Across the Lifespan

The majority of participants are looking for housing, suggesting some level of dissatisfaction with their current living arrangement. The sources of dissatisfaction include noise, physical difficulties, and high costs, which mean they have to live in smaller places and often with many other people.

Finding housing has led to anxiety for many, as it can be a scary and frustrating process. Many encountered barriers including discrimination because of income and they realize, with current demands for housing, others may be given priority over them.

By far, the biggest challenge is cost – not being able to afford due to current prices, with low job rates not helping them during their search.

Solutions:

Since finances were identified as the largest barriers, most solutions focused on improving the financial situation of Autistic people. Autistic adults believe the government has a role to play in providing funding, tax credit, and affordable housing.

Some also believe that landlord knowledge needs to be improved – part of the wider strategy of educating the public on autism.

Some Francophones mentioned that having a non-autistic person accompany them on visits would help as well as having a list of autism-friendly buildings/landlords.

3. Diagnosis, Supports, and Services

3.1 Adult and Child Diagnosis

Most of the participants have been diagnosed by a healthcare professional. The few who have not received a diagnosis, indicated that they hoped to get diagnosed someday. Those who self-identify have typically been let down by the healthcare system and therefore chose not to pursue a diagnosis or have tried to obtain a formal diagnosis without success.

Of those diagnosed as adults, many indicate that they felt different for years without understanding why or misdiagnosed themselves, leading to potentially traumatic experiences and an impact on their mental health – suggesting that timely diagnosis is crucial.

Solutions:

With timely diagnosis being crucial, most Autistic adults agreed that healthcare professionals, educators, and even parents need to be more knowledgeable and aware about autism so they can recognize it early on (in all types of people) and appropriately refer them to specialists. They indicated that most clinicians have an outdated perception of autism, especially in recognizing it across diverse genders and cultural backgrounds.

Having access to specialized clinics can also help, rather than Autistic adults having to navigate the system themselves.

In addition, most suggested that the cost of the diagnosis process needs to be covered/subsidized for it to be more accessible.

3.2 Adult Supports and Services

The majority of Autistic adult participants did not access any autism-specific services (especially Francophones). While most reasons focused on a lack of available services, some also indicated that they do not qualify for services due to diagnosis status or functional levels. A few also mentioned that they were not able to access services because of their gender, age – services specializing with children or males can ignore others – or location.

There was also a recognition that services can be costly, which can lead to some not accessing them. Other barriers included location of services and suitability of services to meet the diverse needs of Autistic people.

Solutions:

Following a diagnosis, there is a need for increased access and availability of services for all Autistic people that meet diverse needs across the lifespan, particularly during periods of transition. A database of these services should be made available, so Autistic adults can research and access them locally and with ease. For Francophones, knowing which services/support are available in French would be helpful.

Many indicated that a peer or mentor during these critical life-transitions can help, along with workshops/education. Francophones tended to want more traditional healthcare support such as psychologists.

3.3 Health Systems

There is some mistrust with the system as many participants have been let down at some point when dealing with healthcare professionals. Many do not have a family doctor and have no access to dental and mental healthcare due to the associated costs.

Solutions:

Autistic adults realized that their health needs to be handled with a holistic approach by healthcare professionals who understand autism and their needs. Not having a family doctor who understands autism can be a barrier to accessing other healthcare professionals.

Web-Based Focus Groups with Family Members of Autistic People

Methodology

The target population audience for the qualitative online community consisted of family members of Autistic people (either formally diagnosed or self-diagnosed), mainly parents of Autistic children (of all ages) and a few sibling and grandparent supporters.

A total of 22 family participated over a span of two days, from June 15 – 16, 2021. Participants were recruited as part of the Pan-Canadian Opinion Survey (Part 1) and asked to be part of this qualitative online discussion.

Sample details:

- 18 family members completed the exercise in English.
- 4 family members completed the exercise in French.

Separate English and French communities were run concurrently.

Efforts were made to recruit a diverse sample of participants across gender, region, urbanity, income, education, and other key demographic factors. Nevertheless, because the number of participants is low, we cannot draw conclusions about differences among these subgroups. That is the role of the quantitative phase of the research program.

The online community used the Recollective online bulletin board platform (programmed and hosted in Canada). This platform generated an asynchronous threaded discussion that developed as participants completed the research. The discussion guide for this research was developed by CAHS and Environics Research.

Purpose of Report

This report represents the findings from focus group discussions conducted with 22 family members of Autistic people. It is meant to supplement other engagement methods conducted by CAHS and Environics Research. The stories and experiences outlined in this report reflect those of the participating family members of Autistic people.

Qualitative research involves collecting and analyzing non-numerical data (e.g., text, video, or audio) to understand concepts, opinions, or experiences. It is not meant to replace quantitative data analysis methods. To comply with industry standards, this report, like all qualitative research, avoids reporting percentages or other numbers in the observations because it would imply a statistical significance which is not possible with this sample of respondents.

The results provide an overview of participants' views about the issues explored, but these findings cannot be generalized to all members of the targeted audience segments.

Key Observations

Participating family members of all backgrounds agreed that timely diagnosis is key to improving the lives of Autistic people – without it they are unable to access services/supports and are often misunderstood at a very young age.

There were questions and fears about what types of services Autistic people would have access to during adulthood and how they would manage financially. These concerns are more prevalent for parents of Autistic children who experience more challenges with communication and need more caregiver support.

Public education with employers, teachers, and students was seen as a way to reduce the stigma around autism, with hopes of reducing discrimination, especially in school where Autistic children may be bullied because they are seen as different.

Many believed that funding the educational system needs to be a priority of the national autism strategy – and early diagnosis will ensure needs are met at a young age, preparing them for adulthood.

Findings

1. Social Inclusion

1.1 Stigma and Autism Acceptance

Similar to Autistic adults, participating family members believed there was a need for acceptance and understanding among healthcare professionals, educators, and the general public, particularly around the diversity of needs and experiences of Autistic people.

They felt that focusing on improving the educational system should be a large part of a national autism strategy, in addition to focusing on services, supports, and ensuring Autistic people are supported throughout their lives – not just during childhood.

Another theme that family members shared was "empowerment" and recommended parents and caregivers not shelter their Autistic family member but listen to their needs and empower them – which is something the national autism strategy should strive to do as well.

1.2 Experiences of Discrimination Against Autistic People

Family members reported less discrimination than Autistic adults, likely because many of them support young family members, who spend a lot of time around parents or other family members as opposed to being alone. Those that mentioned experiences of discrimination, reported judgment from people in public and bullying in schools, because people do not understand or are aware of autism.

Family members of older children also noticed discrimination in the workplace, particularly when they disclose their autism diagnosis.

Solution:

As with Autistic adults, the main solution offered up by family members is public education.

1.3 Human Rights, Public Safety, and Decision-making

Most family members have feared for the safety of their Autistic family members. These fears focus on being bullied in school because others do not understand autism. Parents also worried about their children running off (sometimes into traffic) because of sensory issues, while not being fully aware of potential dangers.

Some also reported that they fear their Autistic family members will hurt themselves, and realize that as they get older and stronger, they may not realize the harm they can do to themselves.

Solution:

Parents indicated that routine can help their family members feel safe, as well as having understanding/trusting friends, families, and neighbors. This is similar to what Autistic adults mentioned – having people understand them and not judge them helps them feel safe and can reduce discrimination.

1.4 Community Participation, Accessibility, and Education

Generally, early years such as kindergarten can be tough for Autistic children as the experience is new and there is a learning curve for them, family members, and the school staff.

Children who went to schools that specialize in supporting Autistic children, had better support and teachers who were more understanding, resulting in more positive experiences. Having continuity of supports through established relationships between school staff and Autistic students, can enable improved understanding and more effective academic support.

Children who were diagnosed later in life also struggled prior to diagnosis as teachers and students did not understand them – again highlighting the importance of timely diagnosis.

Navigating the schooling system was also stressful for some parents, especially when teachers and schools are not understanding of their situation. This has often led parents to opt to homeschool their child.

Solutions:

Understanding that teachers and educators have a role to play in the school experience, family members suggested that they obtain funding to receive education in teaching Autistic students. In addition, improving awareness and acceptance of autism among other students can enable Autistic children to feel welcomed and make friends.

For those that had positive experiences with schooling, they recognized that proactive teachers and schools have helped their children to achieve those positive experiences.

2. Economic Inclusion

2.1 Economic Inclusion / Financial Stability

All family members worried about the future financial wellbeing of their Autistic family members, especially when they will not be around to help. Their worries stemmed from the extensive costs associated with accessing healthcare and professional services and support; and whether their Autistic family members will be able to find steady, well-paying employment.

Many parents were also unsure about what funding their Autistic family members will receive as they transition into adulthood and move out.

Parents also realized the financial burden upon themselves, especially if they are working in an environment that is not understanding. Having an understanding work environment (flexible schedule, days off, working from home) can help family members care for their children while not having to give up their careers.

Solutions:

To help with Autistic people’s finances, family members would like to see training/education programs on how to manage finances. Some also believed that having a trustee or a trusted advisor with Autistic clients would be beneficial to support with making financial decisions.

Family members also recognized that there is a role for the government, especially when it comes to funding. This can be in the form of subsidies, funded services, or basic income to offset costs associated with autism-related supports and missed time from work. Some families have higher earning incomes and do not qualify for government assistance even though they still experience financial burdens.

2.2 Employment

Family members expressed concerns about their Autistic family members’ ability to find suitable employment. The level of concern varied based on their Autistic family member’s areas of difficulty (such as communication challenges), which may contribute to challenges in obtaining and maintaining employment.

Generally, there was a lack of awareness among family members about what opportunities are available for their Autistic family members to obtain employment.

Solutions:

Similar to what Autistic adults mentioned, support in the form of career counselors or recruiters specializing in autism can alleviate the stresses of finding jobs that suit Autistic people's needs and help them through their careers. The need for employers to be trained on autism and making accommodations to meet the needs of Autistic employees was also mentioned.

2.3 Autism-Friendly Housing Options Across the Lifespan

As many Autistic people still live with their families, families were unsure about challenges faced when looking for housing. Some indicated concerns around being on a long waitlist, whether accommodations will be affordable, safe, and meet their family members' needs, and access to daily living supports (such as paying pills, managing the house, personal care).

Solutions:

Public/landlord knowledge and awareness was stated by some as being helpful – it can make families feel more comfortable about where their children are living and with whom. Most importantly, they felt that the government has a role to play in subsidizing housing or developing group homes where the needs of their children can be met.

3. Diagnosis, Supports and Services

3.1 Adult and Child Diagnosis

Almost all participants indicated that their family members have been diagnosed by a healthcare professional. The experiences were divided, with some having difficulty accessing a diagnosis and others having an easier time – they stated that having an understanding healthcare professional who listens to them was key to a smooth process.

While long wait times were reported by all, there seemed to be higher wait times in Quebec. Delayed diagnosis can also delay access to needed accommodations as well as supports and services.

All participating family members agreed that having a timely diagnosis at a young age would have helped in understanding their family members' needs, accessing services, planning, etc.

There was also recognition that trying to access a diagnosis as an adult is associated with even more barriers, such as cost; and that certain autism profiles, such as that of girls, may not be recognized as autistic.

Solutions:

Having healthcare professionals who understand autism and are aware that it can present in all types of people was cited as one of the most important ways of improving the diagnosis process, followed by reducing wait times to meet specialists.

3.2 Child Supports and Services

In contrast to what the Autistic adults indicated, most family members reported that their Autistic family member accesses some autism-specific services – mostly social programs (such as camps) and educational programs in school. Most of these were accessed and suggested by the school; others required research, diagnosis confirmation, and financial planning as they were accessed privately.

There was recognition that finances, time, eligibility criteria (such as family income and age), and location have influenced access to services – some indicated having to move because of services.

In Quebec, support and services in schools were extensively used and were noted to be very helpful.

Parents and caregivers of older children noticed that services and support become more limited as their Autistic family members get older – most focus on the needs of children and not adults – and this worried some of them as their children transition to adulthood.

Very few parents have accessed services for themselves, mainly parenting classes or educational webinars which they themselves proactively sought out and found to be helpful when used. These services can be costly, and with parents focusing on their children, they may not always access support for themselves. Many relied on healthcare professionals, autism organizations, and other parents for advice and guidance.

Solutions:

As with Autistic adults, family members also indicated that services need to be available and accessible locally, with efforts to make them aware of what is available to them. These supports need to cover various transition points in life, such as schooling, post-secondary education, and work life.

In addition, they also believed that diagnosis at an early age can help them access these services earlier. Parents of newly-diagnosed Autistic children may also benefit from mentorship from others in the same situation or parent support groups.

3.3 Health Systems

As with the diagnosis process, family members had differing views on the healthcare system; some had positive experiences, while others experienced a lack of understanding by healthcare professionals.

Dental care and mental health support can be a challenge as they can be costly and professionals may not be aware of how to support and accommodate Autistic people, for example: at the dentist office, some children may need to be sedated or require special accommodations (low light, reduced sound, etc.).

Solutions:

Receiving a timely diagnosis was mentioned as important for accessing quality healthcare as it helps families navigate the healthcare system to identify appropriate supports to meet their Autistic family members’ needs.

Also, having a list of healthcare professionals that accept Autistic children can help parents know where to go when they need to access healthcare, especially dental care, where required accommodations will be made.

Pan-Canadian Opinion Survey – Part 2

The data presented in this report is from the second **Pan-Canadian Opinion Survey**, one part of a variety of engagement activities. The purpose of this **Pan-Canadian Opinion Survey** was to gauge the receptivity and support for potential approaches that could be used to address issues related to social inclusion, economic inclusion, and diagnosis, supports, and services.

The survey was live from July 20th to August 18th, 2021.

Where appropriate, data from all four groups is shown together. The four groups are:

- Surveyed Autistic adults (n=401),
- Surveyed non-autistic family members (n=345),
- Surveyed service providers (n=144), and
- General public with no connection to autism (n=1000).

All groups were asked questions in general, about their support for policy changes for Autistic people.

Sample Description

- The sample participating in the second Pan-Canadian Opinion Survey consisted of 401 Autistic adults, 345 non-autistic family members, 144 service providers, and 1000 individuals from the general public.
- Most of the Autistic adults, family members, and service provider participants (74% – 94%%) were between the ages of 18 – 45, whereas 46% of the general public participants were under the age of 45.
- 33% – 49% of Autistic adults and family members identified as Indigenous, compared to 24% – 8% of service providers and the general public.
- 29% – 45% of Autistic adults and family members identified as white only, compared to 51% – 69% of service providers and the general public.[1]
- 19% – 21% of Autistic adults and family members identified as another ethnicity only, compared to 21% – 23% of the general public and service providers.
- 1% – 2% of all groups identified as white plus another ethnicity.
- Most participants were from Ontario, Quebec, British Columbia, and Alberta. Participation from the Territories (0 – 3%), Atlantic (0 – 8%), and Saskatchewan (0 – 4%) were limited.
- 33% of the Autistic adults indicated having a personal income of $40,000 or less and 25% family member participants indicated having a household income of $40,000 or less, compared to 27% of the general public participants.

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[1] Participants could select more than one ethnicity, (e.g., black and another category or white and another category. For analysis and sample purposes, participants were grouped into one category. As such anyone who selected white and something else was grouped as “other” whereas other were grouped as the ethnicity they selected.

Surveyed Autistic Adults

- 89% of surveyed Autistic adults self-reported that they received a formal diagnosis and over half of participants received a diagnosis after the age of 18.
- Among surveyed Autistic adults, almost half identified as a girl/woman and 10% identified as gender-fluid, non-binary two-spirit, and/or transgender.
- Just under half of surveyed Autistic adults live independently and almost a quarter live with family.
- Over half (55%) of the surveyed Autistic adults are married or living with a common-law spouse.
- More than half of surveyed Autistic adults have a university or post-graduate education.
- 14% indicated they have an intellectual disability; and 20% indicated they have a learning disability.
- Over a quarter are parents, with approximately 20% of Autistic adults being parents of Autistic children.

Surveyed Non-Autistic Family Members

- 72% of them are a parent of an Autistic child, while almost 14% are a sibling.
- 63% of surveyed family members have a university or post-graduate education.
- Most of the surveyed family members indicated that the Autistic family member(s) they support are male and under the age of 18.
- 90% of surveyed family members indicated that their Autistic family member received a formal diagnosis.
- About 47% said that their Autistic family member received a diagnosis between ages 0 – 5, 40% indicated that it was between ages 6 – 12, 2% indicated it was between ages 13 and 18, and 7% indicated it was after the age of 18.
- About a third (36%) of them indicated that their Autistic family member have mild support needs, 40% have more consistent needs, and 24% considerable support needs.

Surveyed Service Providers

- Approximately half of surveyed service providers are healthcare professionals which include: (25%) general practitioners/family physicians, (15%) pediatricians, (13%) social workers, (11%) nurses, (7%) psychologists, (1% – 4%) instructor therapists / senior therapists, mental health counsellors, neurologists, dentists, occupational therapists, physiotherapists, opticians, chiropractors, etc.
- The other half of surveyed service providers work with Autistic people which include: (38%) teachers, (19%) aides, (10%) music therapists, (8%) interventionists, (7%) personal aides or assistants, (7%) job counsellors, (3%) school principals.
- The majority (74%) of surveyed service providers have been working with Autistic people for over 5 years.

Key Observations

When asked about key areas that need improvement, surveyed Autistic adults were unable to pinpoint specific areas – indicating that almost all areas need attention. Surveyed non-autistic family members, service providers, and the general public placed more importance on timely diagnosis than mental health support.

Indigenous Autistic adults ranked employment services higher than other supports, and those with an intellectual disability ranked housing as a high priority. Non-autistic family members of Autistic family members with complex support needs ranked community accessibility higher.

With a wide array of areas that require attention, improvements to supports, policy, and programs had widespread acceptance among the surveyed groups – including the general public.

The data demonstrates that there is overall strong support for policy that provides meaningful and appropriate programs to help ensure that Autistic people feel seen, supported, and able to live full lives.

To ensure that there continues to be support from the public and those directly connected to autism, it is important that the voices of Autistic people are centered first and foremost. The policy recommendations and programs developed also need to be optimized for different life stages, needs, family dynamics, and socio-economic status and ensure that public support is maintained and increased through public education and awareness.

Findings

1. Social Inclusion

1.1 Stigma and Autism Acceptance

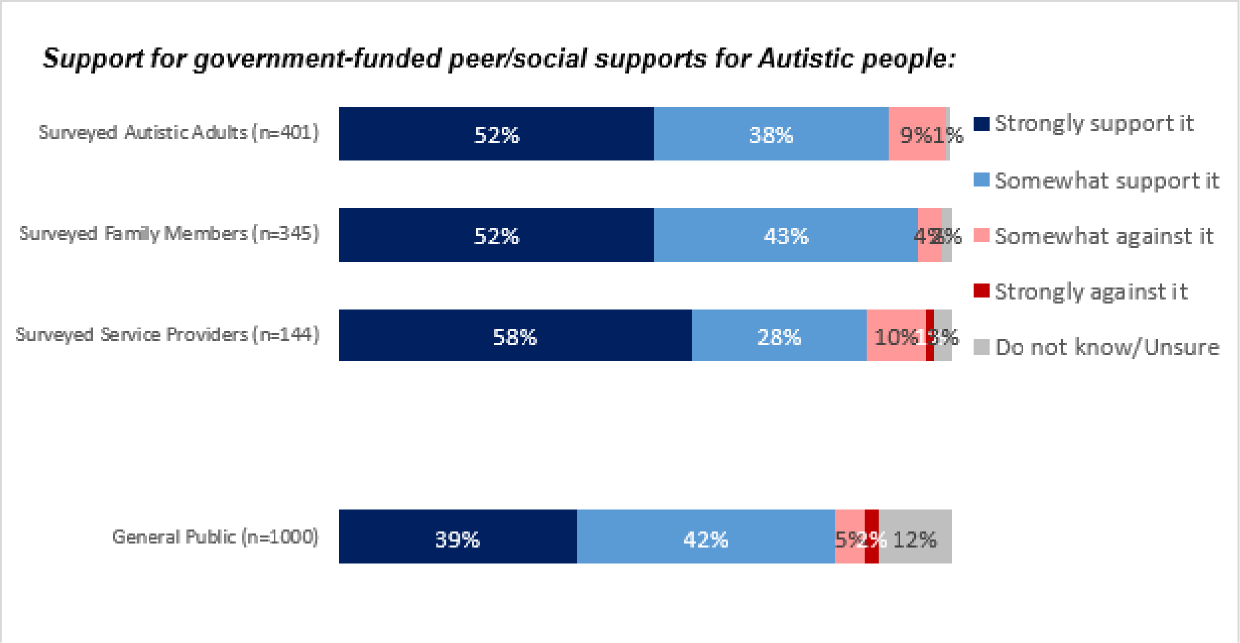
Over 6 in 10 surveyed participants – in all groups – stated that it is important for a variety of people who interact with Autistic people to be mandated to receive autism acceptance training. Surveyed service providers were especially mindful that healthcare professionals, educators and other school staff, and social service workers require training.

There was consensus among self-diagnosed, lower income, older Autistic adults and Autistic parents that there is greater importance for everyone they interact with to receive training. Non-autistic family members of Autistic family members with complex support needs also placed greater importance on more professionals to receive training.

It is important that any autism training or campaign include neurodiversity, practical tips, be co-designed by Autistic people, be sensitive to the language used, have autism-friendly signs/lists, be diverse, and strength-based.

1.2 Community Participation, Accessibility, and Education

The majority of all groups supported government-funded peer/social supports for Autistic people.



These peer/social supports should be accessible both in-person and online. They must also be available 24/7, give access to Autistic peers, and should provide support to Autistic people and their family members. Autistic adults and non-autistic family members with lower income placed more importance on all aspects of peer/social support.

2. Economic Inclusion

2.1 Economic Inclusion / Financial Stability

Surveyed Autistic adults and non-autistic family members agreed that receiving disability supports while working and expanded access to the Disability Tax Credit and a Universal Basic Income are financial programs and policies that require development.

2.2 Employment

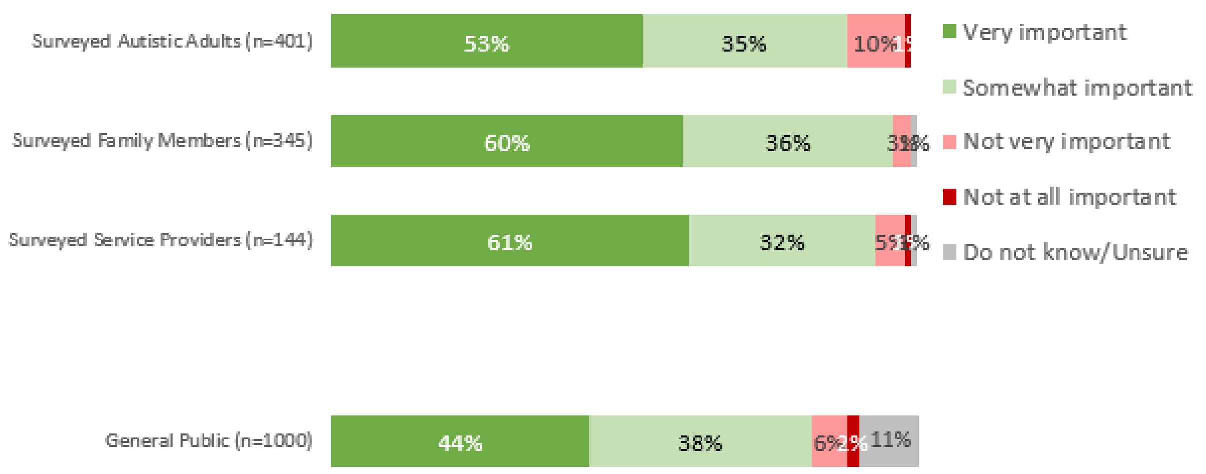
While surveyed Autistic adults would like to see a variety of programs as part of an Autism Work Experience fund, other surveyed groups believed that a program that matches the strength and skills of Autistic people with suitable jobs should be prioritized.

2.3 Models of Social Enterprise and Supportive Employment in Working Age Adults

Governments and public institutions can lead the way in the employment of Autistic people by having inclusive hiring practices and creating supportive work environments. This can then be a guide for other employers as well. Older and 2SLGBTQIA+ Autistic adults were in greater support of policies that support the employment of Autistic people.

2.4 Autism-Friendly Housing Options Across the Lifespan

All groups surveyed, particularly Autistic adults, non-autistic family members, and service providers, indicated that it is imperative that the government address the housing needs of Autistic people who require assistance for daily living.



Importance for the Canadian government to address the housing needs of Autistic people who require assistance for activities of daily living (e.g. dressing, eating, showering)

Autistic adults with intellectual or learning disabilities and non-autistic family members with Autistic family members who have complex support needs placed greater importance on addressing housing needs.

In addressing housing needs, there are several things to consider, such as financial supports, increasing residential settings, creating “autism-friendly” designations, expanding design principles, and expanding criteria for affordable housing.

Surveyed Autistic adults and non-autistic family members are most comfortable with affordable housing that is only available for Autistic people and their families.

3. Diagnosis, Supports, and Services

3.1 Adult and Child Diagnosis

With timely diagnosis being important, there was strong support for approaches to improving it; from clinic and clinician expansion to standard screening being the most supported.

Self-diagnosed Autistic adults and those with lower incomes offered stronger support for approaches that improve timely assessments, as did non-autistic family members with Autistic children.

3.2 Preschool Supports and Services

Since timely diagnosis is important, it is unsurprising that emphasis was placed upon allowing children with suspected autism (without a formal diagnosis) to have access to early supports and services, especially among surveyed service providers and the general public.

Early access to supports and services for Autistic children can take a few forms: integration into daycare and preschool with specialty support as well as specialty daycare or preschool programs. Specialty daycares were more supported by Indigenous Autistic adults, those with learning and intellectual disabilities, and non-autistic family members of Autistic children.

3.3 School-Aged Supports and Services

The majority of surveyed respondents, especially non-autistic family members, believed that it is important to have guidelines to ensure inclusive education for Autistic students in elementary and high school.

There are many things that are important to include in these guidelines, including access to health professionals, training educators, environmental adaptations, individualized education programs (IEPs), and prohibiting the use of restraints.

There was also widespread support for government-funded, autism-specific career counseling in secondary school.

3.4 Adult Supports and Services

As with guidelines in elementary and high school, it is also important for there to be Canadian guidelines to ensure inclusive education for Autistic students in vocational, college, and university programs.

Similarly, there are many things that are important to include in these guidelines to ensure inclusivity in vocational, college, and university programs – with training for teachers being the most important for all surveyed groups.

There was also widespread support for government-funded, autism-specific career counselling in vocational, college, and university programs.

Surveyed Autistic adults and non-autistic family members are likely to use all suggested solutions to help them navigate autism services and supports. A chatline or 1-800 autism number is least likely to be used, suggesting those surveyed prefer to speak with professionals. Autistic adults with an intellectual disability are more likely than others to use phone supports (peer support chatline or 1-800 number).

3.5 Health Systems

With mental health being amongst the top priority areas where attention and improvement is needed, it comes as no surprise that there was unanimous support for government-funded, mental health support for Autistic people – even amongst the general public.

There are many things to consider when developing mental health supports for Autistic people: they should be easily accessible, conducted by specially trained professionals, and available to families of Autistic people.

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