Summary
of Online Platform
(The Engagement Hub)
Stakeholder Engagement 2021

Canadian Academy of Health Sciences

Assessment on Autism

This report was developed as a working document to inform CAHS Oversight Panel and Working Group discussions

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Overview

Description of the Hub

Environics, an independent research firm, developed an open online engagement platform, which offered a variety of tools for collecting input from participants. The purpose of the Engagement Hub was to provide participants with a multi-modal, accessible, and convenient social media-style platform that allowed for structured engagement amongst stakeholders. The use of a web-based platform allowed participants to engage and return multiple times when convenient for them. The Engagement Hub was open to Autistic people, family members, and supporters[1] from April to June 2021.

Once registered, participants had the option to share their views by

(1) Taking a survey,

(2) Posting ideas about different topics, and

(3) Joining a discussion using the online chat forum.

The survey included multiple choice questions as well as space for participants to elaborate further on their response choices. The questions covered the topics of autism diagnosis, healthcare system, autism supports and services, education, human rights, communication, transportation, safety, community programs, Registered Disability Savings Plan, housing, employment, and financial stability.

The ideas page was a public forum where participants could share and respond to each others' ideas. Further, participants also had the option to show support for another participants' idea by 'liking' their comment. Separate ideas pages were made available to the different participant groups. For example, the ideas page for Autistic people was separate from that of family members. Guiding questions were made available and included the following:

- How can services and programs better meet the needs of Autistic people?
- How can we create autism-friendly community spaces?
- How can we promote inclusion of Autistic people?

Similar to the ideas page, the discussion page was a public forum where participants could engage in discussions with one another. A member of the Environics team regularly monitored the discussion page to facilitate the discussion

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[1] In the Engagement Hub, supporters were described as service providers, educators and volunteers.

by asking prompting questions. The discussions were structured around the following topics:

- Creating a society that is safe for all,
- Describe good quality of life, and
- Understanding autism and neurodiversity.

Accessibility and Mental Health Considerations

The Engagement Hub allowed participants to contribute at their own pace and at a time that was convenient for them, which made it a good option for people who require assistance to participate or for people who have intermittent access to the internet. Measures were taken to promote the accessibility of the Engagement Hub including the use of large font, plain language, web pages that were compatible with screen readers, as well as bright and contrasting colours on all of the activity pages. The website met compliance with current Accessibility for Ontarians with Disabilities Act and Web Content Accessibility Guidelines.

Recognizing that the questions asked on the Engagement Hub could elicit difficult memories or be upsetting to think about, a Canadian mental health resource list was provided to respondents in French and English at registration.

Description of Participants

There were a total of 1021 participants[2] on the Engagement Hub (375 Autistic adults, 464 family members, and 182 supporters). Participants self selected which group they wanted to join. For example, twenty one percent (21%) of the Autistic adults indicated they were parents and 47% of family members indicated they were Autistic parents. The majority of participants were from Ontario (36%), followed by British Columbia (19%), Quebec (15%), and Alberta (11%), with low participation from Nunavut (.3%) and the Northwest Territories (.3%). Table 1 provides additional self-reported information regarding participants.

	Autistic Individuals	**Family members**	**Supporters**
Total participants (N = 1021)	375	464	182
Age			
18 - 45	70%	43%	52%

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[2] Some participants may have joined more than one group, over estimating the number of individuals on the Engagement Hub.

46 +	23%	48%	36%
Language			
English	87%	86%	86%
French	13%	14%	14%
Gender			
Male	24%	10%	12%
Female	59%	88%	85%
Identity			
2SLGBTQIA+	51%	5%	9%
Newcomer to Canada (arrived in the last 10 years)	2%	2%	2%
Indigenous (First Nations, Metis, Inuit)	5%	3%	4%
Black	2%	2%	0%
Person of color	8%	6%	4%
Urbanity			
Urban centre	59%	59%	58%
Medium population centre	17%	15%	18%
Small population centre	13%	14%	15%
Rural	4%	6%	4%

Table 1. *Description of participants*. This table provides more detailed information on the characteristics of the Engagement Hub participants.

Report Organization

As previously noted, the Engagement Hub allowed participants to engage in three different ways: (1) taking a survey, (2) posting ideas about different topics, and (3) joining a discussion using the online chat forum. Information submitted through each of these platforms were carefully reviewed and analysed collectively.

The following report summarizes the qualitative findings obtained across the themes of Social Inclusion, Economic Inclusion and Diagnosis, Supports and Services. Broad statements are made in areas where there was a high level of agreement among Autistic people, family members, and other supporters. When relevant, specific participant groups (Autistic person, family member, or other supporter) are mentioned to highlight their unique perspectives.

Thematic Findings

1. Diagnosis, Supports, and Services

1.1 Adult and Child Diagnosis

Participants identified barriers to obtaining a formal diagnosis including cost, health professionals' limited knowledge, limited availability of professionals able to carry out assessments, limitations of the current diagnostic criteria and tools, as well as challenges in obtaining a referral for an assessment and navigating the system. They also noted that such system limitations often pushed families to seek out private assessments, which has resulted in financial hardship.

Some parents also talked about not having family support or being fearful themselves in seeking out a diagnosis for their child, due, in part, to prevailing stigma about autism.

To improve access to assessment for diagnosis, all participant groups indicated a need to build the capacity of services and service providers, through more interdisciplinary diagnostic teams, revising current diagnostic criteria and tools, offering the option for virtual assessments, and improving the knowledge of health professionals. They also indicated that more funding allocated towards assessments could mitigate the need for private assessments. Family members suggested universal screening practices within schools or through well-child checkups as a strategy to enable earlier identification of autism.

Participants noted that obtaining a diagnosis is often required to access services and funding. As such access to a timely diagnosis was viewed as a gateway to receiving necessary services. Autistic participants indicated that a delayed diagnosis contributed to financial hardship (i.e., in terms of not being able to access disability benefits), as well as mental health concerns.

Autistic adults and family members discussed both positive and negative experiences with autism assessments. Whether autism assessments were experienced positively or not was largely attributed to the professionals' level of understanding of autism and the degree to which Autistic adults and their family members felt heard and validated. Some suggested that having an Autistic peer support on the assessment team would be helpful. They indicated that having post-diagnostic support (such as having a service plan, being referred to supports, and/or receiving follow-up) was helpful. However, this was often not available, leaving individuals and families with minimal guidance and having to do their own search for supports and services.

Both family members and supporters described incidents of disagreement during assessment processes. Service providers noted that families sometimes disagree with the diagnosis they provide, while conversely families expressed feeling judged or that their concerns are not always taken seriously.

Autistic adults identified multiple reasons for seeking out a formal diagnosis including experiencing difficulty coping with life events or feeling different and wanting to understand why. Encouragement from family and friends as well as personal learning about autism were facilitators for some Autistic participants to seek a formal diagnosis. Many Autistic participants indicated that obtaining a formal diagnosis led to greater understanding from others, contributed to self-acceptance, and allowed them to meet other Autistic people.

Some participants from across the other stakeholder groups suggested that only formal diagnoses should be recognized. However, many Autistic adults indicated that it was important to legitimize self-diagnoses as obtaining a formal diagnosis can be difficult, particularly for adults. Family members also noted the many barriers in obtaining a formal autism diagnosis, and understood this could be a reason for self-diagnoses. Self-diagnosed Autistic participants described having to do their own research and seeking online resources to confirm their diagnosis.

1.2 Health Systems

1.2.1 Health and Allied Health

All participant groups acknowledged that Autistic people and their families often go without needed supports and services (including occupational therapy, speech-language pathology, physiotherapy, and mental health supports). These supports along with others are often costly and, when accessed privately, can contribute to financial hardship. Some family members and other supporters suggested that autism services and supports should be covered under provincial health plans.

Both Autistic adults and family members expressed a lack of trust in the health system due to experiences of discrimination and biases held by health professionals. This sometimes led Autistic people to avoid seeking required medical care. Family members described the efforts they made advocating for their Autistic family member when seeking healthcare. Many expressed feeling alone and unsupported during this process. Some Autistic adults described feeling a need to bring an advocate or supporter with them to appointments in order to be taken seriously or to avoid maltreatment. Family members highlighted that the use of restraints and the involvement of public safety personnel could represent safety concerns for Autistic people when accessing emergency health services.

Cited barriers to accessing health services included requiring a referral from a health professional, lack of coordination across health services, cost and long wait times. Further, supports for Autistic adults are particularly limited as their needs remain largely overlooked. Family members expressed concern over the lack of systems in place to enable supported decision-making. Family members also highlighted that the health system lacks resources and many healthcare providers are overworked, leading to 'quick-fixes' as opposed to addressing root causes of health problems.

Lack of knowledge about autism including sensory and communication differences was also seen as a barrier to accessing health services. Autistic participants indicated that health providers did not give them enough time to express themselves. Additionally, the stress and overstimulation of being in healthcare settings often contributed to communication difficulties. Many service providers expressed concern over their lack of training and a desire to receive more education about autism and neurodiversity.

Suggestions made to improve the health system included providing universal health coverage (including covering dental and eye care), improving training for health professionals, easier navigation of the health system, using strength-based approaches, and promoting self-determination.

1.2.2 Mental Health

All participant groups noted that Autistic people encounter multiple barriers to accessing mental health support including cost, autism diagnosis being an exclusionary criterion for accessing public mental health supports, health professionals' limited knowledge and capacity to support Autistic people, and limited availability of mental health services which contribute to long wait times.

When mental health services are accessed, Autistic participants expressed concern that medications are often prescribed before alternative solutions are fully explored. All participant groups indicated a need to improve access to mental health services for Autistic people. Other supporters highlighted that mental health concerns often stem from traumatic experiences of stigma and exclusion (i.e., related to persistent bullying). Participants suggested a need for more funded mental health supports that are culturally-relevant and neuro-affirming. Both Autistic adults and other supporters suggested that encouraging and enabling more Autistic people to work in the field of mental health could contribute to improved services. To support Autistic people in crisis situations, Autistic adults expressed a need for autism-specific crisis lines, while both family members and Autistic adults suggested having civilian-based crisis response teams available in the community.

1.3 Supports and Services

Families felt that they often had to try out multiple supports and services to determine the best fit for their Autistic family member. This trial and error approach contributed to high costs.

There were mixed views on Applied Behavioural Therapy (ABA). Some Autistic participants described negative experiences with ABA, while some family members found that ABA enabled their Autistic family member to learn important life skills.

Both family members and Autistic adults expressed concerns around the implementation and fidelity of behavioural interventions. Family members and other supporters indicated that these interventions require improved regulation to ensure their quality.

All participant groups expressed a need for more evidence-informed therapies in addition to ABA, available across environments, including home and school settings. For example, other supporters suggested that services and supports should have a greater focus on addressing Autistic people's communication needs. These services should be provided by trained professionals such as speech-language pathologists and should honour all forms of communication.

2. Economic Inclusion

2.1 Autism-Friendly Housing Options Across Lifespan

Most participants expressed a preference for dispersed, community-based housing, which they describe as being:

- In proximity of or with access to services, work, school, and social activities, and
- Well-connected to transportation and green spaces.

While dispersed and independent living was preferred by many, some family members described the need and value of residential service models, such as group homes, particularly for Autistic individuals with more complex support needs. These participants suggested that these settings should be home-like rather than having an institutional feel or look.

All participant groups highlighted the limited availability of all community-based housing and residential options. They expressed a need for more affordable supported living arrangements that fall along a continuum and that offer wrap-around services and supports to meet a diversity of needs. Examples of needed housing supports included: self-care and daily life planning, cleaning services, managing finances, and regular emotional support check-ins. Autistic adults and family members expressed a desire to have options so that they can choose the most appropriate arrangements to meet their needs. They also expressed wanting more support to find suitable housing and supports.

Autistic adults described *safe* housing as long-term, stable living arrangements in spaces that are clean and comfortable and located in safe neighborhoods where Autistic people are accepted and protected. Autistic adults suggested incentivizing developers to work with Autistic people and Autistic-led organizations to create autism-friendly housing that incorporates universal design principles and meets accessibility needs of Autistic people (such as sensory, physical, social and communication, and chemical considerations). Further, Autistic adults emphasized the importance for buildings to be pet-friendly as many of them rely on their pets for support. Autistic adults and their families also indicated that home modifications are often needed, which can be costly and that additional funding to offset these costs can be helpful.

Family members frequently expressed worry and concern over their adult child’s ability to live alone without necessary supports once they are no longer around to support them. Some families recognize that their child will likely live with them their entire life. However, these families expressed a need for more supports for their Autistic family member (such as funding, assistance with home care, and respite) in order to continue their caregiving role. In addition to improving access to independent living supports, Autistic adults and families suggested that life skills training along with peer mentorship programs could be particularly beneficial. Family members also proposed having transitional housing arrangements that can prepare Autistic people for more independent living.

2.2 Employment

There was general consensus that Autistic people experience high rates of unemployment and underemployment. Family members noted that even with a post-secondary education, many Autistic adults remain unemployed. Identified barriers to obtaining and maintaining employment from the perspective of Autistic adults and family members included:

- Misconceptions held by employers about autism as well as stigma and discrimination in the workplace,
- Autistic people’s accommodation needs not being met,
- Concerns regarding potential loss of government income benefits, and
- Social and communication challenges that often lead to workplace miscommunication or misunderstandings.

All participant groups indicated a need to promote more quality employment opportunities for Autistic people that offer appropriate compensation and full-time/permanent positions. Offering incentives for employers to hire Autistic people, providing education and training to employers and other colleagues about autism, and allocating jobs specifically for Autistic and/or disabled people were suggested as ways to increase employment opportunities for Autistic people.

There was also agreement that Autistic workers often do not receive the workplace accommodations they need. Autistic adults indicated that having the option to work from home, paid sick leave or mental health days, flexible working hours, and a quiet space to work are some potentially helpful accommodations. They also noted, however, that employers often have a lack of understanding of why accommodations are needed and how to provide these accommodations. Autistic adults emphasized that a lack of workplace accommodations can contribute to burnout or mental health concerns. Other supporters noted that greater protection for Autistic employees is needed, including legislation that is appropriately enforced. This would ensure that necessary accommodations are provided and that Autistic workers are protected from human rights violations and workplace discrimination.

Participants also provided suggestions on employment services that could be helpful, such as:

- Support in finding a suitable and meaningful position,
- Vocational or career planning,
- Mentorship programs with Autistic role models/mentors,
- Training on workplace social etiquette and on requesting accommodations, and
- More co-op and internship opportunities.

2.3 Financial Security

Many Autistic adults and family members indicated that they were struggling to meet basic needs, and at times, living below the poverty line. This financial instability could make it challenging to access needed diagnostic and support services. Family members noted that supporting an Autistic child can make it difficult to take up or maintain full-time employment, which can exacerbate existing financial challenges. They indicated that having legislation and policies in place for parents that allow for more flexible working hours might enable them to maintain their employment while supporting an Autistic child.

All participant groups noted that government financial assistance programs are often difficult to access due to complicated application processes and narrow eligibility criteria. When Autistic people and families were able to access these programs, they often felt that the funding provided was insufficient. Many continued to live below the poverty line. Further, all participant groups have noted that the loss of benefits that occurs when Autistic people get married not only represents a significant barrier to accessing funding, but also creates inequities for those who continue to need financial assistance.

All participant groups suggested that more needs to be done to ensure that Autistic people can meet basic needs, whether that is through universal basic income or improving government financial assistance programs. Other supporters noted that access to government financial assistance programs could be improved by:

- Increased availability of funding,
- Shorter waitlists, and
- Streamlining the application process.

Autistic adults would like to see more direct funding options so they can choose how they spend the funds. Other supporters noted, however, that providing funding to service agencies may be beneficial as families are not always aware of direct funding opportunities available to them, and management of these processes can be taxing to families or individuals. Both Autistic adults and family members also noted that Autistic people may require additional support to manage their finances through financial literacy training or access to support persons.

All participant groups recognized the benefits of contributing to a Registered Disability Saving Plan (RDSP) as a means to plan for the future. Many family members suggested that the RDSP can offer them a peace of mind about the future. However, many Autistic adults, family members, and other supporters did not feel well-informed about the RDSP and how to access it. They indicated a need for clearer and more accessible information.

Having to qualify for the Disability Tax Credit (DTC) was identified as one of the main barriers to accessing RDSP. Participants noted that the DTC uses a more restrictive definition of disability, which was suggested to render some Autistic people ineligible. Autistic adults and families also discussed the hassle of annual reassessments since the DTC does not recognize autism as a lifelong condition.

All participant groups expressed a desire for more flexibility in making contributions to and withdrawing funds from the RDSP. They suggested:

- Increasing the maximum amount that individuals can contribute,

- Removing cut-off dates for making contributions, and
- Allowing people to withdraw money sooner to pay for things like a house, daily living supports, or post-secondary education.

Autistic adults and family members would also like to see increased government contributions through bonds and grants.

2.4 Post-secondary Education

Autistic adults discussed many barriers to completing post-secondary education including cost of education, a lack of support and/or accommodations, and not being adequately prepared for college/university life. Other supporters suggested that education grants and publicly-funded college or university studies can make post-secondary education more affordable for Autistic people. Autistic adults also noted that additional funding for students, along with more autism training for post-secondary staff and professors can promote greater inclusion of Autistic students in post-secondary settings. Autistic people and other supporters identified helpful supports and accommodations such as:

- The option for online studies,
- Greater flexibility in how students complete their degrees,
- Access to supports to apply for grants and student loans,
- Improved disability services, and
- Peer support and mentorship.

Autistic adults and other supporters also expressed a need for more programs and course options that meet the interests and strengths of Autistic people, as well as more flexible qualification processes.

2.5 Life Transitions and Emerging Adulthood

Participants highlighted domains where more support for Autistic adults may be warranted, such as supports for social skills, sensory processing, life skills, relationship and sexual health, executive functioning, mental health and self-regulation, and self-advocacy. Such supports could be provided through case managers, personal support workers, advocates, and service animals.

Support for families was also highlighted as an integral, but often overlooked area of need. Family members discussed playing significant roles in supporting their Autistic family member, which can contribute to mental health concerns and experiences of burnout. Services such as respite, mental health supports for the entire family, family coaching and peer support were recommended.

Participants indicated that Autistic adults and families encounter barriers to accessing services such as:

- Cost,
- Long wait times for publicly-funded services,
- Service providers’ limited knowledge and understanding of autism,
- Narrow eligibility criteria (such as age, requiring a diagnosis, intellectual quotient cut-offs, level of functioning),
- Challenges in navigating the system to identify appropriate supports,
- Language and communication barriers,
- Sensory barriers,
- Minimal access to transportation,
- Services not being reliable or consistent, and
- Challenges introduced by the COVID-19 pandemic.

Further, the limited availability of supports for adolescents and adults was highlighted as a key service gap which, from the perspective of Autistic adults, cumulatively impacted quality of life and financial stability over their lifespan.

Other supporters indicated that accessing services can be facilitated through up-to-date and readily available information and systems navigators to provide guidance, such as social workers. Family members indicated that improved service coordination across provinces/territories and regions is greatly needed. All participant groups also highlighted the importance of offering a range of supports to meet diverse needs and giving families options to identify the services that best meet their needs.

To improve the quality of services, participants emphasized the importance of building the capacity of service providers as many hold biases, have limited knowledge about autism and neurodiversity or may not know how to support Autistic people. Services that are tailored to individual needs, adopt strength-based and neuro-affirming approaches, and focus on improving quality of life as opposed to ‘fixing’ Autistic people were recommended. Autistic adults and family members also expressed a preference for services that are Autistic-led or developed collaboratively with service users.

3. Social Inclusion

3.1 Community Participation and Accessibility

3.1.1 Transportation

Family members and other supporters noted that transportation can be either a barrier or facilitator to community participation. Family members, particularly parents, suggested that they are heavily relied upon to drive their Autistic family member around. This message was reinforced by Autistic adults, who noted that a lack of affordable and accessible transportation was a barrier to accessing programs and services, particularly in small or remote communities.

Some Autistic adults expressed a desire to drive, but felt that misconceptions about their driving ability was a barrier to obtaining their license. All participant groups noted that drivers' education programs can be made more accessible by:

- Providing training to driving instructors about autism,
- Offering accessibility considerations (to accommodate sensory and spatial processing challenges), and
- Allowing Autistic people more time to complete their course/take their test.

Other barriers to driving that Autistic adults and family members mentioned included transportation costs and limited access to accessible parking spots for Autistic people.

The need for more dedicated funding to strengthen and improve public transportation infrastructure to be more reliable, available, and accessible was highlighted by all participant groups. The need for more support to navigate the public transportation system, which can be a challenge for some Autistic people, was also emphasized. Participants also expressed a need for more direct funding to Autistic people to cover the cost of public transportation services, as well as supports and special equipment they may need to use public transportation.

The safety of Autistic people on public transportation was of particular concern for all participant groups. Other supporters indicated a need to improve public awareness and acceptance of Autistic people and to train drivers on understanding autism and supporting Autistic people with complex support needs. Further, they suggested working with transportation services (including airports and airlines) to make spaces more autism-friendly. Family members recommended the use of autism alerts or identifiers as a tool to communicate some basic, but important information about the Autistic individual. Safety on school buses was another area of transportation concern for many family members. They indicated a need for greater bullying prevention, training drivers on supporting Autistic students, and ensuring appropriate accommodations and safety mechanisms.

Finally, many participants noted that public transportation may not be a safe or accessible option for some Autistic people due to sensory challenges and/or behaviours that challenge. Alternatively, participants suggested that taxis and ridesharing services may be more suitable options. Autistic adults also indicated that housing in close proximity of needed services and resources can reduce their need for transportation services.

3.1.2 Accessibility

Autistic adults and family members discussed the need to improve and enforce accessibility measures in public spaces to promote the inclusion and participation of Autistic people. Sensory accessibility was highlighted by all participant groups as a key area of consideration that is often overlooked. Other accessibility considerations included communication and information accessibility (such as the use of plain language) and physical accessibility (such as access to changing tables that can accommodate larger children and adults). It was also noted that accessibility accommodations can contribute to financial hardship for Autistic people and their families as sensory equipment and other assistive devices can be costly.

3.1.3 Communication

Autistic adults identified several communication challenges including difficulty communicating verbally when overwhelmed. This can occur in healthcare settings or when interacting with public safety personnel. Other supporters and family members noted that communication challenges, including difficulty expressing oneself or not feeling understood, can lead to frustration that can sometimes manifest itself through behaviours that challenge. In these situations, they noted that the focus tends to be on managing the behaviours as opposed to addressing the communication breakdown that may be at the root of the behaviour.

All participant groups suggested that communication with Autistic people could be improved if the general public was more accepting of diverse ways of communicating. There was recognition of prevailing stigma towards non-verbal forms of communication.

Some tips for improving communication included:

- Checking in for understanding more frequently,
- Offering alternatives to verbal communication (such as written communication options, alternatives to phone calls, closed captioning),
- Giving extra processing time and patience,

- Being more direct and specific, and
- Using plain language.

Autistic adults also indicated that having a support person with them to help them communicate their needs was often helpful.

The use of augmentative and alternative communication (AAC) devices were also suggested to facilitate communication for many Autistic people, however, family members and other supporters noted several barriers to accessing these supports, such as costs, waitlists, and eligibility criteria. Furthermore, service providers' may have limited knowledge of AAC tools and thus do not promote diverse communication methods. Families also suggested there is a lack of guidance for families on how to support Autistic family members in communicating. Suggested communication services that could be helpful included routine vision and hearing tests, speech-language pathology, occupational therapy, functional communication training, sign language classes, and social skills training.

3.1.4 Community Participation

All participant groups talked about the importance of fostering meaningful inclusion, where Autistic people have opportunities and are supported to participate and meaningfully contribute to their communities (i.e., through work, volunteer, research, and peer support). All participant groups indicated a need for more public education and awareness about autism and specific training for community program leaders. Involvement of Autistic people and their families in this public education was recommended.

Other supporters and Autistic adults also noted that community programs and spaces could be more sensory-friendly by having fewer people, reducing noise, improving temperature regulation, dimming lighting, having a no-scent policy, and offering low sensory hours. Autistic people and family members suggested that many Autistic people feel unwelcome in community programs. For instance, peers may be judgemental or not accepting of differences. They noted that information about existing community programs, with details about the program and what is involved in participating, could help Autistic participants better prepare before attending.

Other tips for involving Autistic people in programs, included:

- Developing peer or buddy systems,
- Offering breaks from socializing, and
- Being around like-minded individuals.

Family members also emphasized particular safety considerations such as having enclosed areas as some Autistic participants may wander, as well as having safety protocols in place in the event that a participant is feeling overwhelmed.

Autistic adults and family members expressed a need for more community programs/activities, camps, and day programs that are affordable, accepting of Autistic participants, and offer needed supports and accommodations. They also indicated a need for more collaborative or Autistic-led programming including peer support and advocacy groups.

3.1.5 Citizen Engagement and Shared Decision-Making

There was consensus that multiple stakeholder groups (including Autistic people, family members, and other supporters) should be involved in program and policy decisions about autism programs. It was especially highlighted that the perspectives of diverse Autistic people (both those with and without co-occurring intellectual disability) should be prioritized. Autistic people also noted that when consulted, they should be appropriately compensated for their time and contributions.

3.2 Education

Overall, participants expressed a preference for inclusive education as opposed to segregated classrooms or programs. They also recognized that resource limitations, particularly within the public school system, contribute to a lack of support and accommodations to enable Autistic students to be meaningfully included within mainstream education programs. As such, some family members and other supporters noted that special education classrooms and programs can offer certain advantages such as access to more one-on-one support and smaller class sizes. Further, many family members described feeling they had no other choice but to enrol their child in private schools due to the lack of support in the public school system. This shift could contribute to significant financial hardship for families, as well as inequities for families who cannot afford the cost.

Autistic adults identified sensory challenges and group projects or presentations as areas of difficulty in schools. Family members and Autistic adults noted that the needs of certain Autistic students are often overlooked, particularly for those who are deemed to be ‘high functioning’, who do not disrupt the class, who do well academically, or who are able to mask well. Many family members also felt that schools were not always willing to involve them in their child’s education planning. At times, when their Autistic child was struggling, they felt blamed.

Family members and other supporters discussed further educational challenges that emerged as a result of the COVID-19 pandemic including:

- A lack of educational supports for Autistic students at home,
- Previously offered school services (such as occupational therapy and speech-language pathology) being placed on hold, and
- Abrupt changes to the school schedule.

Some Autistic adults felt that the lack of structure associated with online learning presented a challenge, while others enjoyed the flexibility of learning at their own pace and within the comfort of their homes.

All participant groups recognized that Autistic students do not always feel safe in schools. For instance, the use of restraints and seclusion, and school exclusion were described as harmful practices still in use. Further, participants noted that Autistic students experience challenges making friends and are often bullied or excluded by their peers. As such, it was recommended that all children be taught early on about diversity so that they be more accepting of differences. Autistic adults and family members indicated that negative school experiences can contribute to trauma and experiences of burnout and/or other mental health concerns, which can lead to Autistic students having to drop out of school.

On the other hand, Autistic adults and family members identified several factors that contribute to positive school experiences, such as:

- Openness of teachers and educational assistants to understanding the needs of an Autistic student,
- Staff fostering a trusting relationship with the student and their family,
- Using strength-based approaches and individualized teaching strategies,
- Advocating for the student and encouraging the student to self-advocate, and
- Being flexible to accommodate the students’ needs.

Further, Autistic adults and family members emphasized the importance of having appropriate expectations for Autistic students and ensuring that they are sufficiently challenged so that they can obtain a meaningful education.

Family members and other supporters identified several helpful classroom accommodations such as:

- Being sensitive to sensory and communication differences,
- Providing access to necessary assistive equipment and technology,
- Adapting teaching methods to various learning styles, and

- Offering more flexible ways for students to complete their work or degree requirements.

They also suggested mandating accommodations in schools so that students are not sent home when their needs cannot be accommodated, which, as stakeholders noted, can place parents in a difficult situation as they have to leave work unexpectedly to pick up their child from school.

Participants emphasized the importance of having access to a range of school services such as individualized education plans, psychoeducational assessments, educational assistants, communication supports, socialization support, occupational therapy, physiotherapy, speech-language pathology, behavioural-based supports, and mental health supports. Other supporters also suggested that offering structured skill-based playgroups can enable Autistic students to learn new skills and generalize them to different settings. Further, they recommend having high school, college, or university preparatory classes to better prepare Autistic students for the next phase of their education. Family members further noted that experiential learning opportunities and job skills training can help Autistic students transition from school to work.

Finally, there was general consensus that educators require better training to support and accommodate Autistic students. Suggested content for such training included:

- How to make accommodations,
- Adapting teaching strategies to individual students,
- Understanding the root causes of behaviours as opposed to just managing them, and
- Understanding and attending to sensory and communication differences.

3.3 Human Rights and Public Safety

All participant groups noted that Autistic people are more likely than others to experience violence and abuse. They may be particularly vulnerable to being taken advantage of – a significant concern for family members. Autistic adults noted that they are often reliant on others for care and/or financial support, which can sometimes lead them to remain in unsafe situations, such as abusive relationships, just to have their basic needs met.

All participant groups acknowledged that Autistic people deserve to live dignified lives, but currently experience inequitable treatment and have fewer opportunities to participate in society. All participant groups indicated a need for greater protection of Autistic people against experiences of abuse and discrimination, maltreatment, and other human rights violations. Such protection may include explicitly mentioning Autistic people in human rights legislation and having appropriate measures in place to ensure enforcement and accountability.

To improve community safety, Autistic people suggested designing community crisis protocols in consultation with Autistic people that could offer safe spaces for Autistic people in times of crisis. From their perspective, these protocols could serve as a safer alternative to involving law enforcement. Autistic people also indicated that access to service animals could help them feel safer. The use of autism identifiers/status cards (such as the Sunflower Lanyard Program introduced in the United Kingdom and recently implemented at Pearson Airport in Toronto) with information about the Autistic person was suggested by all participant groups as a way to improve community safety, particularly in interactions with public safety personnel or other authority figures. Family members noted that law enforcement has a role to play in ensuring the safety of Autistic people, but that Autistic people frequently have negative interactions with them. All participant groups emphasized the need for more education and training for law enforcement to better support Autistic people, particularly in the event of a mental health crisis.

All participants groups also recognized the importance of providing Autistic people with the tools to self-advocate and to make their own decisions, along with appropriate legal and advocacy support. Examples of such tools or processes suggested by stakeholders included:

- Being taught about healthy relationships and rights,
- Having support to leave abusive situations,
- Having more accessible pathways to report human rights violations, and
- Having a support person to help with advocacy, seeking justice, and decision-making.

3.4 Stigma and Autism Acceptance

Autistic adults indicated that stigma and discrimination are key barriers to accessing needed supports, services, and opportunities. Further, a lack of community acceptance often leaves them feeling unsafe to be themselves, creating pressures to mask their autism traits in order to fit in. All participant groups indicated a need to move beyond autism awareness towards fostering greater public acceptance of autism. From their perspective, moving towards acceptance requires a change in narrative from one that views autism as something that requires fixing or a cure, to respecting and valuing Autistic ways of being. In this regard, public education about autism and neurodiversity as well as training for specific professionals was mentioned by all participants as being critically needed.

Autistic adults and family members highlighted the importance of having diverse representations of Autistic people in media and in other forums to avoid perpetuating stereotypes and to foster a greater recognition of the diversity that exists among Autistic people. Autistic adults noted that wider societal acceptance of their differences and more positive representations of Autistic people can contribute to greater self-acceptance and pride among Autistic people. In line with this thinking, Autistic adults and family members noted that adopting an intersectionality lens is needed given that experiences of social advantage or disadvantage are influenced by other aspects of an individual's identity. These other identities intersect with autism to create unique experiences and contribute to particular challenges or opportunities.

4. Cross-Cutting Themes

4.1 Governance

All participant groups indicated that for a national autism strategy to be useful, it should:

- Reflect the diversity of needs of Autistic people and their families,
- Lead to concrete actions that improve their quality of life,
- Be accompanied by mechanisms to hold the government accountable,
- Be flexible enough so that it can be tailored to local contexts, and
- Provide pan-Canadian standards, coordination and leadership.

Autistic adults and family members further highlighted the importance of adopting a disability justice, and Equity, Diversity, and Inclusion lens to policy and decision-making. All participant groups stressed the importance of ensuring that a national autism strategy be accompanied by adequate and equitable funding. All participant groups noted that the national autism strategy should be developed in collaboration with diverse stakeholders and that the voices of Autistic people should be prioritized.

4.2 Research

Participants indicated that more research was needed to understand co-occurring conditions/comorbidities, the different presentation of autism traits, and the experiences of diverse Autistic people. Some family members expressed an interest in research to better understand the factors that contribute to autism and to improve supports and services for Autistic people. Autistic adults mentioned a need for research to focus more on improving quality of life for Autistic people. Family members and Autistic adults emphasized the importance of strengthening research ethical standards, ensuring that research is being translated and applied in practice, as well as promoting a greater involvement of Autistic people in autism research.