VIRTUAL STAKEHOLDER CONSULTATIONS

Prepared for CAHS by Audrey Wubbenhorst
2021

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

Table of Contents

Virtual Stakeholder Consultations

Two series of zoom-based stakeholder consultations were carried out by Audrey Wubbenhorst and Leena Sharma Seth, third-party engagement specialists, as part of the stakeholder engagement process for the CAHS' Assessment on Autism. Zoom was chosen due to its access and accessibility features, which are described in greater detail below. The first series of consultations sessions (Community Conversations) ran from April to June 2021, where participants were asked to provide feedback on services and programs for Autistic people as well as fostering inclusion. The second series of consultation sessions (Policy Discussions) took place in July 2021 and aimed to obtain stakeholder perspectives on potential solutions-focused strategies and approaches across the assessment themes of Social Inclusion, Diagnosis, Services, and Supports, and Economic Inclusion.

Key considerations were made to promote accessibility and participant safety:

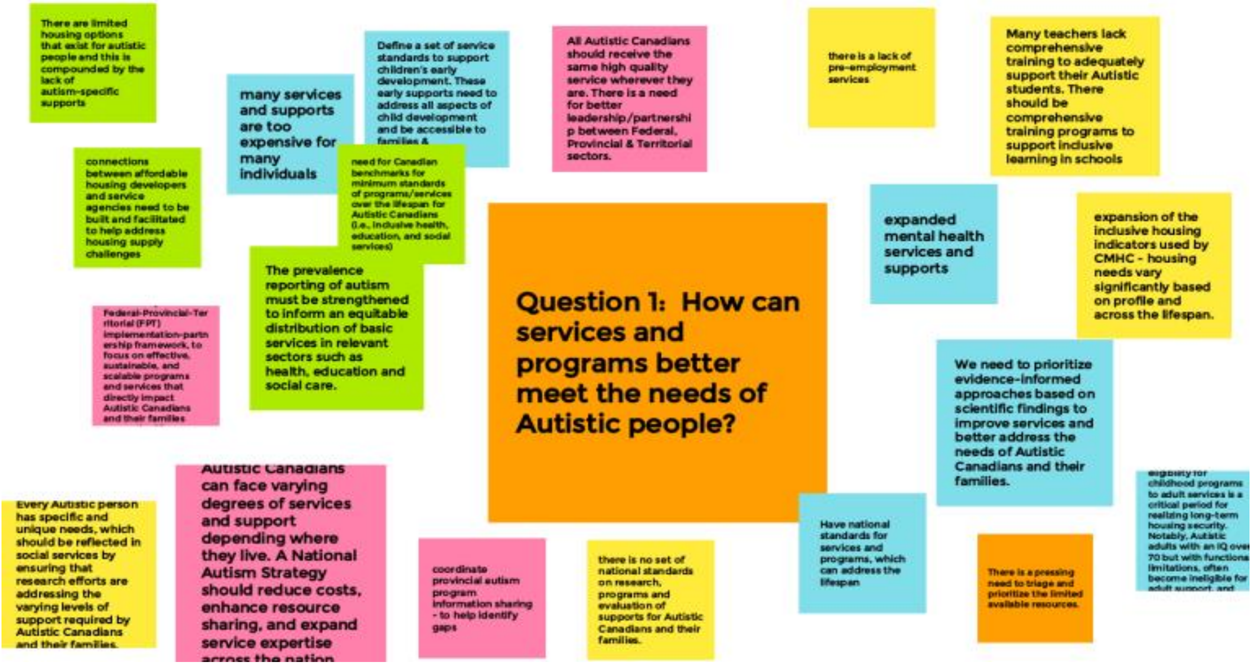
Accessibility Considerations

The following considerations were made to ensure that the virtual meetings were as accessible as possible:

- The Zoom platform allowed for participants to either phone in or use internet connections,
- Participants could request accessibility accommodations in advance. American Sign Language/Langue des signes québécoise interpretation was provided on request,
- Closed captioning was enabled for the majority of the meetings,
- The Zoom platform supports common screen readers. Presentation slides were posted in the chat to use with screen readers and/or for participants to use as reference,
- During the breakout sessions, participants could provide input by speaking, writing, or using their augmentative and alternative communication devices,
- Participants' personal information was not shared publicly, and
- Participants were advised that they did not need to enable their videos.

Further, the sessions were designed for a wide range of communication styles and preferences. There were several ways that participants could provide feedback during the meeting:

- *By speaking:* The facilitator provided a speaking order at the start of the session to ensure that everyone had a chance to answer the question and circled back to participants for additional thoughts.
- *On a Google Jamboard (sample in Figure 1 below):* Each breakout room had its own Jamboard where participants could add "sticky" notes with their ideas and thoughts, as well as build on other participants' ideas.
- *Through the Zoom chat:* Participants could provide their thoughts and contribute to the conversation through the chat function, while others were speaking. Some participants who used augmentative and alternative communication devices provided feedback through the Zoom chat function, while others provided feedback using their devices with audio by unmuting their microphones.



There are limited housing options that exist for autistic people and this is compounded by the lack of autism-specific supports

many services and supports are too expensive for many individuals

Define a set of service standards to support children's early development. These early supports need to address all aspects of child development and be accessible to families &

All Autistic Canadians should receive the same high quality service wherever they are. There is a need for better leadership/partnership between Federal, Provincial & Territorial sectors.

there is a lack of pre-employment services

Many teachers lack comprehensive training to adequately support their Autistic students. There should be comprehensive training programs to support inclusive learning in schools

connections between affordable housing developers and service agencies need to be built and facilitated to help address housing supply challenges

need for Canadian benchmarks for minimum standards of programs/services over the lifespan for Autistic Canadians (i.e., inclusive health, education, and social services)

expanded mental health services and supports

expansion of the inclusive housing indicators used by CMHC - housing needs vary significantly based on profile and across the lifespan.

Federal-Provincial-Territorial (FPT) implementation-partnership framework, to focus on effective, sustainable, and scalable programs and services that directly impact Autistic Canadians and their families

The prevalence reporting of autism must be strengthened to inform an equitable distribution of basic services in relevant sectors such as health, education and social care.

Question 1: How can services and programs better meet the needs of Autistic people?

We need to prioritize evidence-informed approaches based on scientific findings to improve services and better address the needs of Autistic Canadians and their families.

Every Autistic person has specific and unique needs, which should be reflected in social services by ensuring that research efforts are addressing the varying levels of support required by Autistic Canadians and their families.

Autistic Canadians can face varying degrees of services and support depending where they live. A National Autism Strategy should reduce costs, enhance resource sharing, and expand service expertise across the nation

coordinate provincial autism program information sharing - to help identify gaps

there is no set of national standards on research, programs and evaluation of supports for Autistic Canadians and their families.

Have national standards for services and programs, which can address the lifespan

There is a pressing need to triage and prioritize the limited available resources.

eligibility for childhood programs to adult services is a critical period for realizing long-term housing security. Notably, Autistic adults with an IQ ove 70 but with functiona limitations, often become ineligible for adult support, and

Figure 1: Sample Jamboard for Illustrative Purposes

Safety Considerations

In advance of and at the start of each meeting, the following engagement guidelines were reviewed to foster a safe space for discussion:

- *Ask for what you need. Give what you can. Take care of yourself and honour your needs.*
- *Conversations in the breakout sessions are confidential. Please do not share with anyone outside of the meeting.*
- *Please be respectful to others. People have different views and that is okay.*
- *Bullying, abusive, or threatening behaviour is not acceptable. If we feel that a participant is behaving this way, we will ask them to leave the session right away.*

To promote maximal participation and emotional safety, participants were typically divided into smaller breakout rooms (less than 15 participants), each led by a trained facilitator. Where possible, participants were divided in advance into three discrete groups based on how participants identified themselves during the registration process:

- Autistic people,
- Non-autistic family members of Autistic individuals, and
- Service providers and organizations – these included a wide range of service providers representing agencies, educators and professions (occupational therapy, psychology), researchers, and organizations working within the Autistic community.

Further, recognizing that the conversations could be difficult for participants, each session had one or two separate breakout rooms staffed by an Autistic peer support person. Although it was seldom used, participants were made aware that this support was available to them if needed. As well, a mental health resource list was provided in French and English as part of the registration process.

Methodology for Collecting Information

Prior to the sessions, participants were notified that the sessions would not be recorded to encourage participation and confidentiality of the information shared. However, in each session, facilitators took notes to try to record as much detail as possible on the verbal conversation, which allowed for the extraction of personal narratives to help illustrate key points that emerged from the consultations. Jamboard and chats were also saved if participants used these methods to communicate. Files were kept for each session and were reviewed.

The following reports provide a summary of the key findings emerging from the Community Conversations and Policy Discussions.

VIRTUAL STAKEHOLDER CONSULTATIONS SUMMARY OF COMMUNITY CONVERSATIONS

April - June 2021

Prepared for CAHS by Audrey Wubbenhorst
June 30, 2021

Community Conversation Overview

The Canadian Academy of Health Sciences (CAHS) ran 22 virtual Community Conversations between April 22 and June 5, 2021. These conversations were 90 - 120 min Zoom meetings where participants were invited to provide feedback into two key questions:

- How can services and programs better meet the needs of Autistic people?
- How can we promote inclusion of Autistic people?

These questions were sent to participants in advance of the meetings and many participants prepared answers in advance of the sessions. Facilitators prepared prompts for each question to stimulate conversation and ensure that a wide range of topics were covered.

Participants were invited to take part in the discussions through a multi-pronged communications strategy, which included:

- A distribution list of organizations which included service providers, researchers and government contacts,
- Information made available on the CAHS website,
- Social media posts through CAHS' social media account, and
- A Facebook page that was set up for the events.

Participants registered in advance of each session. The sessions were scheduled to account for both geographic locations and for specific, in-depth sessions with equity-seeking groups as an opportunity to amplify voices that have traditionally been overlooked. Not atypical for online events, 58% of registrants attended the sessions meaning that we had about a 42% attrition rate.

Session Format

In early April, the facilitation team tested the Community Conversation format with CAHS' Lived Experience Advisory Committee to ensure that the format was conducive to Autistic people and their families.

The conversations were structured to maximize participation and ensure that everyone felt heard in a safe space. The format of each session was identical. There was a brief, opening session covering logistics, the process and participants were welcomed by a member of CAHS' Lived Experience Advisory Committee. The introductory remarks described the structure of the session and informed participants of other stakeholder engagement platforms (such as the Engagement Hub) through which they could provide their feedback as well as how the information would be used and reported back to CAHS. The session then moved to small breakout rooms, each led by a facilitator.

Making Space for Marginalized Voices

Autistic people are diverse and have a range of needs, interests, and perspectives. Based on consultation with the CAHS' Lived Experience Advisory Committee, the following groups were selected for specific in-depth sessions:

- 2SLGBTQIA+,
- Autistic parents,
- Autistic women,
- Black people,

- English as a second language (ESL)/Newcomers,
- First Nations, Inuit and Métis,
- Non-Speaking Autistic individuals/Augmentative and Alternative Communication (AAC) users,
- People of Colour/Racialized, and
- Young Autistic adults.

Other than the session for Autistic women, the Community Conversations for each equity-seeking group above involved less than ten participants.

The initial invitation was sent primarily to agencies and organizations, which may have limited CAHS' reach to equity-seeking groups in that those organizations may also be under-represented in terms of diversity. More specific outreach to those traditionally under-represented could have improved representation from equity-seeking groups.

Bilingualism

Through the registration process, participants identified their preferred language (English or French). Two specific sessions were run in French (for Québec and Francophones) with English interpretation available for the Québec session.

Due to low registration from French-speaking participants for earlier sessions, an additional three sessions were scheduled in early June. Two of those sessions were advertised as bilingual with interpreters on hand and with all material made available in French and English. A final session was held for a Québec audience in French.

Report Organization

For the Assessment on Autism, the Public Health Agency of Canada had identified three key themes of Social Inclusion, Economic Inclusion and Diagnosis, Supports, and Services[1] to serve as lines of inquiry to guide the broad and extensive consultation and engagement process. These themes recognize the many interconnected social, economic, environmental, and cultural factors that affect the lives of Autistic Canadians.

Following the 22 sessions, all the material (including facilitator notes as well as Jamboard and chat conversations) was reviewed carefully. Below you will find a summary of the conversations, which were written to align with the three assessment themes.

The information is summarized to highlight broad ideas across all the themes according to participant groups: Autistic individuals, family members, and service providers/organizations. We have also provided some geographic considerations where feedback diverged by region or setting. Key ideas from each of the equity-seeking groups have been summarized to highlight critical feedback which may be obscured in the broader thematic summary.

---

[1] Originally the theme Diagnosis, Supports, and Services was referred to as Interventions, but through stakeholder and CAHS' Lived Experience Advisory Committee feedback, the name was changed to better reflect our current understanding of autism supports and services.

Summary of the Conversations

Below, please find specific feedback from each participant group organized according to the three key themes: Social Inclusion, Economic Inclusion, and Diagnosis, Supports, and Services.

Autistic Individuals

Social Inclusion

Autism Acceptance Needed

- Autistic participants expressed a desire to live full lives through social and family connections and acceptance
- There were pervasive feelings that autism is not widely understood, even within one's own family
    - Participants indicated that families often struggle with the diagnosis and sometimes make decisions on their behalf that can contribute to low self-esteem and mental health concerns
- Participants feel that autism is not well understood in Canada
    - Unnecessary stigma hampers Autistic individuals' ability to thrive in society
    - Widespread public campaigns are needed to show the gifts of Autistic people and move beyond awareness towards promoting acceptance

Economic Inclusion

Underemployment and Unemployment

- Many Autistic participants indicated that they struggle with underemployment or unemployment, but wish to contribute their skills more fully
    - Strengths and skills are underutilized leaving many Autistic people financially constrained, dependent on families, and/or in poverty
    - Inadequate job readiness can be a barrier
    - When employed, employers often do not accommodate or work with Autistic employees to set them up for success leading to negative experiences in the workplace
    - There are opportunities for a broad employment strategy and subsidies available to employers complemented by training in managing/recruiting Autistic people

Struggle for Affordable and Safe Housing

- Housing options are limited
    - Often Autistic people do not qualify for supportive housing and need to stay with their families despite a desire for greater independence, which, from their perspectives, can make Autistic individuals susceptible to significant mental health concerns
    - As Autistic individuals age, they are looking for more choices in housing within inclusive communities where they can live independently and/or with assistance

Diagnosis, Supports, and Services

Inadequate and Inaccessible Mental Health Resources

- Autistic adults indicated that anxiety can be pervasive and debilitating but coping strategies can alleviate this
- They also mentioned that there are few, if any, publicly-funded mental health support. Even when available, supports may only be publicly-funded for a limited number of sessions

ABA Interventions Have Induced Trauma

- Many Autistic adults who participated felt that the applied behavioural analysis (ABA) intervention they received was inadequate or worse, led to trauma
    - Calls for the availability of a wider range of evidence-based therapies to meet diverse needs
    - Autistic parents often make decisions for their Autistic children and want more flexibility and options

Family Members

Family participants were primarily parents, but also included siblings and friends of adult Autistic individuals.

Social Inclusion

Focus on Family Wellbeing

- Engage fathers more deliberately as support groups are predominantly for women
- Supporting an Autistic family member can be stressful for parents, which can create challenges for the entire family unit
- Need better support and “onboarding” for parents when children are diagnosed
    - Toolkits
    - Buddy programs with other families with other children
- Prioritize respite services

Access to Services Across Communities

- Broader availability of programs and services in remote and smaller urban centres
    - Many families making difficult choices around moving to large urban centres to be closer to services
    - Families often have to consider tough trade-offs related to support networks and employment
    - Options for virtual services can mitigate geographical limitations

Public Safety

- Better training is needed in police forces to ensure they are better equipped to interact with Autistic individuals and to prevent negative interactions, which can contribute to trauma
- Autistic behaviours can sometimes be misinterpreted by police. It would be helpful for Autistic people to be accompanied by a trusted individual if or when they are interviewed by law enforcement
- Family members suggested that police need more accountability
- First responders to be more attentive to instructions given by family or supporters

Economic Inclusion

Better Support for Employers

- More direct support is needed, including creating new positions within workplaces, working with the employers to ensure the position is suitable for Autistic people, and offering flexibility around any disability supports for the individual
- From family members' perspectives, employers do not always understand the benefits of putting in the effort up front to support and accommodate the Autistic employee. For example, the training needs to go at a pace that is not overwhelming for the individual. When the Autistic person becomes more comfortable in their job, participants noted the many strengths that Autistic people bring to the workplace such as loyalty, good with routine, very reliable, etc.
- Many agencies help with the resume, interview skills, etc., but do not work closely with the employer to make sure the job itself suits the needs of the Autistic employee

Diagnosis, Supports and Services

Problematic Funding Models

- Funding models need to be more open-ended – allow for more choices and let parents make these decisions – to be flexible, not one size fits all with a broad range of choices and options
- Funding models need to be stabilized over much longer periods. Models often change with incoming provincial governments leading to upheaval for organizations and a reset of care/programming
- Long waitlists create a barrier and leave many children without services in years where these services can really make a difference
    - Availability of services has not kept up with demand
    - Need to scale up autism services, especially for young children
- Due to minimal public services available and limited choices, many families seek private services on their own at great expense
    - High cost of services is a significant barrier for many families
- Childcare for Autistic children (ages 5 and under) are almost non-existent, leading families to provide care themselves and make difficult economic choices
    - Work towards better integration of Autistic people at a young age including providing subsidies for childcare spaces and training for childcare workers so that Autistic children can thrive early on
- Services and programs for adults are minimal or non-existent

Training for Professionals

- Some family members felt that professionals across services such as occupational therapy, physiotherapy and speech-language pathology are often minimally trained in autism, if at all
    - Work with professional organizations to upskill their members
    - In remote communities, where services are limited, parents would like to receive basic training so they can continue therapies at home
- Navigating the system requires tremendous effort and perseverance
    - There are many obstacles in a fragmented healthcare system

    - Improve paperwork and electronic records so families can share information about their child's background, clinical history, and programs accessed with a wide network of therapists

Service Providers and Organizations

Service providers include educators, occupational therapists, speech language therapists, recreation workers, and psychologists, as well as representatives of advocacy and research organizations, who work with and/or support Autistic people.

Diagnosis, Supports, and Services

Close Service Gaps

- Need better coordination across programs and services
    - Organizations and services are not well aligned leading to supplication of services and redundancies, as well as significant gaps
- Services providers' focus tends to be on individuals aged 6 and under
    - Support for individuals aged 6 and above is much more ad hoc despite being badly needed
        - Integration and coordination with schools can be spotty and overlaid with additional bureaucracy and barriers
    - Very few programs and services are offered for Autistic adults, representing a significant unfilled need
    - Frequent changes to provincial funding models can lead to upheaval in organizations and affect the continuity of services to families
        - Funding models need to stabilize to allow service providers to upskill and support children over many years
- Level of services and availability of programs varies widely across Canada
    - Urban centres very likely to be better served
    - Remote communities have minimal services and choices although demand is there

Autistic-led Decision-making

- Need greater representation of Autistic people in shaping programs and services
    - Where committees and advisory boards exist, they are often well-meaning but feedback is not always integrated
- A need to strike a balance between listening to Autistic voices as well as that of family members and other supporters, particularly in situations where Autistic people require support to advocate for their needs

Improve Professional Training

- Many professionals have developed expertise in autism organically through their own interest and experience
    - Need basic training for professionals, especially teachers
    - Quality of care and services needs to be improved with better training and education for all including healthcare professionals and educators

Geographic Considerations

Although the Community Conversations were organized by geography, there were many similarities in the themes and feedback provided in the Community Consultations across regions.

Specific concerns related to geography coalesced around availability of services across provinces as well as the urban and rural/remote divides.

Challenges in Remote Areas

Participants from northern communities indicated that they often had to travel significant distances for diagnosis and basic services. In cases where services (such as occupational therapists and speech therapists) came to them, it was often for a limited period of time and with high staff turnover. This led to inconsistencies and gaps in therapy. Service providers also cited this issue and indicated that serving remote communities was a challenge.

Due to geographic considerations, participants often indicated that they moved their families to be closer to services and schools that could accommodate their Autistic child. Those that did not move, chose not to because of employment challenges or not wanting to leave much-needed family support networks. Many family members discussed these difficult choices.

Smaller Urban Centres Also Limited

Although participants acknowledged that smaller urban centres had more programs and services than remote areas, there was still a clear gap compared to larger cities. Smaller communities also provided fewer (or no) choices in terms of housing or services for Autistic adults.

Cross-Province Migration Challenging

Restrictions in cross-province mobility is a serious issue affecting many families. One participant shared that they had already engaged in a two-year process of trying to obtain a diagnosis, and if they moved provinces, they would have to start this process all over again.

Challenges and Opportunities with Virtual Solutions

While virtual care was cited as a possible solution for overcoming service gaps in remote communities, the issue of broadband access was often cited as a limitation to accessing these services by families in remote areas.

From a social inclusion perspective, many Autistic individuals indicated that they had found peer support through private chat groups and social media, which helped them feel less alone and part of a larger community – especially if they lived in a smaller town or city.

Equity-Seeking Groups

Below is a summary of key ideas emerging from the Community Conversations with equity-seeking groups. Where possible, we have highlighted unique issues and experiences pertaining to these groups. While a First Nations, Métis, and Inuit Community Conversation was held as well, the contents of this conversation is reflected in a separate report.

2SLGBTQIA+ Community Conversation

This session was attended by six Autistic people identifying as 2SLGBTQIA+. Participants articulated many challenges including the difficulty of sharing their stories.

Social Inclusion

Finding Peer Networks for Support and Acceptance

- Participants sought out more opportunities for peer networks such as queer Autistic groups
    - Especially needed for Autistic individuals who are transgender and non-binary
    - Helps to fill gaps in resources especially in smaller communities

Human Rights and Public Safety

- Discussion around border requirements to enter Canada
    - Training for Border Services in working with Autistic individuals and ensuring that they can communicate effectively

Diagnosis, Supports, and Services

Diagnosis and Supports

- Need for more research on gender and autism framed within a supportive context that is not about "fixing" the individual
- If diagnosed late in adolescence or adulthood, sexuality and gender issues are not always addressed
- Seeing doctors in-person can be difficult for some people – virtual solutions can be less stressful, with a lower risk of sensory overload
- Frustration in managing burnout and fatigue
    - Need to balance this with self-care, work requirements, and other pressures
- Many participants were diagnosed later in life
    - Requested a simple "welcome package" that could be found online describing how to deal with late diagnosis along with coping strategies framed by an intersectional lens
- Professional training for doctors and other diagnosticians should include information about gender non-conformity and sexuality

Economic Inclusion

Representation in Higher Education

- Discussion around research and scholarship
    - Need for disability-led research about disability
- More scholarships and funding needed for Autistic people
- More information about Autistic people and trans people, as well as the intersectionality of the two, within university curriculums such as that for social workers

Unwelcoming Workplace Cultures

- Challenge the system of social etiquette, which is often unrealistic for Autistic people as they are held to a workplace standard they may not fully understand. This compromises their ability to contribute and succeed, despite having the skills to do their job well
- Limited workplace support and accommodations often leaves Autistic people feeling like they have to educate their employers and colleagues, contributing to experiences of burnout

Autism and Parenting Community Conversation

This session was attended by 17 Autistic parents as well as non-autistic family supporters of Autistic individuals. For the breakout session, participants were in small groups of either Autistic parents or parents of Autistic individuals. For clarity, below, we have indicated which feedback was provided by which group.

Social Inclusion

Stigma and Autism Acceptance

Autistic parents articulated a need for a more inclusive and accepting system.

- Autistic parents often did not feel comfortable disclosing their autism diagnosis due to fear that this may lead to false assumptions about their ability to parent
- Need services for adults that embed understanding of parenting experiences
- Trauma-informed care is needed
- In terms of support for their Autistic child, Autistic parents suggested there was too much focus on the child's behaviour rather than what the behaviour means, with most supports based on ABA, with few alternative options
- Autistic parents described high rates of legal and medical discrimination

Education

Parents of Autistic individuals provided feedback on inconsistent and unpredictable support models across Canada.

- From their perspective, support varies from year-to-year depending on school and educational assistant support
- When funding models keeps changing due to policy decisions, families are forced to change their service plans and work with new partners and therapists
- While there are more services and programs available now than ever before, many barriers still persist:
    - Costs,
    - Service providers may not have strong training, hard to know if therapists are qualified to work with Autistic children, and
    - Urban centres have more offerings, very little in smaller communities.

Parents would like to see a greater focus on building friendships and social networks.

- Programs specifically for Autistic individuals and programs where Autistic individuals are integrated with non-autistic peers
- Better professional training (teachers, educators) can contribute to greater inclusion
- Support for families in navigating systems and understanding choice and availability of programs

Diagnosis, Supports, and Services

Health Systems

Autistic parents identified a need for widespread change in the health systems.

- Many Autistic parents suggested a desire to minimize the use of ABA as a gold-standard/first line form of support service, and offer alternatives such as speech language pathology, occupational therapy, and physiotherapy
- Better education for doctors, nurses, and other clinicians

- Transparency of services available: easily available/findable services

Economic Inclusion

Life Transitions

Parents of Autistic individuals expressed worry around care for their children after they die.

- Primary family supporters are unsure of the available options for their adult child once they are no longer around. In many cases, it is likely their child will reside in some kind of group home
- Minimal choices and a constant worry for families

Autistic Women Community Conversation

This session was attended by 12 Autistic women.

Diagnosis, Supports, and Services

Late Diagnosis and Underdiagnosis

The women who participated shared varying experiences with diagnosis calling for more early diagnosis/assessment of young girls and publicly-funded adult diagnosis.

- Medical system needs to be setup/educated to identify autism in young girls
- The group shared that they were all diagnosed in their 30s, with the exception of one woman who was self-diagnosed. She reported that cost was a barrier to getting diagnosed
- At time of diagnosis, autism is often framed as a negative diagnosis, but stakeholders suggested that it should also be presented as a strength
    - Social workers to focus on gifts and strengths to help families
- Earlier diagnosis could have contributed to earlier access to supports, leading to different life choices (such as education supports, alternative career paths etc.) and mitigating potential negative experiences

Social Inclusion

Acceptance and Belonging

Participants shared feedback around the challenges of finding peer networks and services especially if diagnosed in adulthood.

- Mental health support required for mothers/family supporters especially when they are diagnosed at same time as their child which can be overwhelming
- Limited supports for Autistic adults (such as how to ask for accommodations, sexual health and relationships etc.), particularly for those who receive a late diagnosis

Black People Community Conversation

This session was attended by eight Black family members of Autistic people.

Diagnosis, Supports, and Services

Eliminating Unconscious Bias in Diagnosis

- Discussion around biases in diagnosis and the need to eliminate unconscious bias by professionals (including potential racial prejudice)

Social Inclusion

Autism Acceptance and Cultural Misconceptions/Stigma

- Misconceptions about autism may also be cultural
    - Stereotypes exist around the potential causes of autism (blaming parents) which need to be dismantled
- Culturally-responsive resources are needed
- Language and terminology used by professionals can be overwhelming
- Language barriers may limit ability for families to advocate

Vulnerability related to Racial Profiling

- Lack of eye contact and different communication styles are sometimes treated as suspicious or disengaged
- Concern that Black Autistic individuals are seen as more aggressive
- Potential negative interactions with law enforcement is of particular concern

Economic Inclusion

Financial Barriers

- From the perspective of Black participants, white families may be better equipped to understand and navigate the system and have their needs met
- Socioeconomic barriers to services include:
    - Challenges associated with paying out-of-pocket for many services and therefore having to wait on long waitlists, which contributes to the loss of valuable time
    - Grants for people of colour may help to close these gaps

Francophone Community Conversation

Two specific sessions were run in French (for Québec and Francophones) with English interpretation available for the Québec session. Four individuals attended the Francophone session. However, other French-speaking individuals attended the other sessions that were offered.

Diagnosis, Supports and Services

Federal Leadership

Participant expressed a desire for greater federal leadership:

- To coordinate services and to share information and innovative ideas across provinces and territories
- To reduce long wait times for services across provinces and territories
- To support research initiatives that focus on the translation of knowledge into practice

Education and Training for Professionals

Participants emphasized the need for more training of diverse professionals (including educators and frontline service providers):

- Training should address stereotypes and improve professionals' capacity to work with Autistic children and adults
- Francophone participants also indicated that frontline service providers need be more aware of the additional barriers they experience in situations where they represent a language minority

Autism-specific Services

- Broader disability services may overlook the particular needs of Autistic people - services need to be tailored to the unique needs of Autistic people
- Mental health initiatives for Autistic people need to be prioritized

Social Inclusion

Autistic Leadership

Participants indicated that Autistic people should not be underestimated and called for increased opportunities for leadership and to have their voices heard.

Economic Inclusion

Inclusion in the Workplace

Participants emphasized a need for employers to receive training on hiring and supporting Autistic employees and improving access to workplace accommodations.

English as a Second Language (ESL)/Newcomers Community Conversation

This session was attended by six Autistic individuals and service providers who work with newcomer communities.

Social Inclusion

Access to Services

- Recognition that newcomers are new to the entire health and social system
- Need specific support in navigating the system and to access programs and services as they have limited experience
- Recognition that the aforementioned challenges create an additional burden and can be time-consuming for families

Acceptance

- Continue to destigmatize autism
- Broad public awareness is needed in many languages
- Families often struggle with cultural barriers as well which need to be addressed without stigmatizing those families

Diagnosis, Supports, and Services

Language Barriers

- Participants cited the need for interpreters particularly during assessment and diagnosis
- Information needs to be available in multiple languages
- In remote communities, interpreters may not be available so need to consider virtual alternatives

Non-Speaking Autistic individuals (AAC Users) Community Conversation

This session was attended by seven augmentative and alternative communication (AAC) users.

Social Inclusion

Acceptance of AAC Users

- Participants articulated their desire for more acceptance and understanding of AAC and the honouring of all forms of communication. They indicated a need to challenge ableism in society and to have their contributions and perspectives valued
- Participants noted that AAC can be beneficial to those who are non-speaking or minimally speaking, but can also be helpful for many Autistic individuals in times of stress or shutdowns
- From the perspective of this group, advisory groups need to include diverse Autistic experiences, including that of AAC users, people who are deaf/blind, multiply disabled, as well as other intersecting identities

Vulnerability Related to Safety

- Participants expressed a lack of safety and feeling particularly marginalized and at risk
  - Gender diversity in Autistic community can lead to further marginalization and safety concerns across various domains such as the health and legal system
  - Tracking bracelets and apps can make AAC users feel more susceptible to abusive situations
  - Providing AAC users with sex education including providing them with tools to talk about sexual assault

Diagnosis, Supports, and Services

Health Systems' Needs for AAC Users

- Government offices and healthcare clinics should be accessible through text-based options (email, SMS etc.)
- AAC devices should not be removed in healthcare settings
- Prioritize trauma-informed mental health and addiction services, recognizing that many mental health concerns can stem from experiences of trauma that occur through services that were intended to help Autistic people
- Focus tends to be on compliance-based supports and services
  - Shift focus on support and inclusion
  - Services and programs should be informed by Autistic people

People of Colour/Racialized Community Conversation

This session was attended by seven racialized Autistic people and family members.

Social Inclusion

Autism Acceptance through Media

- Focus on acceptance – moving beyond "awareness"
  - Combat the autism tragedy narrative
  - Having acceptance and neurodiversity resources available in multiple languages and in consideration of cultural differences
- Recommend media advertisements about autism that are racially-diverse

- Provide funding for Autistic-led arts and culture to show diverse perspectives including that of AAC users

Diagnosis, Supports, and Services

Rethinking Research Models

- Focus on more participatory, community-based research
- Shift from a biased understanding that often leaves out Autistic perspectives
- Include diverse perspectives and participants in all research

Young Autistic Adults Community Conversation

This session was attended by 11 young Autistic adults and service providers who work with young adults.

Social Inclusion

Necessity of an Intersectional Lens

- Having services and supports grounded in intersectional and culturally-sensitive approaches
- Recognize that many forms of discrimination exist especially towards racialized and 2SLGBTQIA+ communities
- Understand diversity among Autistic people and recognizing that representation matters

Economic Inclusion

Financial Considerations

- Many Autistic people living in poverty
- Consider a universal basic income or increasing disability supports

Coping with Life Transitions

- Minimal support and services available after age 18
- Difficult to navigate post-secondary options and transition to job market
- Life coaching that is customized to individual needs (not generic) is needed
  - Could be provided through virtual services
  - Focus needs to be on building confidence and self-esteem to combat underemployment
- Ideally, programs for Autistic people should be designed with input from Autistic people, provide mental health support, and value people for who they are, not what they can do/level of productivity

Diagnosis, Supports, and Services

Lack of Mental Health Services

- Publicly-funded mental health services are needed for young adults
  - Participants noted that specific mental health diagnosis is usually needed to access these services
  - Long wait lists for limited available services
- Training for mental health professionals and upskilling needed for working with Autistic people
- Integrate a trauma-informed lens into mental health services for Autistic people

Variety and Options in Services

- Offer a variety of supports (aside from ABA exclusively) such as Cognitive Behavioural Therapy and Dialectical Behavioural Therapy, art therapy, speech and occupational therapy, sensory integration therapy
- Involve Autistic people in designing models and solutions

VIRTUAL STAKEHOLDER CONSULTATIONS SUMMARY OF POLICY DISCUSSIONS

July 2021

Prepared for CAHS by Audrey Wubbenhorst
July 23, 2021

Policy Discussion Overview

On July 19 and 20, 2021, the CAHS hosted four policy discussions, which were organized around four themes:

- **Social Inclusion** - topics such as rights, safety, accessibility, belonging, sports and recreation, public acceptance and awareness, and knowledge-sharing
- **Economic Inclusion** - topics such as employment, education and training, housing, transportation, and financial stability
- **Diagnosis, Supports, and Services** - topics such as system-wide improvements (for example, access to services and supports, research gaps, and recommendations for future research) and evidence for current and newer practices across the lifespan (for example, diagnosis, programs, services, and supports)
- **Overarching Issues** – broader topics that cut across the above three themes

Participants were invited to take part in the discussions through a multi-pronged communications strategy, which included:

- A distribution list of organizations which included service providers, researchers, and government contacts,
- Personal invitations to those who previously attended the Community Conversations in May and June and those who contributed to the Engagement Hub,
- Information made available on the CAHS website,
- Social media posts through CAHS' social media account, and
- A Facebook page that was setup for the events.

Participants registered in advance of each session. The topline key issues under each theme were sent to registrants in advance of the Policy Discussions.

Session Format

The Policy Discussions were structured to maximize participation and provide the opportunity for everyone to feel heard in a safe space. The format of each discussion was identical. Each session opened with 30-minute plenary sessions. The team welcomed participants and provided a land acknowledgement. Indigenous educator, Audrey DeRoy, generously opened each session with a song. Aaron Bouma, Vice Chair of the Oversight Panel, welcomed participants. Dr. Lonnie Zwaigenbaum, Chair of the Oversight Panel then provided an overview of the assessment, the theme of the meeting, and the two key issues which formed the basis of the breakout sessions. After a short break, participants moved into seven breakout rooms each led by a facilitator.

Bilingualism

Through the registration process, participants identified their preferred language (English or French). Interpretation was available during all sessions. Materials were available in French and English.

Collating of Information

Following the four sessions, all the material was reviewed carefully. In presenting this summary, we looked for stakeholder feedback on policy or practice approaches to key issues identified by the Oversight Panel based on a synthesis of academic and policy evidence. Individuals have not been named in the report, but we have indicated their identity when it was known (e.g. Autistic people, family supporter or service provider).

Summary of the Policy Discussions on Key Issues

Session 1: Social Inclusion (July 19)

Key Issue #1: Stigma, Discrimination. and Self Advocacy

Stakeholders discussed how stigma creates barriers, overlooks the strengths of Autistic people, and contributes to poor outcomes. Possible approaches to address stigma included: training and acceptance/awareness campaigns, combating stigma, self-advocacy, and the recognition of autism as a lifelong neurodevelopmental condition. In the breakout rooms, facilitators sought feedback on these approaches.

Summary of Feedback on Approaches

Combating Stigma

Language and communication approaches were cited as important considerations. Autism is often framed as a deficit as opposed to a difference, which can be pathologizing and stigmatizing. Many participants, particularly Autistic people, highlighted the importance of language as being critical to combating stigma.

Many participants reflected on the fact that stigma can be pervasive and may manifest itself in many ways, and that it needs to be considered in its broadest sense:

- While tracking hate crimes is important, microaggressions are common and when compounded, can erode Autistic people's self-worth
    - Training and education programs need to ensure that professionals are aware of hurtful stereotypes and train them to lead with empathy. Training needs to include criminal justice professionals, especially the police, and emergency room doctors
    - Setting up Canada-wide helplines for education and crisis support that allows for all forms of communication for Autistic people
- Participants spoke about how stereotypes of Autistic people often misrepresent autism and how discrimination against Autistic people and their family members exists in the medical system, the school system, the work environment, and the community
- Training and educational programs for healthcare providers, teachers, employers and employees, and sports and recreational professionals who work with Autistic people can reduce discrimination
- The content and how training is presented could significantly impact how the information is received and, in some cases, have reinforced stigma about autism. Autistic people need to be involved in developing and delivering up-to-date training content. An intersectionality lens should be applied to all training

Acceptance and Awareness Campaigns

Participants indicated that acceptance/awareness campaigns and positive representations of Autistic people in the media was a meaningful approach.

- Much of what society knows about autism is produced by representations of autism in novels, television, and film. Diverse representation of Autistic people is needed. Participants commented on the lack of Autistic people in media (film and television). The few Autistic characters that do exist represent only a narrow view of autism
- The presence of Autistic people in media needs to be normalized and characters developed with input from Autistic people to ensure that Autistic representation is accurate and appropriate

Self-Advocacy

Some Autistic participants felt that the term self-advocates (instead of just advocates) has been used by non-autistic people as a way to diminish the value of advocacy groups that are Autistic-led. Many participants raised concerns around advocacy and the burden it places on individual Autistic people and their families. Advocacy needs to be taught. Autistic people should be taught that their voices count and that they can make a difference in their own lives.

- Alternatively, society needs to seek ways to improve systems and services so they are truly inclusive
- Increased awareness and acceptance of self-diagnosed Autistic people
- Constant self-advocacy can lead to high levels of stress and other mental health issues – self-advocacy is emotional labour and when not appropriately compensated for, can be re-traumatizing
- One participant raised the idea of reframing this to “group advocacy” and focusing instead on improving quality of life for Autistic people in Canada
- Participants noted that when advocating for oneself, some dimensions of intersectionality may be overlooked or downplayed

Autism as a Lifelong Neurological Condition

Participants endorsed the idea that autism needs to be considered as a lifelong neurodevelopmental condition. Framing autism this way would help:

- To promote access to services across an individuals’ lifespan – Autistic individuals felt that they should not have to re-sign up or update their information for continuous access to supports and services
- To recognize that it is a condition people live with that cannot (and should not) be fixed

Key Issue #2: Access to Services and Community Participation

Autistic people and their families experience systemic barriers, which prohibit access to equitable, high quality, appropriate and/or culturally-responsive services. Possible approaches to address service access and community participation included: removing barriers to mental health services, offering a wide range of recreational opportunities for diverse groups, focusing on safety, implementing system navigation, and developing “centres of excellence” with highly trained teachers.

Summary of Feedback on Approaches

Removing Barriers to Mental Health Services

Participants reiterated the importance of this approach and the need for an increase in both the quantity and quality of mental health support available to Autistic people.

- Trauma due to stigma is common for Autistic individuals and participants acknowledged a high likelihood that Autistic people need mental health services

- Services can be costly and may not be provided with empathy or consideration of the lived experiences of Autistic people. If available, mental health services are often suboptimal
- Having an autism-specific crisis line that can accommodate all forms of communication
- Training and upskilling are needed for mental health professionals to understand Autistic experiences

Safety

Many participants (Autistic people and family members) raised the issue of safety and reiterated that Autistic people are vulnerable to assault and abuse.

- One approach is to launch a Canada-wide help line for crisis support
- Training for first responders in supporting Autistic people was also raised as another approach. In particular, participants underscored the need for better training for police services

Stakeholders suggested that there may be a higher occurrence of assault (physical/sexual) for Autistic individuals.

- Autistic people may also experience higher sensory overload and traumatic responses to experiences of assault
- An approach to address this issue would be to proactively teach Autistic people about safety, boundaries, relationships, intimacy, communication, and consent as well as increase access to mental health services. Comprehensive sexual health and intimacy education and training for teachers can ensure they are well-equipped to provide appropriate sex education to Autistic students

System Navigation

Non-autistic family members indicated their support for better system navigation and for simplifying a complex web of services and programs. Many participants, especially parents, cited barriers in navigating the patchwork of services, namely:

- Challenges in sourcing high quality service providers
- Changing eligibility criteria when governments transition
- Funding programs that require burdensome administration which is shouldered by parents

Some participants also discussed how services are often inequitable, disparate, and not client-centred:

- In many provinces, services are only available to individuals who meet a very specific and narrow criteria, leaving many families to source their own services at their own cost – if those services are available and if they can fund them. Consequently, many families are left without any services

Centres of Excellence

Some participants expressed some agreement with the development of “centres of excellence” with consideration for:

- Ensuring these centres are developed with Autistic input
- Grounding any curriculum in current research and not outdated information

Session 2: Economic Inclusion (July 19)

Key Issue #1: Labour Market and Education Pathways to Employment

There is widespread un- and underemployment of Autistic people. Possible approaches to address this issue included: creating opportunities and internships, mandating autism acceptance/awareness training for employers, service providers, and human resource professionals, implementing pan-Canadian media campaigns, and building supported pathways from high school to post-secondary and beyond.

Summary of Feedback on Approaches

Creating Opportunities and Internships

Participants voiced concern that Autistic people are having a hard time finding meaningful work despite often having the appropriate academic qualifications.

- Jobs and job support for Autistic people are typically only offered in certain employment fields – such as tech jobs – which may be limiting for Autistic people with wider interests
- Many Autistic people with high levels of education and other qualifications may be overlooked for employment opportunities
- Opportunities and internships should move beyond the tech sector and consider other industries and skills
- Government sector may have better options for Autistic people compared to the private sector, but government jobs are challenging to acquire, particularly for Autistic people
- Some participants suggested that governments can be leaders in this area by employing more Autistic people across a wide range of jobs
- Mandating increased inclusion of Autistic individuals in the workplace was suggested by some
- Encouraging Autistic entrepreneurs, who are more likely to hire other Autistic people, was also suggested
- Providing opportunities for Autistic people to join and participate in the Canadian military

Autistic participants and family supporters expressed frustration with recruitment methods which often favour non-autistic communication styles. Traditional recruitment processes need to be reviewed:

- When requesting accommodations (e.g., asking to see the interview questions in advance), Autistic people are often asked to disclose why they need accommodations. The implications of disclosing their diagnosis are often unclear, but in some cases results in their exclusion from job opportunities
- In job interviews themselves, differing communication styles can result in the Autistic person considered not a “good fit” for the organization. Participants advocated for a need to ensure interviews are respectful of many communication styles and screen for skills required for the job as opposed to peripheral social skills

Participants identified the role of stigma and discrimination in gaining well-paid and meaningful employment.

- When Autistic people try to apply for jobs the traditional way, they tend to be filtered out. When Autistic people apply for jobs designated for Autistic people, the jobs do not provide sufficient or stable income (e.g., either they do not offer enough hours and/or not enough compensation)

- Jobs designated for Autistic people often feels like tokenism, just so companies/businesses can say they hire disabled people. From the perspective of some stakeholders, it is a means for companies/businesses to look good as opposed to do good

Mandating Autism Acceptance/Awareness Training for Employers

This approach was seen as necessary and critical. When employed, Autistic people are often unable to excel due to a lack of support:

- Autistic people often burnout due to "masking" and/or misunderstanding office politics and not necessarily participating in the "social" aspects of the job despite being able to perform the job itself. Some participants did note wider acceptance of remote work may help to alleviate burnout
- Managers and employers need to be more accepting of differences and be better supported to support Autistic employees more effectively
- Employer training and creating more accessible and inclusive workplaces were considered major desired strategies by many stakeholders. Employers need support to understand how and where to foster an inclusive workplace. Education and support are needed for employers, and sometimes they are not aware that such training exists. Some workplaces can mandate training and education for employers to create more inclusive spaces. Autistic-led initiatives in the workplace are needed
- Autism training needs to be accessible, digestible, and easy to understand
- There needs to be new employment placements and internships. Having more diverse options for employment and internship placements and shadowing/mentorship support are important
- Parents of Autistic children may face additional challenges in maintaining employment due to being called away with little notice to pick their child from school or childcare

Post-Secondary Educational Pathways

Participants expressed that this approach was important but indicated that many post-secondary institutions are not currently set up to help Autistic students succeed. Structural barriers and biases still need to be dismantled.

- Some Autistic people may require more time to complete their university degree. While universities will sometimes allow Autistic people to take on a reduced course load, they are still expected to pay full tuition, which creates a financial barrier to completing their degree
- More Autistic people need to be included in academia as role models, administrators, and faculty
- Provide opportunities for Autistic high school students to learn or gain work experience in school. Provide resume building, vocational programs, peer mentorship, interview practice, etc. These are not nationally available and there is a need for more nationally-mandated pathways to employment and post-secondary education

Additional Approach: Improved Data Collection

Many participants advocated for better data collection to understand the pervasiveness of unemployment and underemployment of Autistic people, loss of employment, and education/skills.

Key Issues #2: Poverty reduction and meeting basic needs such as housing

Without a basic level of financial and housing stability, many Autistic people cannot be fully and meaningfully included in society. Some approaches may include a universal basic income, improved eligibility for the Disability Tax Credit, funding in-home supports over a lifetime, minimizing disincentives, and improving inter-ministerial partnerships and whole government approaches to addressing housing waitlists.

Summary of Feedback on Approaches

Universal Basic Income

Many participants suggested that a universal basic income would help Autistic people and that a cost of living allowance clause might be useful in implementing a basic income.

- Autistic people often struggle to finance their basic needs
- Poverty and access to employment are deeply interconnected
- Access to employment and access to funding after losing employment should be changed to support those with disabilities who may be looking for different kinds of employment depending on what their needs are (e.g., employment with flexible hours, shifting schedules, etc.)

Improved Eligibility for Disability Tax Credit

Participants indicated that the Disability Tax Credit is complex and difficult to access. Autism is a lifelong condition and yet Autistic people need to re-apply with a doctor's letter. The tax credit is framed around "impairment" and requires regular renewal, which is an unnecessary burden for Autistic people.

- Stakeholders felt that support and eligibility should not be restricted to those with a formal diagnosis as many self-diagnosed Autistic people are left without access to accommodations, tax credits/funding, and needed services and supports. This contributes to physical and mental health issues and burnout
- How do inheritances impact tax credits and other government assistance? Supported decision-making for Autistic people who have been left an inheritance is needed, to ensure that they are not taken advantage of by fraud, sinister people, bureaucratic errors etc.
- Basic income/disability tax credit should still allow people to work (improves mental health and independence) without worrying that their supports will be taken away

Addressing Housing Waitlists

Participants indicated that shortening housing waitlists should be prioritized.

- The supply of housing for Autistic people does not meet the demand; waitlists for supportive/affordable housing is a moving target
- Many parents of Autistic adults are aging and concerned about housing needs for their child when they can no longer support them
- Autistic people are looking for purpose-built housing that meets their needs (e.g., quiet, low lighting, low sensory)
- Having landlords and neighbours who understand autism and are accepting of Autistic people
- One approach may be to allow Registered Disability Savings Plan to be used as equity in buying a home without a withdrawal penalty (similar to the Registered Retirement Savings Plan home buying program)
- Receiving support should not be attached to where you live so that you can easily change from one unit to another
- The issue of housing is not just a matter of having a place to live, but also having access to services/outdoor spaces/community and daily living supports (personal support worker, managing finances, maintaining home etc.)
- Accessible transportation and public spaces are an aspect of housing and social planning (e.g., quiet spaces, easy to navigate)

Session 3: Diagnosis, Supports, and Services (July 20)

Key Issue #1: Adult Diagnosis and Services

There is limited access to publicly-funded, high quality assessments for adults. Some approaches to alleviate this issue might include building professional capacity, ensuring more equitable access, creating structures for service coordination, and recognizing autism as a lifelong neurological condition.

Summary of Feedback on Approaches

Building Professional Capacity

Many participants cited a lack of trained professionals to diagnose adults, especially outside of large urban centres.

- Service providers indicated some success with virtual diagnosis services, especially within the last year (in response to COVID-19 impacts)
- More diagnosticians are needed who can speak/communicate in multiple languages
- Diagnostic tools are not culturally-sensitive, especially for Indigenous individuals which may mean that the information is inaccurately captured and assessed

Creating More Equitable Access

More equitable access to diagnosis across the lifespan was seen as a necessary approach. Access to assistance and services is usually limited to those with a diagnosis.

There was wide agreement that there is limited access to adult diagnosis in Canada.

- Participants cited two significant barriers to adult diagnosis: cost and a lack of professionals qualified to do adult diagnosis
- Autism may present much differently in adults who have been “masking” compared to children
- Low income contributes to barriers to diagnosis
- Families may be reluctant to seek services due to cultural beliefs and stigma
- There is a lack of qualified diagnosticians, especially for Autistic people who are French-speaking. Many French-speaking Autistic people reported they were required to get tested in English
- Assessment and diagnostic tools are not culturally-sensitive. Mis- or under-diagnosis may be even more prevalent in adults who are not Caucasian and not male – referrals for diagnosis often rely on a very narrow understanding of autism
- Parents are often times diagnosed when their children are diagnosed leading to feeling overwhelmed and needing more support both for themselves and their children at the same time

Autistic seniors continue to be marginalized and may also be underdiagnosed.

- Lifelong experiences of masking may contribute to challenges in obtaining a formal diagnosis

Some Autistic adults questioned the need to get a diagnosis when there were very few services available. The later the diagnosis, the fewer the available services.

- Need access to mainstream/general services that everyone can access (not just autism-specific services), however many of these services are not accessible to Autistic people and/or not adapted to the needs of Autistic people

- The medical system, in particular, was mentioned as not being accessible. Some barriers include the presence of stigma, Autistic people not being given enough time to express themselves, as well as healthcare settings not being sensory-friendly

Different Autistic people require different supports. When unsure, Autistic people should be asked what they need, with the purpose of providing appropriate supports.

Key Issue #2: Early Childhood Support and Services

Access to early childhood supports and services that emphasize functional skill development, social inclusion, and quality of life is inconsistent across regions. Approaches to address these inconsistencies may include implementing evidence-based service models, providing interventions prior to diagnosis, creating structures for interdisciplinary services, and creating structures for coordination and oversight.

Summary of Feedback on Approaches

Providing Supports and Services prior to Diagnosis

Due to long waitlists, many participants agreed with this approach. Concern was expressed that due to long waitlists for diagnosis, often early childhood supports and services are delayed.

Some stakeholders expressed concern over the use of the term “intervention” as it can imply “fixing” people who are deemed to have a problem:

- From their perspective, there is a need to move away from the term “interventions” towards terms that are more supportive and trauma-informed, such as saying “providing support”
- Providing support should be done in such a way where there is buy-in from the people receiving support (and support is not being forced on them)

Screening and Diagnosis for Children of Autistic Parents

Some participants suggested that children born to Autistic parents should be priority tested, as they have a higher likelihood of being autistic. In these situations, Autistic parents suggested that support for the mother and child are essential.

Participants indicated a need to mitigate unconscious bias in the diagnosis/assessment process

- Many young girls are undiagnosed and learn to “mask”
- Autistic children of the 2SLGBTQIA+ and racialized communities are greatly overlooked. Under- and misdiagnosis are very common in these groups and contribute to increased challenges for these groups
- Concern expressed around assessments being offered in English to Canadians whose first language is not English, which can lead to misunderstanding of questions

Evidence-Based Service Models

There were differing perspectives amongst stakeholders regarding behavioural approaches.

- Some participants questioned the assumption that ABA is effective given concerns raised by Autistic people
- There was concern from stakeholders that ABA is often the only service being offered to every Autistic person
- Some family members indicated that ABA had helped their children with foundational skills such as crossing the street safely and basic toiletry

- Family members suggested that parents should have access to a wider range of early childhood supports and services so they can choose what is best for their child

Session 4: Overarching Issues (July 20)

Key Issue #1: Autism Education and Training

Lack of knowledge and skills hinders acceptance and respect for Autistic people and access to high quality supports and services. Potential approaches to ameliorate these issues included professional training and continuing education that is co-developed with Autistic people and family members.

Summary of Feedback on Approaches

Autism Education and Training for Professionals

Participants cited the importance of autism education with the following considerations:

- Ensuring it is developed with Autistic input and their ongoing involvement
- Adopting a cultural, intersectionality, and neurodiversity lens to recognize the varying experiences of Autistic people
- Training needs to be iterative. Professionals likely need to receive training at multiple stages of their career to cover a range of topics. A one-time workshop is insufficient to understand the complexities of autism and Autistic people
- Offer more virtual training opportunities that allow for one-on-one education. Peer mentoring can be very useful as well
- Education and training initiatives should be targeted at everyone - the general public, community, the people in our neighbourhoods, corporations, and professionals. Training on autism should also be embedded into professional training for mental health professionals, educators, healthcare professionals, emergency response personnel/first responders etc. to ensure that a baseline understanding of autism is required to practice those professions as opposed to an “add on” or extra certification
- Training needs to reflect current research. Concern was raised that some training reflects outdated research and approaches and is often not underpinned by autism acceptance

Key Issue #2: Autistic Leadership

Autistic leadership was defined by stakeholders as active and meaningful involvement of diverse Autistic people in agenda-setting and policy development. Approaches may include participating in, developing, and implementing educational strategies, ensuring Autistic people are in leadership roles, and involved in setting research priorities.

Summary of Feedback on Approaches

Participants agreed that Autistic lived experience needs to be central in decision-making and that Autistic people should hold leadership roles and be given opportunities to influence key decisions. Some caveats to this included:

- Ensuring that Autistic people are compensated appropriately for their time, expertise, and emotional labour
- Ensuring that the voices and perspectives of Autistic individuals who are non-verbal or communicate in diverse ways are equitably valued and heard as those of Autistic individuals who can articulate their needs verbally. Additionally, there is concern that the voices of parents of Autistic people and other supporters are also not heard

While Autistic leadership was seen as a meaningful approach, there was some concern raised about setting Autistic people up for success in leadership roles. Ideas to ensure they are effective leaders included:

- Partnering them with experienced Autistic leaders in a mentoring capacity
- Developing mentorship programs for Autistic youth to develop leadership skills
- Widespread acceptance of Autistic people as valued members of society so that Autistic people are empowered to take on leadership roles. Autistic stakeholders felt that the perspectives of non-autistic people are often privileged over the perspectives of Autistic people, which can be disempowering
- Disability and autism organizations should hire diverse disabled and/or Autistic people
- Some Autistic-led organizations already exist but have a low profile – find ways to amplify these voices

Appendix A: Community Conversations Schedule and Attendance

In addition to the public conversations listed below, the team ran a “test run” of the conversation format with CAHS’ Lived Experience Advisory Committee in early April.

Date	#	Audience	EST	Registered	Attended
22-Apr	1	Manitoba/Saskatchewan	12:00 PM	26	18
23-Apr	2	2SLGBTQIA+	12:00 PM	8	6
27-Apr	3	British Columbia	2:30 PM	34	11
29-Apr	4	Black	6:30 PM	6	8
30-Apr	5	Québec	12:00 PM	12	7
01-May	6	Autistic Women	12:00 PM	22	12
01-May	7	People of Colour/Racialized	2:30 PM	9	7
03-May	8	Young Autistic Adults	6:30 PM	17	11
04-May	9	*English as a Second Language/Newcomer	6:00 PM	9	6
06-May	10	Ontario (Outside of GTA)	12:00 PM	69	39
06-May	11	Atlantic	6:00 PM	68	39
07-May	12	Territories + Northern Communities	2:30 PM	12	4
07-May	13	Francophone	12:00 PM	10	4
10-May	14	First Nations, Inuit and Métis	12:00 PM	9	8
10-May	15	Autistic Parents	6:30 PM	39	17
11-May	16	Alberta	2:30 PM	31	20
11-May	17	Ontario (GTA)	7:00 PM	60	30
12-May	18	*Non-Speaking Autistic individuals	12:00 PM	11	7
13-May	19	Pan-Canadian Organizations	12:00 PM	31	34
01-Jun	20	Pan-Canadian	6:30 PM	55	25
04-Jun	21	Pan-Canadian	2:30 PM	48	29
05-Jun	22	Québec	2:30 PM	9	3
			Total	595	345
				Participation Rate	58%

***All sessions were 90 min except for English as a Second Language and Non-Speaking Autistic individuals (AAC users) to allow for more time**

Appendix B: Policy Discussion Schedule and Attendance

Policy Discussion	Date / Time	Registered Attendees	Live Participants
Social Inclusion	July 19, 2021, 11:30 – 2:00 EST	244	116
Economic Inclusion	July 19, 2021, 3:00 – 5:30 EST	210	93
Diagnosis, Supports, and Services	July 20, 2021, 11:30 – 2:00 EST	251	121
Overarching Issues	July 20, 2021, 3:00 – 5:30 EST	220	114
	Total	925	444

Appendix C: Registered Organizations

Following is a list of 54 service providers and organizations who registered for one or more Policy Discussion.

Autism BC
Autism Canada / Canada Autisme
Autism Edmonton
Autism Home Base
Autism Nova Scotia
Autism Ontario / Autisme Ontario
Autism Society Alberta
Autism Speaks Canada
Autism Support Network
Autism Support Network Society
Autisme Chaudière-Appalaches
Autisme Québec
Autistics for Autistics, Canada
Autistics United Canada
Azrieli Centre for Autism Research / Centre Azrieli de recherche sur l’autisme
Balance Support and Self Care Studios
Canadian Association of Occupational Therapists / Association canadienne des ergothérapeutes
Canadian Autism Spectrum Disorder Alliance / L’Alliance canadienne des troubles du spectre de l’autisme
Canadian Transportation Agency / Office des transports du Canada
CanChild, McMaster University
Canucks Autism Network
Central West Specialized Developmental Services / Services spécialisés du Centre-Ouest pour les personnes ayant une déficience intellectuelle
Centre for Autism Services Alberta
CT Labs
Durham Crew
Empower Simcoe
Every Canadian Counts Coalition
Fédération québécoise de l'autisme
FIREFLY
Government of Saskatchewan Ministry of Health
Healthy Families Healthy Babies / Familles en santé, bébés en santé
Inclusion NWT
Institut universitaire en déficience intellectuelle (DI) et en trouble du spectre de l'autisme (TSA)
Key Assets
Kids Uncomplicated
Level IT Up
Mushkegowuk Council
New Haven Learning Centre
Nishnawbe Aski Nation

Nunavummi Disabilities Makinnasuaqtiit Society
Ontario Association for Behaviour Analysis
Ontario Autism Coalition
Queer Squared
QuickStart Early Intervention for Autism
Recreational Respite
SaskAbilities
Sioux Lookout First Nations Health Authority
Speech-Language & Audiology Canada / Orthophonie et Audiologie Canada
Surrey Place
Technology North Corporation
The Centre for Child Development
The Other Autism
VIA Rail Canada