



# Stakeholder Engagement Report

# Autism in Canada: Considerations for future public policy development

Weaving together evidence and lived experience



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Canadian Academy of Health Sciences

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# The goal of this report

This report provides a brief summary of the stakeholder engagement process undertaken as part of the Canadian Academy of Health Sciences (CAHS) Assessment on Autism. The stakeholder engagement process was guided by the CAHS' Lived Experience Advisory Committee<sup>1</sup>, who provided leadership in the design and implementation of this process. We greatly appreciate the input of all stakeholder feedback received during this process. Information gleaned from this consultation process was used to frame and inform the overall assessment process, the academic evidence review, and the development of the final report.

In this report we describe:

- How stakeholders found out about the consultation process,
- Who participated, and
- The stakeholder platforms in which they could participate.

## Why engage stakeholders?

A key aspect of the CAHS Assessment on Autism was to engage various stakeholders, particularly Autistic people and their families about day-to-day issues pertaining to autism that affect their lives. Collecting information from stakeholders is a way to identify gaps in knowledge and practical challenges that may not be captured by academic evidence.

Engaging with stakeholders was especially important for this assessment as the voices of Autistic people and their families have traditionally been marginalized from decision-making processes about necessary supports and services. As such, this consultation process offered an opportunity for Autistic Canadians and their families to share their perspectives on existing areas of needs as well as possible strategies to improve their day-to-day lives.

We wanted to hear perspectives from a range of stakeholders who had differing experiences with autism. Using many different platforms (described below), we spoke to Autistic adults, family members, service providers, organizations that serve and/or advocate for Autistic clientele, and the general public. You can find definitions of each of these groups in the main report: [Autism in Canada: Considerations for future public policy development](#). You can read more about the stakeholders in the section "**Who Participated?**"

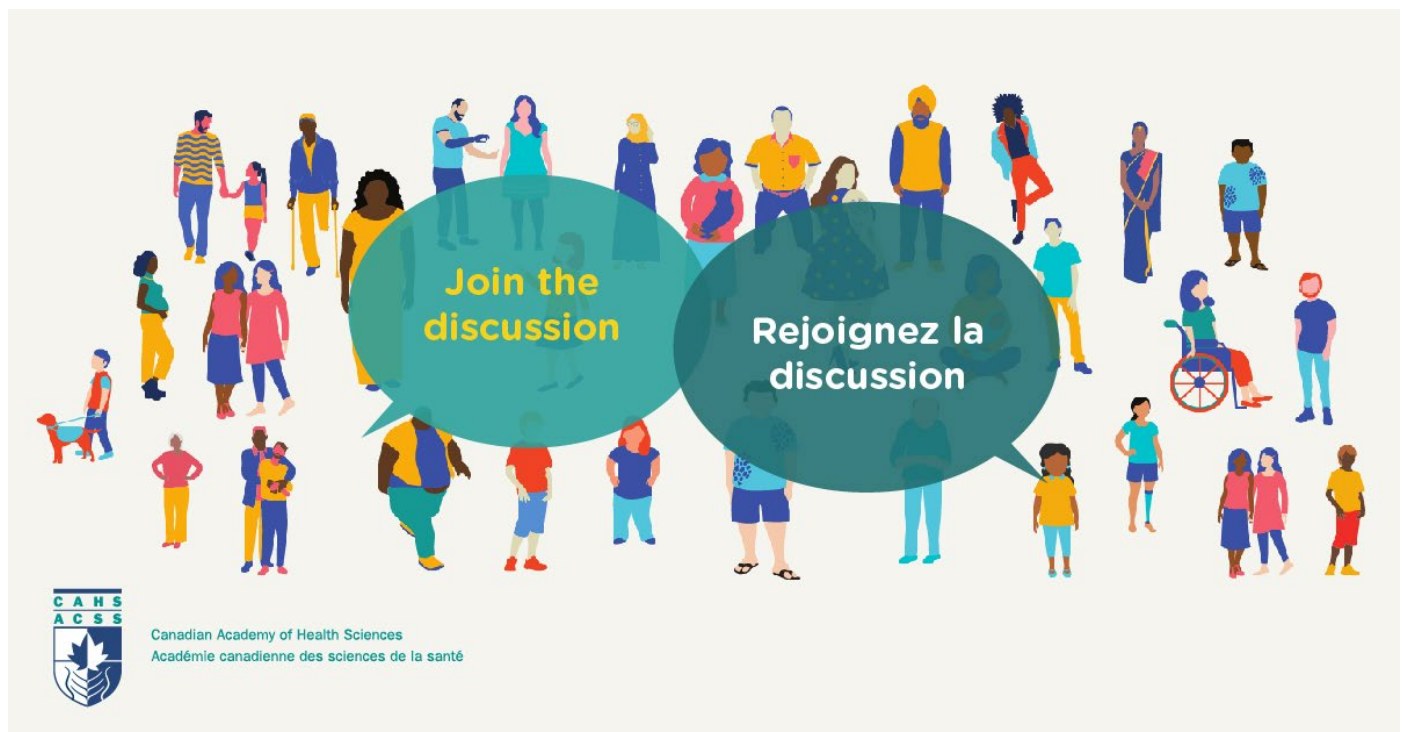
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<sup>1</sup> The Lived Experience Advisory Committee was made up of 12 Autistic individuals and parents of Autistic individuals. The majority of the Committee members also sat on Working Groups and/or the Oversight Panel.

# How did stakeholders participate?

We invited participants to take part in a seven-month stakeholder engagement process in 2021, where they had the opportunity to participate in various ways. Information about the consultation was disseminated through multiple communication channels, including email, the CAHS website, social media postings and ads, word of mouth, and press releases (see Figure 1 for a sample of a social media infographic that was used). Information about the process and how to participate was emailed to more than 800 stakeholder organizations and individuals. More information about dissemination and recruitment for each specific stakeholder platform is provided below.

**Figure 1. Join the discussion.** Sample of social media infographic.



A range of stakeholder engagement platforms were offered in order to promote equitable and accessible participation that could reach diverse communities and generate both qualitative and quantitative insights into key issues experienced by different stakeholders (see Figure 2 for an overview of the stakeholder engagement process). Each platform was offered in English and French.

These platforms included:

1. Stakeholder organization written submissions
2. Pan-Canadian opinion surveys (2) and web-based focus groups (2)
3. Indigenous engagement
4. Online platform (The Engagement Hub)
5. Virtual stakeholder consultations (community conversations and policy discussions)

Each of the stakeholder engagement platforms are described below. For many of the platforms, links to longer and more detailed summaries about the process and findings have been included below to offer further insights into the stakeholder engagement. These reports were developed with the intention of being used as working documents to inform and frame the assessment process.

**Figure 2. Stakeholder engagement process.** Implementation of stakeholder consultation platforms across time.



## Stakeholder Organization Written Submissions

In February, 2021, CAHS invited pan-Canadian, local, and grassroots organizations to provide written submissions using an online survey developed from the autism policy synthesis (phase 1 evidence review). It also offered organizations an option to attach relevant organizational documents. Organizations were given until May 2021 to complete the survey.

The purpose of this stakeholder platform was to gather insights from organizations involved in autism supports, services, policy, and advocacy about the needs and perspectives of their members or clients. Further, many organizations had spent considerable time carrying out their own research and policy analysis to identify potential promising practices or policy directions for supporting Autistic people, which provided invaluable information to consider.

Further details about the Written Submission engagement process and findings can be accessed here: [Summary of Written Submissions](#).

## Pan-Canadian Opinion Surveys and Web-Based Focus Groups

Environics, an independent research firm, conducted nationally-representative opinion surveys and hosted online focus groups. Efforts were made to obtain a diverse participant pool based on gender, region, urbanity, income, education, and other key demographic factors.

The two pan-Canadian opinion surveys were conducted from March - April, 2021 and July - August, 2021 across four key stakeholder groups: Autistic people, family members, service providers, and the general public. Across and within these stakeholder groups, the purpose of the pan-Canadian opinion surveys was to:

1. Better understand the needs, experiences, and perceptions associated with autism, and
2. Validate findings from the evidence review and test the acceptability of possible best practices and policy directions.

In follow up to the first opinion survey, two online focus groups with Autistic adults and family members were held in June 2021. Participants were recruited from those who completed the first Pan-Canadian Opinion Survey. Major topics for discussion included preliminary themes emerging from the Pan-Canadian Opinion Surveys. A second round of focus groups took place in October 2021 with Autistic adults, family members, and service providers. The goal was to obtain feedback regarding preliminary key findings. Participants were offered a variety of ways to provide input including voice video, entering text, or responding using symbols.

Further details about the engagement process and findings of these platforms can be accessed here: [Findings from Pan-Canadian Opinion Surveys and Web-Based Focus Groups](#).

## Indigenous Engagement

The assessment process aimed to include consultations and engagement with First Nations, Métis, and Inuit peoples. The purpose of the Indigenous engagement was to provide an initial description of the perspectives of Indigenous peoples related to autism, while also calling attention to some of the inequities experienced by Indigenous peoples.

A key component of the engagement was a series of in-depth interviews conducted with First Nations Autistic individuals and parents as well as service providers with significant experience working with Indigenous Autistic individuals. The goal of these interviews was to better understand experiences of autism and autism service provision within an Indigenous context. Informed oral consent was obtained and documented from all participants. Participants were offered the option of having an Elder accompany them during the interview if desired.

The collected information, as well as other aspects of the Indigenous engagement work was reviewed by the Indigenous Advisory Committee. Further details about the Indigenous Peoples engagement process and findings can be accessed here: [Brief Summary of Targeted Indigenous Engagement](#).

## Online Platform (The Engagement Hub)

Environics, an independent research firm, developed an open online engagement platform, which offered a variety of tools for collecting input from participating stakeholders. The purpose of the Engagement Hub was to provide participants with a multi-modal, accessible, and convenient social media-style platform that allows for structured engagement amongst stakeholders. This approach allowed participants to build off others' perspectives and to re-enter the platform multiple times when convenient for them. The Engagement Hub was open to Autistic people, family members, and others supporters from April to June 2021 to share their views on autism through:

- 
1. Taking a survey,
  2. Posting ideas about different topics, and
  3. Joining a discussion using the online chat forum.
- 

The tools were selected and designed with the assistance of an Autistic consultant and all content and images were reviewed by the Lived Experience Advisory Committee.

Measures to promote the accessibility of this platform included the use of larger, non-ampersand font, plain language, web pages compatible with screen readers, and bright and contrasting colours. The platform met compliance with current Accessibility for Ontarians with Disabilities Act and Web Content Accessibility Guidelines. A pan-Canadian mental health resource list was provided in French and English at registration.



Further details about the online engagement process and findings can be accessed here: [Summary of Online Platform \(The Engagement Hub\)](#).

## Virtual Stakeholder Consultations (Community Conversations and Policy Discussions)

A third-party engagement specialist developed a process for and facilitated a series of zoom-based stakeholder consultations. Zoom was chosen due to access and accessibility features such as the use of closed captioning, option to use common screen readers, both written and oral responses methods, and support of dial-up for people who have limited internet access. American Sign Language/Langue des signes québécoise interpreters were also available if required.

To promote maximal participation and emotional safety, participants were typically divided into smaller breakout rooms (less than 15 participants) based on how they identified themselves (Autistic individuals, non-autistic family members, or other supporters) during registration, each led by a trained facilitator. Each session had one or two separate breakout rooms staffed by an Autistic peer support person in the event that the content of the conversations was triggering. Similar to the Engagement Hub, a pan-Canadian mental health resource list was also provided to participants in French and English at registration.

The first series of consultations sessions (Community Conversations) ran from April to June, 2021, where participants were asked to provide feedback on:

1. How services and programs can better meet the needs of Autistic people, and
2. How we can promote the inclusion of Autistic people.

In total, 22 sessions were held. The goal of these sessions (90 - 120 minutes) was to provide a platform to hear from a diversity of Autistic individuals and their families with a range of intersecting identities. Accordingly, several sessions (9) were organized to specifically hear from individuals who identified as 2SLGBTQIA+, Black, Autistic women, young Autistic people, Newcomers, People of Colour or racialized peoples, Francophones, Autistic people who are parents, Indigenous People, and non-speaking Autistic individuals. A number (10) of sessions were specific to regions of Canada, as well as some (3) pan-Canadian sessions targeting organizations. Individuals with intersecting identities were also welcome to attend more general community conversations. In total, 22 sessions were held.

The second series of consultation sessions (Policy Discussions) took place in July 2021. Four 90-minute discussions were designed to obtain stakeholder perspectives on potential solutions-focused strategies and approaches across the assessment themes of Social



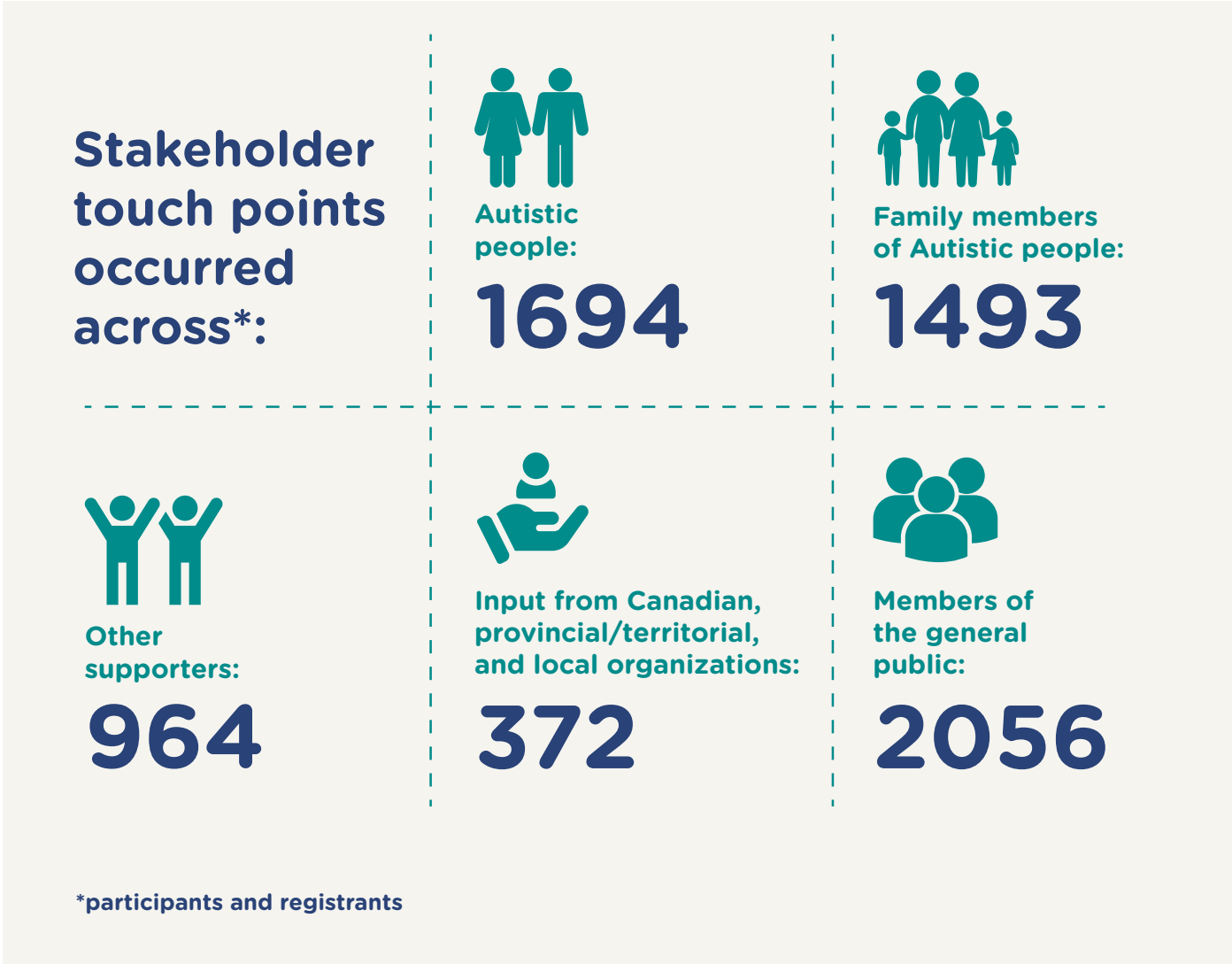
Inclusion, Diagnosis, Services, and Supports, and Economic Inclusion. Possible solutions and strategies that had been identified through the assessment process to date were presented to participants as discussion openers. Participants provided their feedback on these strategies and solutions, as well as suggested other potential ideas.

Further details about the engagement process and findings of the virtual stakeholder consultations can be accessed here: [Virtual Stakeholder Consultations](#).

## Who participated?

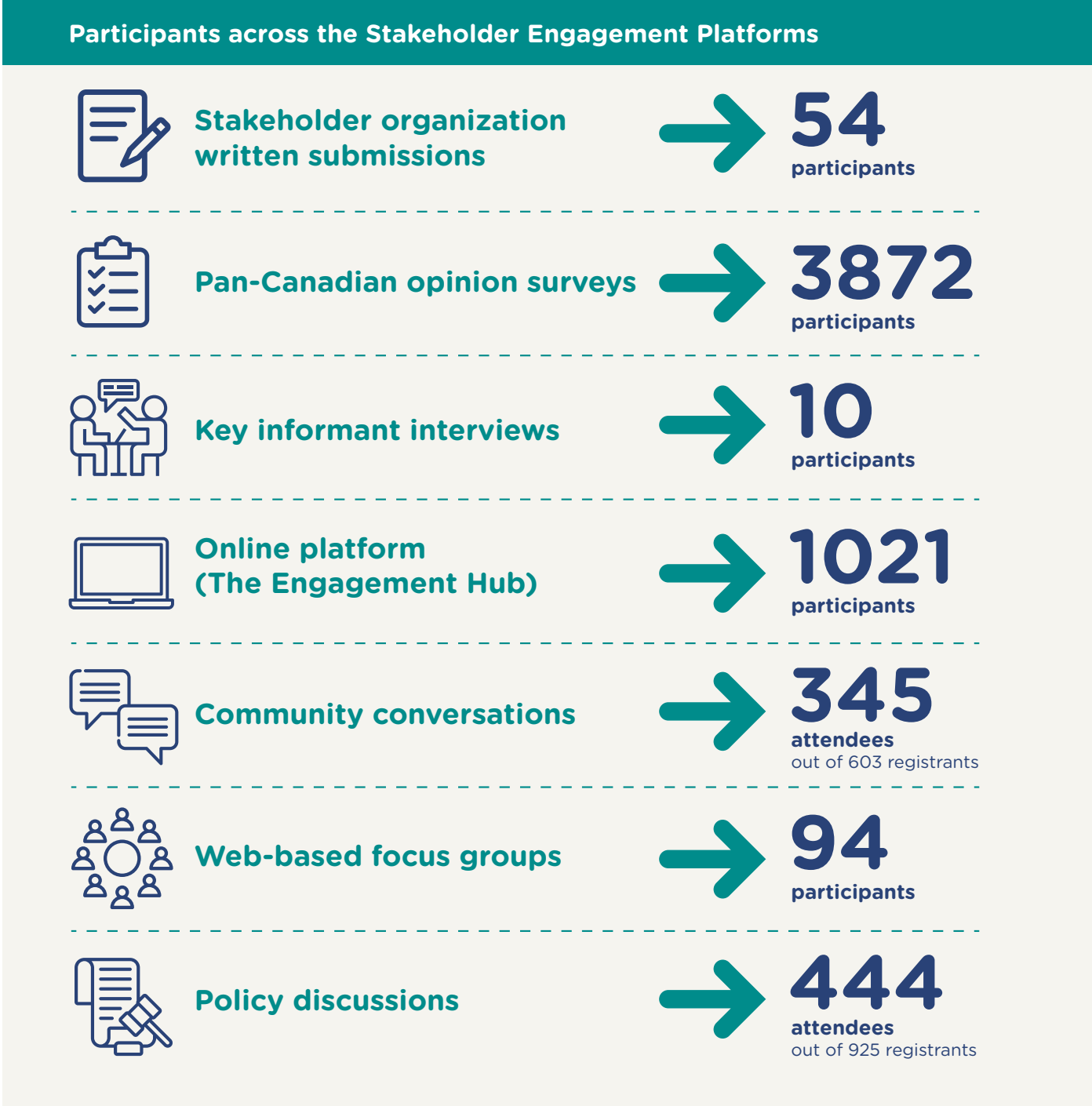
There were more than 5500 touch points across different participant groups (Figure 3) during the stakeholder engagement process. Some stakeholders may have chosen to participate in multiple platforms. Figure 4 provides a breakdown of participants by stakeholder engagement platform.

**Figure 3. Stakeholder Touch Points by Participant Group.**



During the consultation process, intentional efforts were made to include and elevate voices that have typically been absent in previous consultations and research. For example, the pan-Canadian survey oversampled 2SLGBTQIA+ Autistic people, community conversations were held specifically for racialized people, key informant Interviews were conducted with a selection of Indigenous Peoples, and the online Engagement Hub was particularly promoted to francophones.

**Figure 4. Participation across each Stakeholder Engagement Platform.**



## How we used this information

Findings from the stakeholder engagement process were consolidated and presented to the Assessment on Autism Working Groups and Oversight Panel. Upon completion of the consultations, each Working Group was tasked with reviewing and consolidating summary information from the stakeholder platforms with the findings from the research evidence. Summary information from each stakeholder platform was first considered individually and then synthesized collectively across the themes of Social Inclusion, Diagnosis, Supports and Services, and Economic Inclusion. The goal of this comparative analysis was to determine areas of alignment, as well as deduce potential gaps and areas for further evidence review. A parallel process was also undertaken by the Indigenous Advisory Group.

## Strengths and limitations of this process

While there were many strengths to this stakeholder consultation process, as with any consultation process, there were limitations to the design. Strengths of the process included promotion of accessibility principles, attention to diversity and inclusion, offering of multiple dissemination and participation channels, and the duration of the engagement window. In particular, we attempted to reach a diverse group of stakeholders by offering multiple different opportunities for individuals to participate and carefully considering the accessibility needs throughout the process.

We recognize, however, that despite these efforts, the most disadvantaged and harder-to-reach subgroups of Autistic persons and non-autistic family members remain underrepresented. This underrepresentation may be due to several reasons including ongoing systemic barriers (such as low access to internet and technology), competing economic and care priorities, as well as limited trust in public consultation processes due to prior experiences of marginalization and exclusion. Further, our recruitment strategy such as the use of social media and websites, leveraging Environics' database and CAHS' existing stakeholder list, and communication through the assessment committee members, was limited to those individuals who came into contact with these dissemination channels. Furthermore, while participants were provided with the opportunity to self-identify, we may not have fully captured the multiple roles and identities of some participants. For example, an Autistic person who is also a parent, or an Autistic service provider.

While the overall duration of the stakeholder consultation was more than seven months, platforms were available on a rolling basis. Focus groups, community conversations, and policy discussions were carried out over shorter periods of time (typically weeks or months) in order to meet the deadlines of the project. The timing could have prevented some individuals from

participating. Further, due to the compressed scheduling and with participants wishing to participate through multiple platforms, some participants found the ongoing engagement emotionally taxing.

Due to the ongoing global COVID-19 pandemic, all stakeholder consultation was held virtually or through online platforms. Through stakeholder feedback, we heard that the use of online technology was preferred by many Autistic participants. Yet, while online technologies offer many strengths in terms of access and convenience, there are also limitations. For example, we encountered initial challenges with closed captioning and simultaneous translation during breakout room sessions, which required adaptations. Additionally, managing the conversation in the zoom chat presented a challenge for the moderator at times due to the fast pace and high volume of posts.

While ongoing efforts were made to use accessible, plain language, and multiple communication options throughout all phases of the stakeholder consultation, there were areas for ongoing improvement, particularly related to information sharing with multiple audiences. Throughout the process, it was a challenge to find a balance between having short messages with few words and ensuring a bilingual process, while also providing clear explanations of complex issues to support stakeholder engagement without getting lost in details. Important learnings from this process were worked into our final dissemination plan.

This process was not set up to be a research exercise, but rather a valuable opportunity to hear from a range of stakeholders. These perspectives helped to frame the evidence review process.

Due to these limitations, the information collected during this stakeholder consultation may not be representative of all Autistic Canadians and their families. For example, we did not hear from as many Autistic francophones and Autistic Canadians living in remote areas as we had hoped.

## Conclusion

The stakeholder perspective provided essential context for the issues facing Autistic Canadians and family members, as well as strengths and challenges within Canadian systems. This added focus and nuance to the evidence review and key findings. Once again, we greatly appreciate the extraordinary efforts made by so many participants to contribute to this process.