



**Summary  
of  
Written Submissions**  
Stakeholder Engagement 2021

Canadian Academy of Health Sciences  
**Assessment on Autism**

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

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# 1. Process Overview

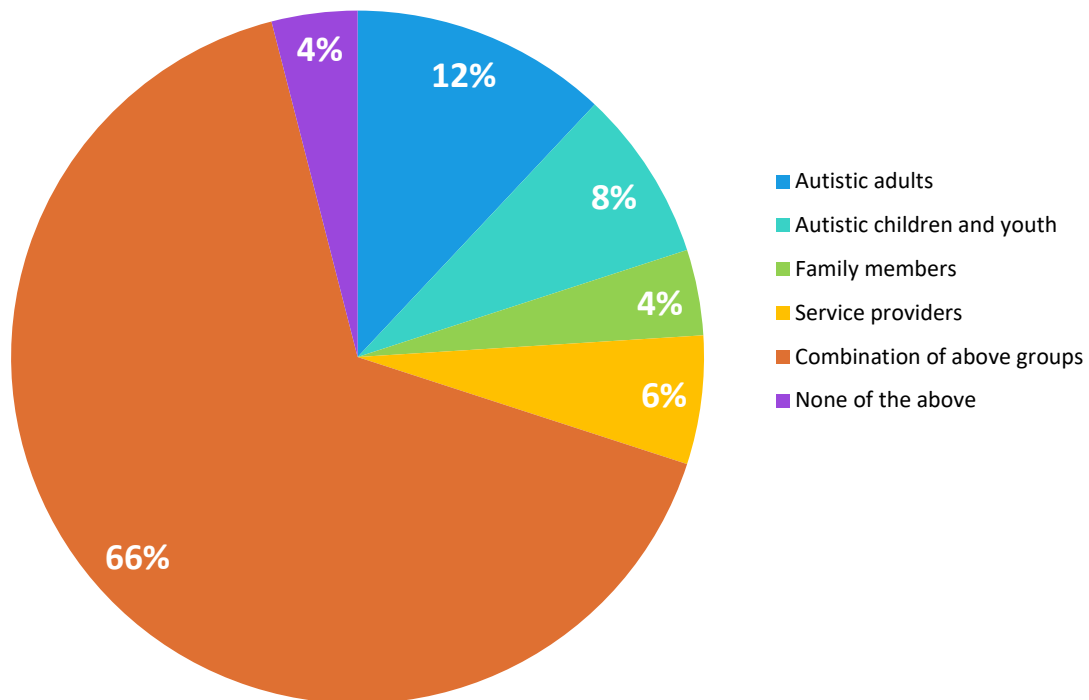
## 1.1 Description of the Process

Requesting a written submission from the stakeholder's organizations was one of the ways we collected information during the stakeholder engagement process. We sent an invitation to our stakeholder list (850 individuals and organizations) on February 26, 2021, with a request for submissions by May 31, 2021. We provided an online template in French and English with focused attention on the three themes of the assessment: Social Inclusion, Economic Inclusion, and Diagnosis, Supports, and Services. Organizations were encouraged to complete sections most important to them and were given the option to attach relevant documents. As a starting point, we asked submitting organizations to rate a list of issues across the three themes. We then invited submitting organizations to comment or attach documents on other autism issues of importance to their organization.

## 1.2 Description of the Organizations

We received a total of 54 written submissions - 50 from organizations and 4 from individuals. A complete list can be found in Appendix A. The majority (65%) of the organizations were either pan-Canadian (22%) or provincial/territorial (43%), while 20% were regional or local in focus. Almost 20% of organizations focused exclusively on serving Autistic people (see Figure 1). About a third of the organizations were established more than 20 years ago.

## Target Clientele of Organizations



**Figure 1.** Target clientele of the participating organizations.

### 1.3 Analysis

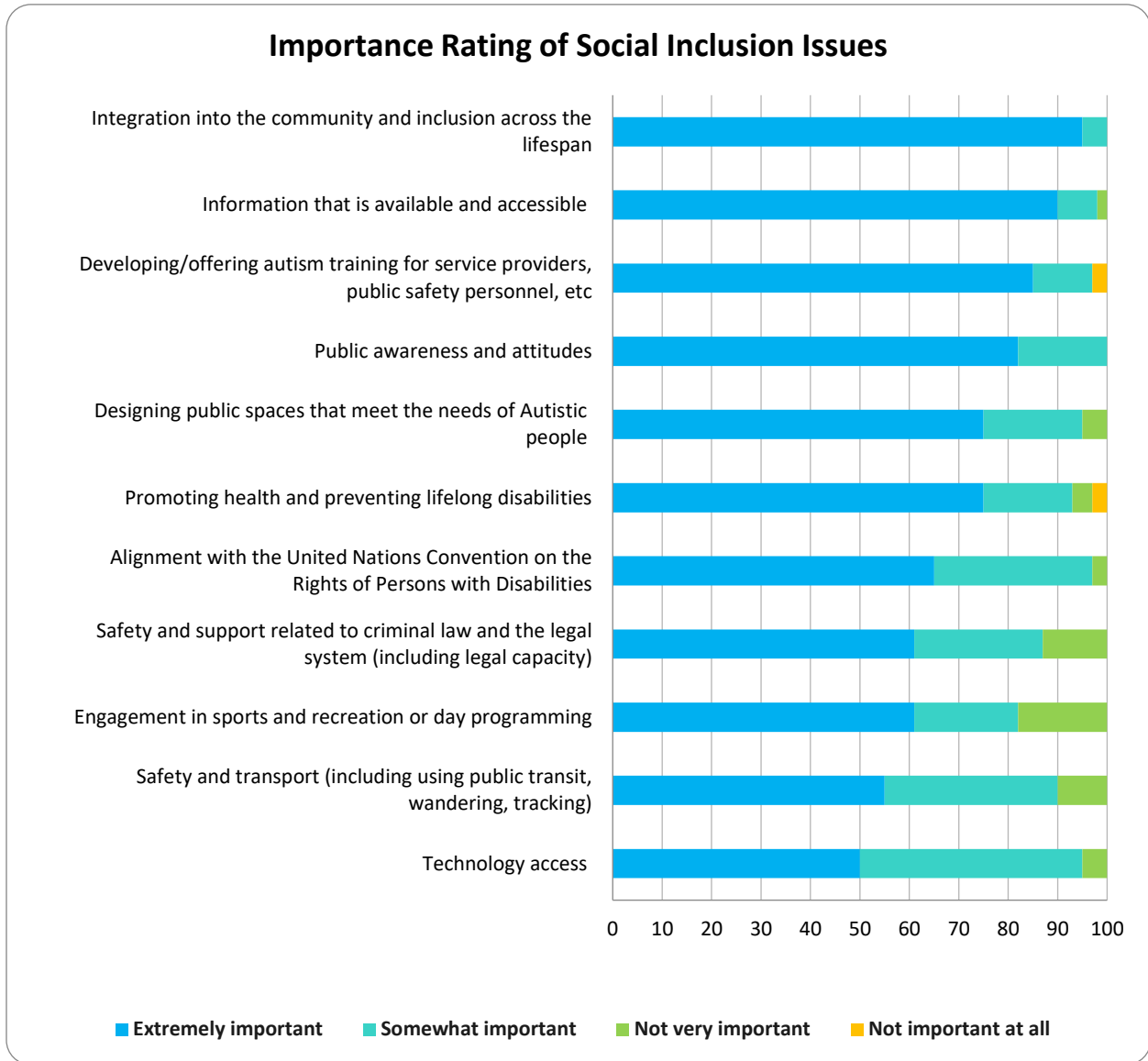
Many of the organizations shared practice and policy recommendations they had developed based on their own research and engagement processes. We used the following process for analysis and consideration of the submitted information and recommendations alongside our evidence summaries based on the academic literature:

1. Reviewed submitted information and attachments and sorted as organizational information, research/evidence, or policy recommendations.
2. Extracted policy recommendations from these documents and categorized according to theme.
3. Collated and synthesized thematic policy recommendations from these organizations for presentation to the Working Groups.

## 2. Summary of Findings

### 2.1 Social Inclusion

#### 2.1.1 Rating of Social Inclusion Issues by the Organizations



**Figure 2.** Social inclusion issues in order of importance from extremely important to not important at all as rated by the participating organizations.

## 2.1.2 Policy Recommendations from Respondents

### 2.1.2.1 Surveillance

- **Collect data** on social and economic inequities to inform policy including data on employment, housing, poverty, healthcare, and barriers faced by Autistic individuals.
- **Invest in sustainable linkages of population-level databases** to determine the trends in prevalence and developmental health of Autistic individuals over time.
- **Conduct a gap analysis** at the provincial level to determine autism policy and program design.
- Collect independent data **about social inequities experienced by diverse groups** of Autistic people.

### 2.1.2.2 Stigma

- **Focus on autism acceptance and awareness** through the use of language preferred by Autistic people, Autistic representation in media and leadership positions, public campaigns, and the recognition and consideration of communication and cultural differences. Also, including a diversity of Autistic people in research and policymaking.
- **Provide public education and training about neurodiversity** to professionals in a wide range of sectors to reduce stigma. Education should focus on neurodiversity, disability justice, and amplifying voices of marginalized groups.
- **Implement universal design principles** and the creation of accessible and less stigmatizing environments for Autistic people.
- **Promote autism acceptance messages** such as promoting strengths, talent, creativity, potential, and self-acceptance.

### 2.1.2.3 Community Participation and Accessibility

- **Fostering inclusion through inclusive and diversity of recreational opportunities** that bring together Autistic and non-autistic people.
- **Provide access to and foster awareness amongst Autistic and non-autistic people** about available services and accommodations, sensory needs, and accessibility in community settings.
- Research and policymaking should **ensure the meaningful involvement of diverse Autistic people**. Promote research and fund programs that include concepts of inclusion, communication, and sensory needs of Autistic individuals.
- **Prioritizing the needs of non-speaking Autistic individuals including access to timely and affordable augmentative and alternative**

**communication (AAC) and ensuring appropriate accommodations** are made for AAC users, which requires education for healthcare providers and first responders. Also, promoting equitable and timely access to necessary AAC services for Autistic people and their families across Canada.

- Ensure access to income supports and **accessible transportation**.
- **Improve media guidelines for accessible and respectful coverage and interviews** of Autistic people and issues that concern them.
- **Implement system navigation and community collaborations** to ensure that community recreation programming across the province is accessible to Autistic children, youth, and adults.
- **Ensure the meaningful and active participation of Autistic people in decision-making processes** (policy and research) through providing opportunities and teaching self-advocacy. Ensuring active and meaningful involvement of Autistic people and Autistic-led organizations.

#### 2.1.2.4 Education

- **Ensuring that Autistic students are included in educational settings** through the use of universal design practices and the creation of inclusive curricula and mandatory inclusive education programs. Policies should be amended to include Autistic students in common learning environments.
- **Ban exclusion and the use of restraint and seclusion in schools** and develop a tool/process for tracking the use of these measures (restraints, exclusions and seclusions) and protecting Autistic students.
- **Also make existing special education classrooms transparent** to prevent abuse including having cameras and allowing family members to enter.
- **Fostering inclusion in education through consultations with diverse Autistic people** as well as employing Autistic educators.
- **Remove barriers to participation in sports/extra-curricular activities at schools** for home-schooled Autistic children.
- **Training and education for teachers and other staff on trauma-informed care**, appropriate de-escalation techniques, neurodiversity, anti-ableism, sensory-friendly schools, and stigma, based on the latest evidence.
- **Ensure that education professionals and support workers have strong autism-specific knowledge and skills** to optimize learning for all Autistic students in the school system.
- **Develop autism education “centres of excellence” in each school board with highly trained teachers** and professional support staff, who understand the unique and complex learning needs of Autistic students and can transfer this knowledge and skill to other educational settings.



- **Foster inclusive classrooms** by improving availability and equitable access to educational supports that are individualized and not based solely on intellectual quotient (IQ).
- **Fund and develop peer mentorship programs** by and for Autistic students in educational settings.

#### 2.1.2.5 Human Rights and Public Safety

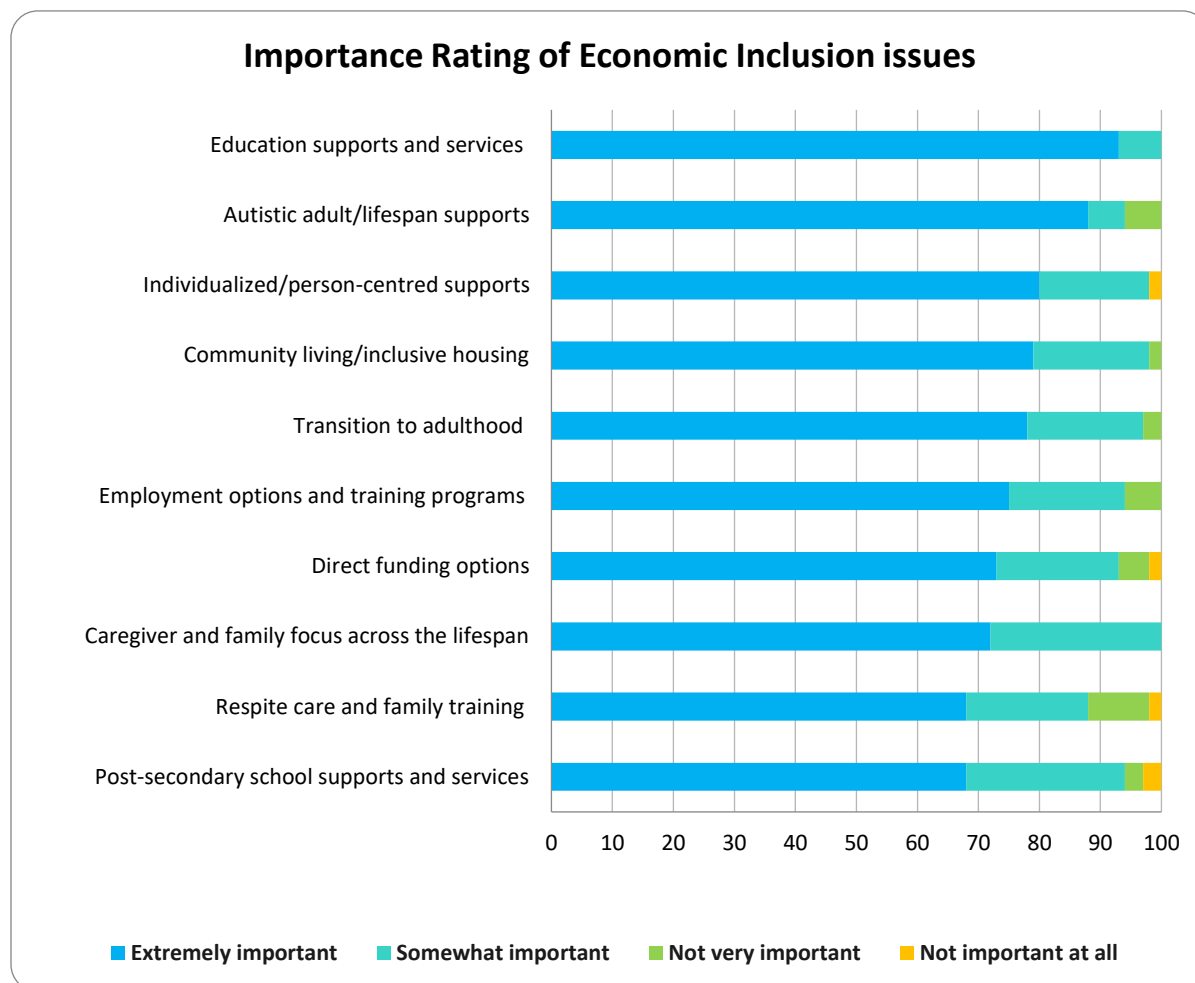
- **Promotion of basic rights and protection against discrimination** by fostering understanding of disability rights and disability justice. This includes the right to marriage.
- **Protection of bodily autonomy of Autistic children and adults** through appropriate policies, practices, and education.
- **Training for parents, guardians, and caregivers on collaborative strategies to support the safety of Autistic people** by consulting with Autistic people.
- **Ensuring that the basic needs of Autistic people are met** including sexual needs and reproductive justice, security, sense of belonging, self-esteem, and fulfillment.

#### 2.1.2.6 Decision-Making

- **Ensure the active and meaningful involvement of diverse Autistic people** at all levels of policymaking and government.
- **Prioritize supported decision-making and autonomy in decision-making over guardianship.**
- **Recognize autism as a lifelong neurodevelopmental condition** to reduce the burden of costly reassessments and ensure Autistic adults do not lose access to their benefits.

## 2.2 Economic Inclusion

### 2.2.1 Rating of Economic Inclusion Issues by the Organizations



**Figure 3.** Economic inclusion issues in order of importance from extremely important to not important at all as rated by the participating organizations.

### 2.2.2 Policy Recommendations from Respondents

#### 2.2.2.1 Financial Stability

In order to offer Autistic people and their families a stable financial foundation from which to experience wellbeing and inclusion in Canadian society, changes to the current financial support, savings, and taxation schemes and programs for disabled people are required. Several organizations made specific recommendations regarding federal or provincial programs, including:

- **Provision of a Universal Basic Income** and/or increase in the amount of disability supports provided to Autistic people.

- **Reflection of autism expenses/equipment in Medical Expense Tax Credit.**
- **Increase in the amounts for Child Care Expense Deduction** for Autistic children.
- **Extend protection of Employment Insurance Sickness Benefits** to 50 weeks for Autistic people.
- **Remove disincentives from disability programs** such as employment claw backs, loss of monetary and/or other benefits after employment/marriage, etc.
- **Relax provincial Developmental Service Eligibility requirements to include Autistic individuals** without co-occurring intellectual disability, but who require support and/or access to services.
- **Reform the Disability Tax Credit** (a gatekeeper process). For instance, ensure clear, accessible, and transparent eligibility criteria is applied to Autistic individuals and allow a wider range of healthcare professionals to complete the forms.
- **Improve access to and raise awareness about the Registered Disability Savings Plan** and other federal tax measures.
- **Continue to provide portable, individualized, and direct funding support to Autistic people.**
- **Better income support and protection from bankruptcies for long-term Autistic employees.**
- **Ensure access to direct, flexible, and sufficient funding** such that Autistic people can live with dignity and carry out activities that are meaningful to them, which may include employment, education, and living independently.
- **Increase the maximum amount and transparency of expenses that can be claimed on taxes for Autistic people.**
- **Support for families to access and navigate funding and services required to better support their Autistic family members** as well as improve their ability to participate in the labour market.
- Make **financial literacy and services** publicly available for Autistic people and their families.
- Increase funding opportunities for **Autistic artists.**

#### 2.2.2.2 Employment

A number of organizations offered recommendations regarding improving employment opportunities for Autistic people. Many of these recommendations

focused on changing the knowledge and attitudes of employers and colleagues with the aim of creating more inclusive and accessible workplaces. Greater autism awareness and stronger skill sets for employment service providers (e.g., job coaches, career counsellors, recruiters) was also recommended. Specifically, organizations suggested:

- **Developing and disseminating evidence-informed employer training** initiatives and creating opportunities for hiring and supporting Autistic employees.
- **Offering workplace incentives to employers to hire Autistic workers** (e.g., accessibility/accommodation fund).
- **Implementing and evaluating evidence-informed employment programs and practices.**
- **Awareness and offering of neurodiverse accommodations** and adjustments (e.g., preferred means of communication, scheduling, etc).
- **Considering reforms of current legislation** (e.g., pertaining to human rights, immigrant/migrant workers, anti-discrimination protections) from an autism lens.
- **Fostering more inclusive and diverse workplaces through educating and training employers** about making accommodations for Autistic people and the benefits of inclusive workplaces as well as developing pre-employment programs.

In addition to these recommendations, there were a number of recommendations made regarding transition into employment such as the provision of employment readiness supports (including internships, co-op education, and peer mentoring opportunities) in secondary and post-secondary education, and direct job entry pathways that are equitably accessible across the country.

#### 2.2.2.3 Further Education

The recommendations from organizations relevant to further education were related to accessing education and pathways into employment for Autistic students as well as ensuring that Autistic people are represented as researchers and in the production of knowledge (including on university campuses, in other research institutes, and think tanks). Organizational submissions suggested:

- **Investing in programs, accommodations, and campus accessibility policies** to support Autistic people to engage in further education, including individuals with co-occurring intellectual disability and/or complex support needs through Inclusive Post-Secondary Education programs.
- **Improving education-to-employment pathways**, for example, by opening eligibility criteria for employment opportunities and job readiness programs to more Autistic youth and engaging in further evaluation of Autistic student outcomes.

- **Improving accessibility in post-secondary application processes.**
- **Reducing bureaucratic barriers to student loans and grants.**
- **Offering more opportunities for Autistic students to participate in leadership and decision-making on campus.**

In regards to including more Autistic researchers in Canadian further education settings, it was suggested that government funding and/or incentives for post-secondary institutions should be based on Equity, Diversity, and Inclusion frameworks, including having benchmarks for Autistic students and researchers.

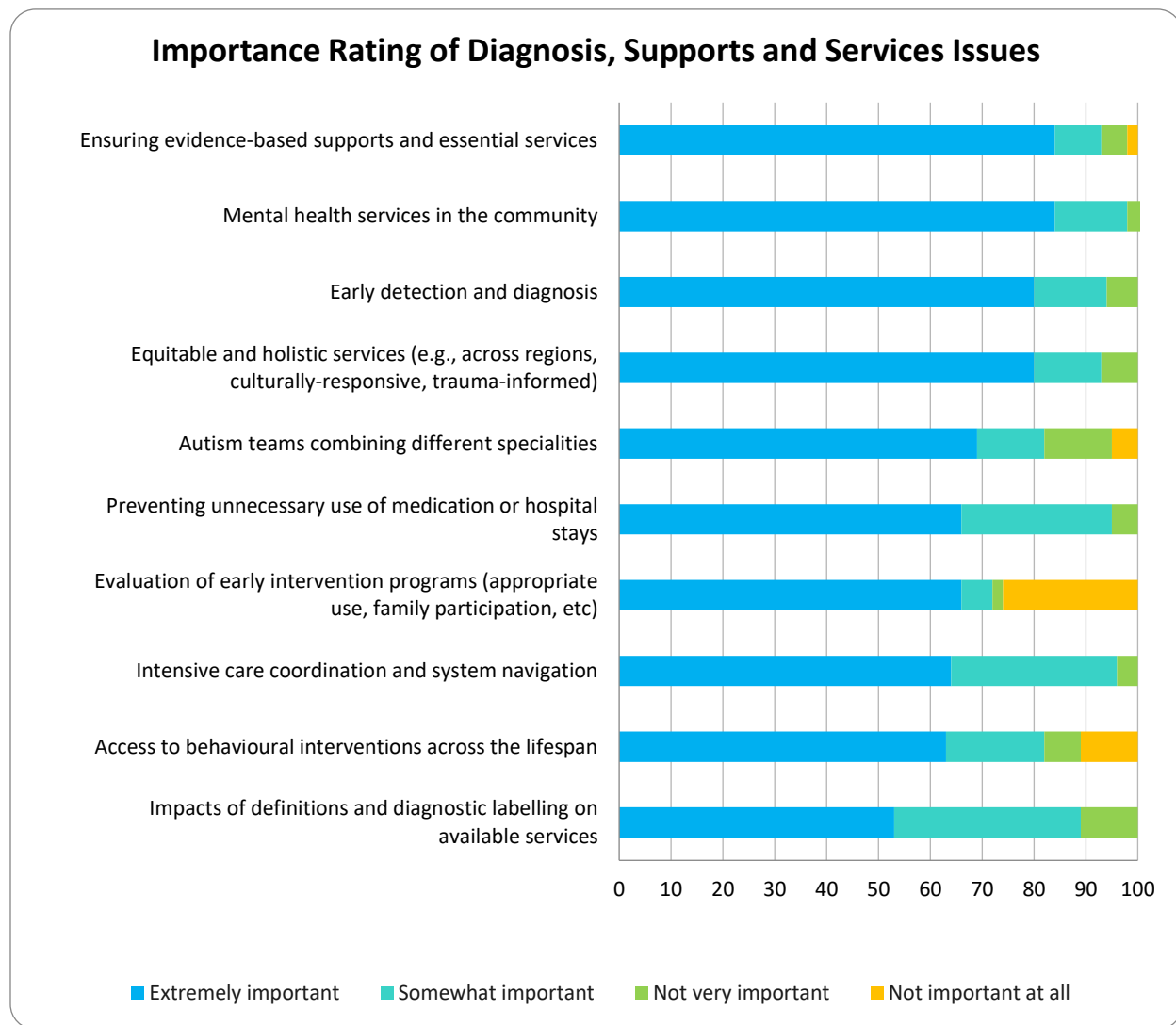
#### 2.2.2.4 Housing

Housing was a priority issue as reflected by the number of organizations that submitted recommendations relevant to housing, and the number of recommendations that were put forth regarding housing such as supply challenges and affordability, accessibility, safety and autonomy, homelessness, and developing new infrastructure, and evaluation. Specific recommendations included:

- **Convening Federal/Provincial/Territorial working group to design a disability supplement to the Canada Housing Benefit.** Work with provinces and municipalities on affordable, stable rent control.
- **Collecting Data on Housing Needs:** Partner to collect comprehensive data on diverse housing needs for Autistic Canadians.
- **Appointing Autistic representation to the National Housing Council.**
- **Auditing of private group home corporations to ensure fairness and transparency in their rules and policies,** with oversight by community members and independent living experts.
- **Ensuring Autistic people have access to affordable and supportive housing** including independent supported living arrangements.
- **Adopting a housing first targeted approach to end homelessness and incarceration among Autistic people,** particularly Autistic people with co-occurring mental health and substance abuse concerns.

## 2.3 Diagnosis, Supports, and Services

### 2.3.1 Rating of Diagnosis, Supports, and Services Issues by the Organizations



**Figure 4.** Diagnosis, Supports, and Services issues in order of importance from extremely important to not important at all as rated by the participating organizations.

### 2.3.2 Policy Recommendations from Respondents

#### 2.3.2.1 Child Diagnosis

- **Improve access to diagnosis.**
- **Increase access to publicly-funded, high-quality multilingual diagnostic services.** This may include hiring additional child psychologists to shorten diagnostic waitlists for school-aged children.

- **Provide appropriate psychological and psychoeducational assessment after an autism diagnosis** to inform future services.
- **Screen for autism** at the 12-month, 18-month, and 24-month child medical exams, well-baby clinics, or immunization appointments.
- **Provide training** for parents, physicians, and other service providers to enhance screening, early detection, and referral to assessment services for children who may be autistic.

#### 2.3.2.2 Adult Diagnosis

- **Expand access to publicly-funded adult autism diagnostic assessments** especially for women, gender diverse, and racialized individuals. This may be supported by training qualified assessors and further research.
- Offer assessments from a **holistic support perspective**.

#### 2.3.2.3 Early Childhood

- **Improve universal access to evidence-informed early interventions based on recent research** and offered through interdisciplinary teams.
- **Ensure access to services as soon as children are screened as having a high likelihood of being autistic, prior to formal diagnosis.** Cover services through Medicare or private health insurance.
- Provide timely access to **supports and services in and across school and community settings**.
- **Support parents to guide their child** by providing access to parent training.
- **Develop pan-Canadian standards for the delivery of clinical autism services**, including appropriate use of initial and ongoing assessments, as well as learning plans, through collaborations between federal and provincial governments.
- In addition to common practice approaches (e.g., behavioural), **offer occupational therapy (OT), physiotherapy, speech language therapy (SLP), and stress management therapies**.

#### 2.3.2.4 School Age/Based Supports and Services

- **Increase availability and access to evidence-based services** (such as OT, SLP, behavioural therapies). This may include school board-based initiatives and an increased ratio of therapists to students.
- **Ensure timely access to augmentative and alternative communication (AAC) supports**, as well as training for healthcare providers, teachers, and other professionals with involvement of non-speaking Autistic individuals.

- Implement **a range of tailored accommodations at school** to mitigate challenges in the school environment.
- **Amend policies to provide greater flexibility and allow student/family input** in the assignment of a classroom support person.

#### 2.3.2.5 Transition

Certain organizations suggested that preparations should start earlier to support Autistic youths to optimally transition into adulthood. Transition into older age was also mentioned as a pivotal point. It was recommended that more investment in community- and home-based services is required to ensure that Autistic adults can continue to engage optimally in these environments and that these services reflect the goals of independence, self-determination, and freedom.

- **Change the ways transition to adulthood is currently supported** so that Autistic people are better prepared to integrate into their communities.
- **Facilitate transition into the workplace.**
- **Provide transitional support across the lifespan**, particularly during the transition into adulthood where there are gaps in service.
- **Invest in home- and community-based services to support greater independence, self-determination, and freedom for aging Autistic people.**

#### 2.3.2.6 Health Systems

- Develop programs to **teach Autistic children and teens how to manage anxiety.**
- **Promote health and prevent chronic illnesses by ensuring equal and equitable access to primary care, emergency healthcare services, and specialists.** This includes implementing standards of care that include 'autism-friendly' spaces in all healthcare settings, ensuring that triage protocols do not create a disadvantage for Autistic individuals, and that Autistic individuals are supported to exercise their right to health-related decision-making, including decisions pertaining to medications.
- **Organize specialized autism teams that are integrated into the wider healthcare system**, use collaborative, proactive, and trauma-informed practices, and are supported by care coordination and system navigation.
- **Increase regulation of behavioural therapists by** adding Board Certified Behavior Analysts as a distinct profession to professional colleges.
- **Increased protection from false marketing claims about autism and exposure to potentially harmful practices.** This may include regulating the use of complementary and alternative medicine such as chelation or fecal transplantation, developing a comprehensive strategy for regulating online



sales and the promotion of health products, and regulating medical tourism to protect the health and safety of Autistic people.

#### 2.3.2.7 Child and Adult Supports and Services

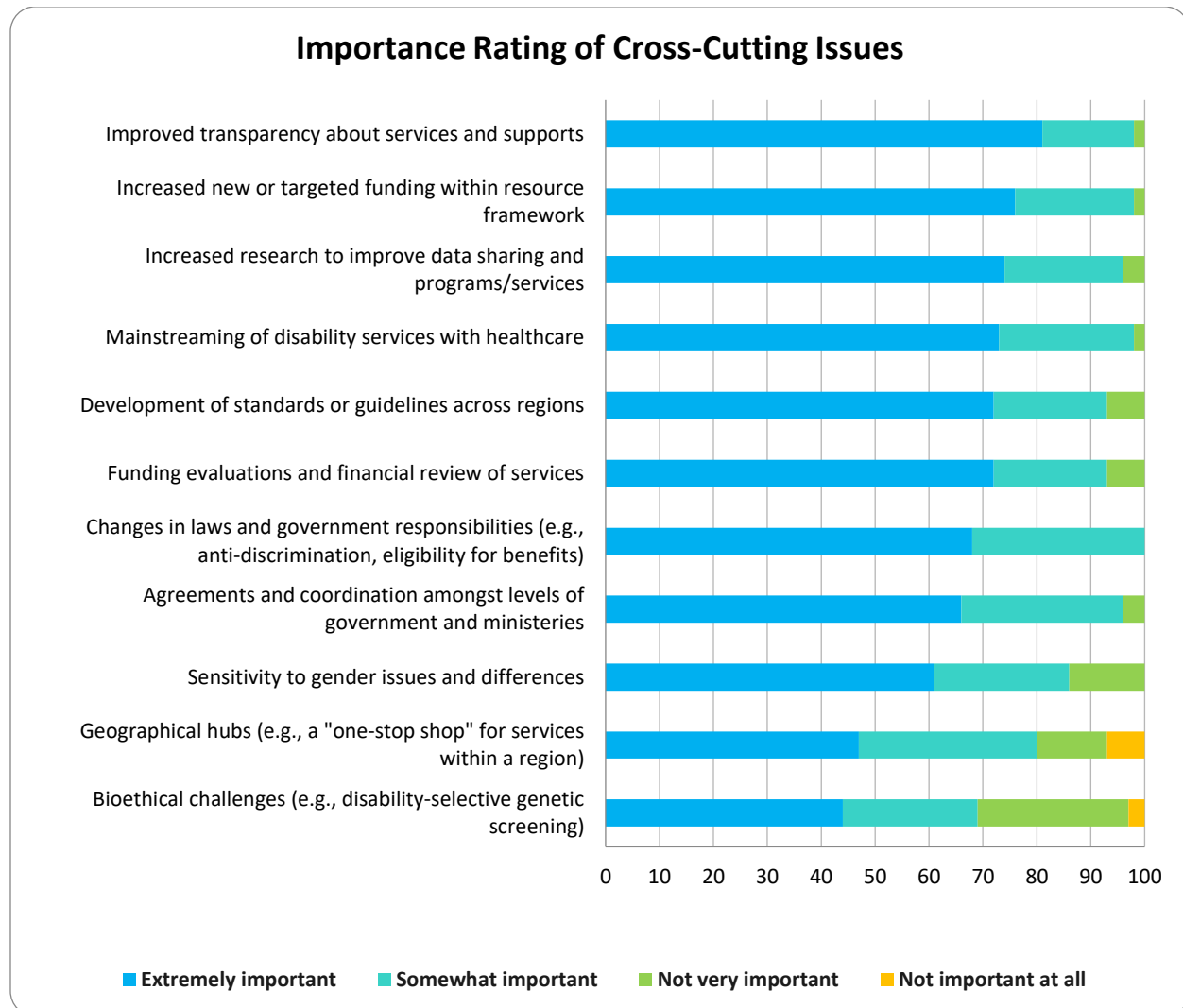
- Fund more **research and accessible services for Autistic people with co-occurring disabilities.**
- **Ensure that intellectual quotient (IQ) cut-offs are not the basis for service provision.**
- **Prioritize mental health initiatives for Autistic individuals** to improve access and affordability of mental health services that understand the needs of Autistic people.
- **Invest in expansion of community-based mental health services** staffed by mental health practitioners who are competent in supporting Autistic people.
- Develop **solutions to mental health crises that do not involve police as first responders.**

#### 2.3.2.8 Supports across the Lifespan

- **Services and supports should be needs-based and offer Autistic people and their families' options that are grounded in understanding and acceptance while also building the skills of the individual in all facets of their life.**
- **Focus supports and services on co-occurring conditions common among Autistic individuals**, such as anxiety, depression, sleep disorders, and epilepsy, rather than seeking to "cure", "prevent", or "treat" autism itself.

## 2.4 Cross-Cutting Themes

### 2.4.1 Rating of Cross-Cutting Issues by the Organizations



**Figure 5.** Cross-cutting issues in order of importance from extremely important to not important at all as rated by the participating organizations.

### 2.4.2 Policy Recommendations from Respondents

#### 2.4.2.1 Governance

- **Provide a vision** of Canada in which autism is better understood, embraced, and all Autistic people are provided with the necessary support to live, work and thrive.
- **Avoid siloing autism policy** and ensure that Autistic people are represented and considered in all of Canada's disability and inclusion policies.

- **Coordination across federal-provincial-territorial jurisdictions** regarding funding, dissemination, monitoring and sustaining programs and services, identifying gaps and reducing waitlists and creating an independent cross-governmental leadership coordinating commission.
- **Provincial/territorial role in advancing policy and human rights**, including monitoring and tracking the use of restraints and seclusion and other harmful practices.
- **Ensuring appropriate processes for monitoring and ensuring accountability of autism services and service providers.**
- **Funding policy that ensures equitable access and funding across Canada** for evidence-based therapies and supports.
- **Develop a distinct Indigenous Autism Strategy in partnership with Indigenous Peoples** respecting government-to-government relationships and the need for culturally-appropriate services that are responsive to the distinctive needs of Indigenous communities.
- **Federal leadership to facilitate cross-government collaboration to improve the lives of Autistic people in partnership with the Autistic community**, creating a learning network for practitioners and policymakers to build evidence and consensus on promising practices.
- **Fair and equal access to sufficient government funding for organizations across the lifespan based on the level of need of clients.**
- **Create an advisory group that models the structure of Accessibility Standards Canada committees** to provide consistent agenda setting across all levels of government for autism diagnosis, research, and services.

#### 2.4.2.2 Training

- **Training for caregivers, family members, and others working in the area of autism should be developed and delivered with input from Autistic people.**
- **Training initiatives** as part of a comprehensive publicly-funded autism system.
- **Improve education of families** about available supports, including those that are aimed at developing social, vocational, and daily life skills for Autistic people.
- **Implement training for service providers on non-escalatory practices** based on double empathy, low arousal, and restorative justice frameworks.
- **Comprehensive training program for teachers to support inclusive learning which include Autistic people in the delivery of the training.** Establish a minimum standard for training across provinces and territories.

- **Training and social media campaigns to combat health misinformation and stop autism pseudoscience.**
- Comprehensive training for all federal employees including the RCMP.

#### 2.4.2.3 Research

- **Fund and conduct research of administrative databases for each service system** (education, social, health) across all provinces and territories.
- **Create and fund Interdisciplinary Centres for Excellence in Autism Research and Care that involve Autistic researchers** to strengthen pan-Canadian and international collaborations, to foster the sharing of research findings, and to engage with policymakers.
- **Support research in employment, financial security, and housing for Autistic people.**
- **Conduct more participatory, community-based research.**
- **Policy decisions around supports and services should consider the quality of autism research**, particularly in regards to behavioural therapies.

### 3. Appendix A: Who Responded?

We have received a total of 54 French and English written submissions – 50 from organizations and four from individuals.

#### **List of Respondents: Organizations and Individuals**

Alberta Association for Behaviour Analysis (AltaABA)  
Algoma Family Services  
Asperger's Society of Ontario (ASO)  
Atlantic Provinces Association for Behaviour Analysis / Provinces De L'Atlantique  
Association pour l'analyse du comportement  
Autism BC  
Aut'Creatifs  
Autism Home Base Durham  
Autism Learning Partnerships, Department of Education and Early Childhood  
Development New Brunswick / Partenariat d'apprentissage en autisme, ministère de  
l'Éducation et du Développement de la petite enfance du Nouveau-Brunswick  
Autism Nova Scotia  
Autisme sans limites  
Autism Society of Newfoundland & Labrador  
Autism Speaks Canada  
Autism Support Network Society  
Autism Yukon  
Autistics for Autistics, Canada  
Autistics United Canada  
British Columbia Association for Behaviour Analysis  
Campaign Against Phony Autism Cures, Canada  
Canadian Autism Spectrum Disorder Alliance (CASDA) / L'Alliance canadienne des  
troubles du spectre de l'autisme (ACTSA)  
Canadian Autism Treatment for Medicare Coalition  
Canucks Autism Network  
Centre for Autism Services Alberta  
Citizens with disabilities Ontario  
Clinique Spectrum  
Corrado, Nicole (Individual)  
Granville Pediatrics and Family Medicine  
Healthy Families, Healthy Babies / Familles en santé, bébés en santé  
Hello Speech  
Kavchak, Andy (Individual)  
Kids Uncomplicated / Enfants Simples  
Kitimat Child Development Centre  
Laing House  
Learning Ability  
Manitoba Association for Behaviour Analysis (MABA)  
Monaghan, Patrick (Individual)

Moore, Nathan (Individual)  
Neurodiversity YMM (Fort McMurray)  
New Heights School and Learning Services  
North star Toy Lending Library EarlyON/ON y va  
Ontario Autism Coalition  
Pacific Autism Family Network  
Productions Spectrum/Productions Spectrum  
Quebec Association for Applied Behavior Analysis / Association Québécoise pour  
l'Analyse du Comportement  
QuickStart Early Intervention for Autism  
Réseau national d'expertise en trouble du spectre de l'autisme (RNETSA)  
Sea to Sky Community Services  
SHO (full name was not provided)  
Society for Treatment of Autism  
Speech-Language & Audiology Canada (SAC) / Orthophonie et Audiologie Canada  
(OAC)  
The Canadian Council on Rehabilitation and Work / Le Conseil Canadien de la  
Réadaptation et du Travail  
The Durham Crew - Autism Advocates  
The Ontario Association for Behaviour Analysis (ONTABA)  
The Portia Learning Centre  
The Sinneave Family Foundation