Brief Summary of Targeted Indigenous Engagement

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 Groups discussions

This report was developed with the support and direction of a CAHS Assessment on Autism Indigenous Advisory Committee:

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Executive Summary

The Public Health Agency of Canada contracted the Canadian Academy of Health Sciences to undertake a pan-Canadian assessment on autism. According to agreed terms, the assessment included consultation and engagement of Indigenous peoples. Canada's Constitution recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit. The purpose of this report is 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.

While the term Indigenous does not reflect the uniqueness of each group, it is used in this report where we cannot be more specific due to small numbers of participants and inability to identify specific groups. This report presents a synthesis of input from self-identified Indigenous individuals who participated in the Assessment on Autism stakeholder engagement.

Participant responses highlight that Indigenous peoples experienced many of the same challenges as other Autistic Canadians, such as difficulties with accessing health and educational services, economic exclusion, and not feeling safe in their communities. However, Indigenous Autistic Canadians and their parents indicated that experience of historical trauma and racism within the public service systems intersect with autism to create additional or more intense challenges.

Participants shared how feeling afraid that their child may be apprehended without cause (rooted in historical intra-generational trauma) and feeling anxious about being mistreated by the healthcare system beyond their local health clinic (due to past racist experiences) added additional filters to their decision-making process that made them hesitant to initiate contact with the healthcare system.

Indigenous participants also experienced additional challenges related to accessing funding through federal programs that other Canadians do not have to contend with. Participants shared the difficulties they experienced when trying to seek support through non-insured health benefits or Jordan's Principle funding, which included excessive and confusing application processes. Parents often had their first application denied due to not understanding how to fill out the forms correctly with sufficient information, resulting in delays and appeals. Community-based organizations supported several parents to access funding and services. This contrasts with the usual experience of most Canadians, where a diagnosis of autism is sufficient to access existing provincial programming.

Parents also perceived that there was inconsistency in the administration of federal programs across Canada. Many respondents expressed appreciation of, or desire for, culturally-based programming including land-based approach/activities, elder guidance, and therapeutic interaction with animals. In some instances, Autistic individuals and parents recounted experiences of being accepted and supported within their rural and remote home communities, leading to positive social and economic inclusion. Respondents suggested that there is merit to developing local, tailored programming that builds on the traditional strengths and contexts of Indigenous communities.

This report is preliminary and limited in scope, with the expectation of future inclusion and consultation with First Nations, Métis, and Inuit health leaders in addressing the needs of Indigenous Autistic people and their families/family members.

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Introduction

The Public Health Agency of Canada contracted the Canadian Academy of Health Sciences to undertake a pan-Canadian Assessment on Autism. According to agreed terms, the assessment is to include consultation and engagement of Indigenous peoples. Canada's Constitution recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit. While the term Indigenous does not reflect the uniqueness of each group, it is used in this report where we cannot be more specific due to small numbers of participants and inability to identify specific groups.

The purpose of this report is 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. The Canadian Academy of Health Sciences Assessment on Autism Oversight Panel and Working Groups include Indigenous individuals who have helped guide the integration of perspectives of Indigenous peoples. However, this report is preliminary and limited in scope, with the expectation of future inclusion and consultation with First Nations, Métis, and Inuit health leaders in addressing the needs of Indigenous Autistic persons and their families/family members.

We recognize and value the distinct cultures of First Nations, Métis, and Inuit peoples. We also recognize the complex and unique histories of European colonization experienced by First Nations, Métis, and Inuit peoples, the importance of geographical challenges (e.g., reserve, remote, northern, urban, settlement), and the historical and contemporary relationships between different Indigenous groups. Jurisdictional challenges across the human service sector for different Indigenous Nations are also recognized in this report as key to health and service delivery and access to healthcare.

This report was developed as a beginning to understanding the experience of autism among Indigenous peoples in Canada, recognizing and honouring the rights of Indigenous peoples to exercise sovereignty over their data.

We further recognize the limitations of our engagement processes to reach and engage with the diverse First Nations (Status and Non-status), Métis, and Inuit peoples to fully explore the rich variations due to history, language, geography, population size, and living on or off reserve, among others. Due to the COVID-19 pandemic, engagement was primarily limited to online options that may have been inaccessible to those without reliable internet connections in rural and remote areas. In addition, only adults with a diagnosis or parents of diagnosed children participated in the survey, perhaps leaving out those who have yet to access a diagnosis, including those involved in the child welfare system. We recognize the need for the

Government of Canada to fully engage with Indigenous peoples on autism to expand and build on this initial report.

Indigenous Engagement Process

The Indigenous engagement work is overseen by an advisory committee that includes three Indigenous individuals (two First Nations and one Métis) that serve on the Oversight Panel and Working Groups, as well as a First Nations researcher focused on autism. Assessment Chair, Dr. Lonnie Zwaigenbaum and Vice-Chair, Dr. Mélanie Couture attended all committee meetings. The committee has overseen the entire process, from data collection to shaping this section of the final report.

Several Indigenous nations and organizations were contacted at various points in the stakeholder consultation process. They participated to the extent they were able during the COVID-19 pandemic and while addressing additional priorities.

Stakeholder engagement included a pan-Canadian opinion survey, an online community conversation, an online engagement platform, and targeted in-depth interviews. This report presents a synthesis of information gathered from those who self-identified as Indigenous through these sources of stakeholder engagement.

The pan-Canadian opinion survey reached a significant number of individuals that identified as First Nations, Métis and Inuit, – Autistic individuals (60, 18%), family members (42, 15%), service providers (17, 5%), and general public (28, 5%). Targeted quotas for ethnicity were predetermined based on total Canadian estimates, which allowed for the oversampling of certain populations including Indigenous people[1]. Although some Indigenous individuals from Quebec participated, there were no Indigenous French-speaking respondents.

The community conversation designated for Indigenous persons was attended by seven individuals, including parents, service providers, and representatives of pan-Canadian Indigenous organizations.

The Engagement Hub, an online platform, included a survey that was responded to by 11 Indigenous Autistic individuals, 10 family members, and five supporters. Respondents were only asked to identify whether they were Indigenous, so it is not possible to state whether they were First Nations, Métis, or Inuit.

In addition to the regular avenues for stakeholder engagement open to all Canadians, including Indigenous peoples, the assessment also included a targeted Indigenous consultation. First Nations, Métis, and Inuit parents of Autistic individuals and Autistic individuals, as well as service providers with significant experience working with Indigenous Autistic individuals throughout Canada were invited to participate in in-depth interviews. Respondents included seven First Nations parents, one First Nations Autistic adult accompanied by a parent, and two service providers. They resided in British Columbia, Alberta, Saskatchewan,

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[1] According to the 2016 Canadian census, 4.9% of the Canadian population identified as First Nations, Métis or Inuit.

Manitoba and Ontario. Unfortunately we were not successful with recruiting any Métis or Inuk individuals to participate in these in-depth interviews.

A synthesis of information gathered through all sources of stakeholder engagement with Indigenous persons, including community strengths and concerns is presented below. This synthesis was based on a thematic analysis of the information, which has been reviewed by the Indigenous Advisory Committee.

1. Social Inclusion

1.1. Awareness and Acceptance

1.1.1 Pan-Canadian Opinion Survey #1

- 95% of both Indigenous Autistic adult and family member respondents reported that their community offers adaptations to be more inclusive of Autistic people, compared to white Autistic adults and family members (61%), Autistic adults of other ethnicities (56%) and family members of other ethnicities (75%).

- Many Indigenous family member respondents indicated that their Autistic family members are interested (83%) and comfortable (71%) with participating in community-based activities. A smaller proportion of white family members stated that their Autistic family members are interested (67%) and comfortable (45%). In comparison, 81% of family members of other ethnicities responded that their Autistic family members are interested in participating in community-based activities and 52% are comfortable.

- Indigenous members of the public were more supportive of several adaptations to support Autistic people to feel more included in the community, including shopping hours with no music (43%) and dedicated parking spots (36%); while white members of the public indicated less support for shopping hours with no music (27%) and dedicated parking spots (15%); and members of the public of other ethnicities indicated a similar level of support for shopping hours with no music (28%) and dedicated parking spots (18%).

- 82% of Indigenous members of the public agreed that autism is a unique strength, compared to those that identified as white (65%) or other ethnicity (67%).

1.1.2 The Engagement Hub

Several Indigenous Autistic adults described feeling supported within their traditional cultural groups. Experiences of stigma and how to enhance acceptance was also addressed. Indigenous family members also spoke about the lack of acceptance of autism in the general community; however, they felt more accepted among their First Nations communities. Indigenous family members also spoke about their Autistic family members' difficulties with participating in community activities and offered several suggestions.

1.1.3 In-depth Interviews

Some First Nations parents described Autistic family members' difficulties with accepting their Autistic family members' diagnosis, as well as some concerns with being accepted in the community.

Participants mentioned low awareness and knowledge about autism in some communities. However, as on the Engagement Hub, they also noted greater acceptance of individuals with different abilities in First Nations communities. They also emphasized the role of community-based organizations and schools to build awareness and provide opportunities for social inclusion.

1.2 Detecting Initial Signs of Autism

1.2.1 In-depth Interviews

First Nations parents recognized daycares as being well-positioned to identify children with developmental concerns, but currently not equipped to do so. They also saw immunization appointments as an opportunity for screening. First Nations parents appreciated the role of community-based organizations to advocate for families if there were developmental concerns and to link them to services.

1.3 Safety

1.3.1 Pan-Canadian Opinion Survey #1

- 42% of Indigenous Autistic respondents said that they have often been subjected to degrading treatment, compared to 35% of those that identified as white or other ethnicity.
- 98% of Indigenous Autistic respondents agreed or strongly agreed that being autistic makes them vulnerable or compromises their safety, compared to those that identified as white (82%) or other ethnicity (80%).
- Only 36% of Indigenous Autistic respondents stated they were fairly comfortable with expressing their feelings online, compared to those that identified as white (74%) or other ethnicity (75%).

1.3.2 The Engagement Hub

Some Indigenous Autistic adults mentioned concerns regarding their personal safety and security. Some had negative experiences with police or first responders, and suggested more training. Indigenous family members also indicated some concern with how police have interacted with their children. Indigenous supporters advocated for individualized support and safety gear to ensure the safety of Autistic individuals.

1.3.3 In-depth Interviews

Respondents indicated a number of safety concerns including being vulnerable to wandering, being taken advantage of financially, and not being safe in schools due to insufficient supports. They also spoke about the importance of having trusted contacts in case of emergency and effective police responses through improved autism awareness and training.

1.4 Appropriate Education Services

1.4.1 Pan-Canadian Opinion Survey #1

- 13% of Indigenous Autistic respondents agreed that their needs were completely or mostly met in elementary school, compared to Autistic respondents that identified as white (26%) or other ethnicity (23%).
- Many Indigenous family member respondents stated that elementary schools and high schools did not meet the needs of their family member(s) (41%), compared to those that identified as white (27%) or other ethnicity (11%).
- A high proportion of Indigenous family member respondents reported that high schools did not meet the needs of their family member(s) (42%), compared to white family members (22%) and family members of other ethnicities (11%).
- Indigenous Autistic adult (86%) and family member (71%) respondents commonly stated that their right or the right of their Autistic family member to an education was often or sometimes violated; while a lower proportion of white Autistic adults (61%) and family members (53%) as well as Autistic adults (71%) and family member (65%) of other ethnicities reported similar concerns.
- 70% of Indigenous Autistic respondents shared that their highest level of education was high school or less, compared to those that identified as white (19%) or other ethnicity (9%).

1.4.2 The Engagement Hub

Indigenous Autistic individuals recalled both supportive and negative experiences with the school system. Negative experiences included bullying, difficulties with transitions, and a lack of mental health and academic supports. Positive experiences included access to academic and extracurricular programs of interest (such as computer classes), openness to sensorimotor approaches/accommodations, and friendships.

Indigenous family members described challenges and mixed experiences with the education system with services sometimes tied to a diagnosis. A perceived lack of training of educational staff and stark differences in available services and programming across schools and educators were major barriers discussed, although some family members also discussed the use of helpful programs and services.

1.4.3 In-depth Interviews

First Nations respondents shared concerns about:

- Behavioural, bullying, and wandering challenges that affect inclusion in schools,
- Requirement of a diagnosis to qualify for an educational assistant, especially in provincially funded schools,

- Educational opportunities designed to meet the needs of Autistic children, and
- Better training for educational assistants.

However, some families persevered in the public systems, and felt they received better supports through Indigenous-based community schools, which led to success for their child.

1.5 Community Participation

1.5.1 The Engagement Hub

Autistic adults noted difficulties with public transportation options and suggested some possible solutions, such as more reliable and accessible public transportation options that are sensitive to the needs of Autistic people. Ride cards, ride-sharing programs, and eligibility for disability transportation options were also discussed.

Indigenous family members noted that living in remote or rural areas makes it difficult to access public transportation options. However, they shared some autism-friendly suggestions, such as having a plain language, visual bus schedule and low sensory times or rides. Indigenous supporters described additional transportation issues associated with living in remote communities, especially the added sensory distress caused by loud bush planes used for fly-in communities.

1.5.2 In-depth Interviews

First Nations parent respondents described having limited social networks beyond family. They reported having supportive networks in small towns but feeling disconnected in large cities away from reserves. Some parents experienced difficulties with accessing daycare.

The importance of close family to provide support was mentioned by service providers and First Nations parents during in-depth interviews. However, sometimes family support was limited due to growing up in care or having family members that were unable to provide the full range of needed support.

First Nations parents also shared how they included Autistic children and adults in traditional and on the land activities, sometimes modified to meet sensory needs. Traditional activities also served as an ad hoc peer support forum.

Similar to the Engagement Hub, First Nations Autistic adult and parent respondents indicated that they had access to limited transportation options beyond family in rural and remote areas.

1.6 Healthcare Services

1.6.1 The Engagement Hub

Indigenous family members described mixed healthcare experiences due to lack of acceptance or accommodations to meet their Autistic family member's needs related to autism.

1.6.2 In-depth Interviews

First Nations parents shared some poor healthcare experiences involving discrimination and structural racism, resulting in low trust of the healthcare system.

2. Economic Inclusion

2.1 Housing

2.1.1 Pan-Canadian Opinion Survey #1

- A higher proportion of Indigenous Autistic respondents reported living in subsidized housing (13%), larger residential care facilities (e.g., nursing homes) (10%), and group homes (10%) compared to other groups. A smaller proportion of white Autistic adults indicated that they lived in subsidized housing (5%), larger residential care facilities (4%), or group homes (1%). A similarly low proportion of Autistic adults of other ethnicities reported living in subsidized housing (8%), larger residential care facilities (3%), or group homes (2%).
- Indigenous family member respondents commonly indicated that long waitlists for supportive or subsidized housing (38%) and no suitable housing options (i.e., pets not allowed, sensory sensitive) (29%) were challenges to accessing housing for their Autistic family member(s). A lower percentage of white family member respondents reported the same challenges - long waitlists (18%) and no suitable housing options (11%). However, a fairly high percentage of family members of other ethnicities listed these challenges - long waitlists (29%) and no suitable housing options (27%).

2.1.2 The Engagement Hub

Autistic adults highlighted their diverse housing needs and suggested several options to make housing more accessible. The suggestions included:

- Better regulation and residential standards,
- Needs-based support services not directly linked to intellectual quotient (IQ),
- sensory and cognitive accessibility features within housing, such as dimmable lights, and
- Pet-friendly buildings.

Indigenous family members noted the need for options to support individuals to stay in the community with sufficient supports. These supports included modifications to the built environment of housing.

2.1.3 In-depth Interviews

First Nations parents advocated for extended supports to meet individualized needs, as well as supportive housing options.

2.2 Employment

2.2.1 Pan-Canadian Opinion Survey #1

- Indigenous Autistic adults (40%) and family member (31%) respondents indicated that they or their family member(s) have often experienced violations of their right to work. This concern was not identified as often by white Autistic adults (23%) and family members (19%). However, Autistic adults of other ethnicities (33%) and family members (29%) also commonly stated this concern.

- Government wage subsidy programs were rated as important to ensuring that Autistic adults could succeed in the workplace by 58% of Indigenous family member respondents, compared to those that identified as white (33%) or other ethnicity (27%).
- A higher proportion of Indigenous members of the public (79%) stated they would be comfortable with having an Autistic work colleague, compared to those that identified as white (64%) or other ethnicity (62%).
- 46% of Indigenous members of the public indicated that improved community supports should be available to assist Autistic individuals in the workplace, compared to those that identified as white (31%) or other ethnicity (28%).

2.2.2 The Engagement Hub

Indigenous family members advocated for the community to welcome their Autistic family member into the job market and onto university campuses.

2.2.3 In-depth Interviews

Some First Nations parents described experience with supportive employers in small towns, while others shared challenges with accessing childcare, which could mitigate their ability to join the labour force.

First Nations parents and Autistic adults spoke about finding suitable employment for Autistic adults with supportive employers and coworkers in small towns. Others were not able to find employment and relied on disability income support. Both First Nations parents and Autistic adults emphasized that Autistic adults can be reliable and trustworthy employees.

First Nations parents also shared how they try to help their adult child with financial literacy. They, along with service providers, suggested more structured opportunities for this kind of learning was needed.

2.3 Life Transitions

2.3.1 In-depth Interviews

First Nations parents indicated that they were primarily responsible for helping their adult children build life skills due to the lack of suitable programs. First Nations parents expressed concerns with how their children will transition to adult disability supports.

2.4 Economic Hardships

2.4.1 The Engagement Hub

Several Indigenous Autistic individuals mentioned economic hardships related to difficulties with finding and keeping a job. They also noted economic hardships associated with the extra costs of meeting their autism needs. Many Indigenous family members and Autistic adults were unaware of the option of opening up a Registered Disability Savings Plan, and those that were aware, noted barriers such as restrictive definitions of disability.

Some Indigenous family members also shared stories of losing their jobs due to their care responsibilities.

2.5 Post-Secondary Education

2.5.1 The Engagement Hub

Some Indigenous Autistic adults shared mixed experiences in the post-secondary education system. Negative experiences involved feeling a constant need to self-advocate for required accommodations and challenges with cultural attitudes. On the other hand, some participants described feeling supported by academic advisors or mentors, especially as they transitioned from undergraduate to graduate programs.

2.5.2 In-depth Interviews

First Nations parents expressed aspirations for their children to attend postsecondary education and the need for supportive opportunities.

3. Diagnosis, Supports, and Services

3.1 Access to Diagnosis

3.1.1 Pan-Canadian Opinion Survey #1

- 64% of Indigenous Autistic respondents reported being diagnosed after the age of 18 years, compared to 45 and 46% for respondents who identified as white or other ethnic group, respectively.
- Only 24% of Indigenous family member respondents indicated that the Autistic individual they support (most commonly their child) was diagnosed by five years of age, compared to those that identified as white (45%) or other ethnicity (47%).
- 32% of Indigenous family member respondents reported that it took 1 to 2 years to get a confirmed diagnosis for their family member, compared to those that identified as white (13%) or other ethnicity (9%).
- 2% of Indigenous Autistic adults and Indigenous family member respondents indicated that the costs of the diagnostic assessments were fully covered (through the public system or private insurance). A higher proportion of white Autistic adults (19%) and family members (36%) and Autistic adults of other ethnicities (20%) and family members (23%) accessed diagnostic assessments.

3.1.2 The Engagement Hub

Indigenous Autistic individuals shared many challenging experiences related to accessing a diagnosis during adolescence and adulthood. Many waited several years for a formal diagnosis and needed to travel long distances to find a qualified and/or available diagnostician. Indigenous Autistic individuals described the perceived impacts of a late or misdiagnosis such as inadequate ongoing healthcare, which, at times, included improper medication management.

Indigenous family members also mentioned difficulties with accessing diagnosis due to long waitlists, inaccessible services, and their family physician not taking their concerns seriously. According to some Indigenous family members, diagnostic delays sometimes occurred due to parents’ difficulty with accepting the possibility of autism. Indigenous supporters emphasized the cumbersome travel and high costs associated with accessing an assessment.

3.1.3 In-depth Interviews

Services providers and First Nations parents noted many challenges to diagnosis leading to delayed diagnosis, such as:

- Travel,
- Infrequent traveling clinics,
- Unstable housing,

- Physician resistance to refer to specialist team, and
- Physician bias contributing to not fully investigating the possibility of autism.

Service providers and First Nations parents expressed feeling hesitant to access diagnostic services due to stigma, racism, fear, or not recognizing the possible benefits of an assessment. They also noted the important role of community-based organizations to support families to access diagnostic and support services and the role of teachers in identifying the possibility of autism.

Flexible, client-centered, and local approaches to diagnosis, sometimes using remote technology, were described by some as being more successful.

3.2 Access to Supports and Services

3.2.1 Pan-Canadian Opinion Survey #1

- 55% of Indigenous family member respondents indicated that their Autistic family member did not receive supports and services before the age of six years, compared to those that identified as white (37%) or other ethnicity (32%).
- Indigenous Autistic respondents stated higher support for full public funding for natural health supplements (43%) and sensory-friendly products (55%) (i.e., light dimmers, headphones) compared to other groups. A lower proportion of white Autistic adults indicated support for full public funding for natural health supplements (34%) and sensory-friendly products (46%). A similar percentage of Autistic adults of other ethnicities supported full public funding for natural health supplements (34%) and sensory-friendly products (38%).
- 53% of Indigenous Autistic respondents indicated they have often or very often gone without autism-related services due to cost compared to those that identified as white (41%) or other ethnicity (38%).
- Indigenous family member respondents commonly reported extensive or some financial hardship due to autism-related costs (81%), compared to those that identified as white (61%) or other ethnicity (56%).
- A fair proportion of Indigenous family members reported spending up to $20,000 annually on autism-related services (57%), compared to those that identified as white (28%) or other ethnicity (22%).

3.2.2 The Engagement Hub

Indigenous Autistic respondents described not being able to access many supports and services, including personal support workers and mental health services. Indigenous Autistic adults expressed positive comments regarding peer supports. Some Indigenous Autistic adults recalled traumatizing experiences with autism therapies earlier in life.

Indigenous family members described how overwhelmed they felt at the time of diagnosis and not well supported to engage with appropriate supports and services. They described various barriers to accessing services, including cost, remote location, program eligibility limits or cuts, and transitions to school services. Some Indigenous family members mentioned they were trying to support their children's communication efforts, but struggled with having enough energy to do so, especially without professional supports. Indigenous family members mentioned the inconsistency in service provision across the country, while Indigenous supporters noted that Autistic people and their families experience difficulty in accessing respite care, speech-language therapy, educational consultation services, mentorship, equipment, and communication devices.

3.2.3 In-depth Interviews

Respondents appreciated community-based organizations that provided early supports and services and worked with funding sources to arrange access to flexible, family-centered supports. Challenges with accessing supports and services included limited services on reserve, delayed access due to lack of formal diagnosis, excessive administrative tasks to manage individualized funding, long waitlists, and aging out of services.

Service providers and First Nations parents described inadequate and disjointed access to school-age services on reserve, often leading to complicated travel and childcare arrangements to access off-reserve services. This included painful decisions about which parent a child would live with in the case of divorced parents. Mentorship programs that provide culturally-sensitive programming were highly valued by these participants.

Service providers recognized the limited services available to Autistic adults, and that many Autistic adults access services through mental health or developmental disability organizations. Both service providers and First Nations parents expressed support for traditional and complementary therapies, such as therapy dogs and nature therapy, to build on the child's interest to support positive outcomes.

3.3 Health System

3.3.1 In-depth Interviews

Service providers and First Nations parents advocated for a health system with integrated, local, culturally-sensitive services with system navigation support. In some cases, out-of-home placement occurred due to lack of local supports.

3.4 Funding

3.4.1 In-depth Interviews

First Nations parents expressed concerns about complicated eligibility requirements and funding applications for provincial and federal programs leading to:

- Delays in diagnostic and support services,
- Limited navigation support to understand and access funding, and

- Insufficient funding to cover reasonable costs.

First Nations parents stressed the excessive parent involvement required to manage funds and schedule workers associated with funding from different sources to cover a range of needs. They also noted that additional funding is available to children in care.

3.5 Policy Suggestions

3.5.1 In-depth Interviews

Respondents suggested policy changes to:

- Improve access to services on reserve and in remote areas, and
- Facilitate cooperation between federal and provincial bodies to provide health and education services that meet children's needs (not diagnosis based).

They also mentioned the need for parents of adult children to have legal authority to arrange services for their adult children.

4. Cross-Cutting Issues

4.1 Historical Wounds and Trauma

4.1.1 Pan-Canadian Opinion Survey #1

- 82% of Indigenous Autistic respondents had at least one chronic health condition (i.e., mental health, heart conditions), compared to those that identified as white (50%) or other ethnicity (35%).

4.1.2 In-depth Interviews

First Nations parents stressed the importance of recognizing the context of historical trauma that shapes experiences for Indigenous people in health and education systems.

4.2 Intersectionality

4.2.1 The Engagement Hub

Many Indigenous Autistic adults shared how co-occurring disorders, ethnicity, and gender magnified the impact of autism in their lives. Some Indigenous family members spoke about poor treatment or misunderstandings by the health system. They mentioned how kindness, caring, and compassion were necessary to achieve equity, and expressed support for diverse Autistic leadership for effective service expansion. Indigenous supporters emphasized individualized planning to meet diverse needs.

4.3 Education

4.3.1 The Engagement Hub

Indigenous family members advocated for public awareness campaigns and education on autism for professionals and the wider community.