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Comparing the autism service needs and priorities of Indigenous and newcomer families in Canada: Qualitative insights

Vanessa C. Fong^a, Janet McLaughlin^{a,*}, Margaret Schneider^b, Grant Bruno^{c,d}

^a Wilfrid Laurier University, Department of Health Studies, Brantford, Ontario, Canada

^b Wilfrid Laurier University, Department of Kinesiology & Physical Education, Waterloo, Ontario, Canada

^c The University of Alberta, Department of Pediatrics, Edmonton, Alberta, Canada

^d Samson Cree Nation, Maskwacis, Alberta, Canada

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ABSTRACT

Background: Indigenous Peoples and newcomers are two of the largest and fastest growing populations in Canada (Statistics Canada, 2022; Zimonjic, 2022). Yet despite this, little is known about their experiences navigating and accessing autism services for their children.

Method: To address this gap, the current study sought to explore the autism service needs and priorities of Indigenous and newcomer families in Canada. A total of 19 participants (9 Indigenous and 10 newcomer caregivers) were selected using purposive sampling to participate in a semi-structured interview.

Results: The findings revealed that Indigenous families prioritized the need for services in rural and remote areas, tailored information to their needs, and support preserving their cultural heritage. On the other hand, newcomer families emphasized the importance of peer support, quality standards for services and therapies, and support during transition periods. Similarities across both groups indicated the need for addressing the lengthy waitlists for services, which have also been reported in the general population in Canada, having services and professionals place a greater emphasis on the child's strengths, and culturally safe services and practice.

Conclusion: The present findings have important implications for the design and implementation of services and supports which reflect the needs and priorities of underserved communities.

Autism is a neurodevelopmental disability characterized by differences in social-communication and repetitive patterns in behaviors, interests, or activities (American Psychiatric Association, 2013). However, despite autism occurring in all races, ethnicities, and cultures, the bulk of the research has focused on white, non-immigrant samples (Milton, 2014; Roche et al., 2020). This has contributed to significant gaps in overall knowledge and has informed the development of policies and programs that may only meet the needs of a small proportion of the population. Indigenous Peoples and newcomers are two of the largest and fastest growing populations in Canada (Reuters, 2023; Statistics Canada, 2022; Zimonjic, 2022). Yet despite this, little is known about the experiences of caregiving for an autistic child and navigating services for them. Although these two groups are very different from each other, both are under-researched, under-served, and equity deserving. Thus, this research aims to fill an equity gap in focusing on their unique experiences.

Section 35 of *Canada's Constitution* recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit and they currently

* Correspondence to: 73 George Street, Brantford, Ontario N3T 2Y3, Canada.

E-mail address: jmclaughlin@wlu.ca (J. McLaughlin).

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make up 1.8 million or approximately 5% of Canada's population (Statistics Canada, 2022). Although there are few studies, existing research has revealed various inequities including access to diagnostic and autism services for Indigenous families. Studies have shown that obtaining an early autism diagnosis has important consequences for the child's access to early intervention and therefore their child's wellbeing and ultimately the family's future outcomes (Rivard et al., 2019; Rivard et al., 2018). However, research has also shown that autism may be underdiagnosed in this population for a number of reasons, including cultural differences in recognizing autism characteristics and clinician stereotyping or bias when interpreting the child's behaviors (Di Pietro & Illes, 2016; Lindblom, 2014; Roy & Balaratnasingam, 2010). Other researchers argue that autism is under-detected in Indigenous children due to a lack of culturally sensitive diagnostic and assessment tools and limited access to diagnostic services in remote/rural areas where they often reside (Lindblom, 2014).

Even after receiving a diagnosis, Indigenous families often encounter additional barriers and challenges accessing autism services for their child. In addition to diagnostic services, access to other services such as speech-language therapy, behavioral therapy, occupational therapy, and physiotherapy, can often be challenging for families for a variety of reasons. These reasons may include geographical barriers, jurisdictional disputes between provinces and the federal government, a lack of trust in the public system, and concerns about potential misdiagnosis, to name a few (Lindblom, 2017). In Canada, a federal policy called Jordan's Principle was created in response to the death of a 5-year-old boy named Jordan River Anderson from Norway House Cree Nation, who died in the hospital after disputes over which level of government (provincial vs. federal) would provide funding for in-home care to manage the child's medical complexity (Government of Canada, 2019). Consequently, Jordan's Principle was established whereby First Nations children on- and off-reserve are given the right to government-funded health and social services. However, barriers related to eligibility criteria where youth transitioning to adulthood are not covered under this policy (despite still needing and requiring supports), as well as inconsistencies in eligibility, lengthy processing time, and excessive paperwork have also been reported with this policy (Antony et al., 2022; Sinha et al., 2021). In order to understand these inequities in access to health and social services, it is crucial to acknowledge the current and historical practices of colonialism and systemic racism that have profoundly impacted Indigenous Peoples (Matthews, 2016). Colonial federal policies such as the *Indian Act of 1876*, which implemented the residential school system, have fueled great mistrust of Western health and social service systems (Fridkin, 2012). This mistrust has created a divide between Indigenous parents and the services they seek for their children.

Much of the research on Indigenous families has focused on barriers and challenges accessing services and supports, however several studies outside of Canada have documented areas of strength and resilience in this population. For example, in the United States, the Navajo people tend to embrace a traditional wellness philosophy which promotes acceptance of people with developmental disabilities (Kapp, 2011). Similarly, a qualitative study exploring attitudes towards autism in Aboriginal and Torres Strait Islander communities in Australia found that although there was stigma associated with autism, there were also positive and inclusive attitudes emphasizing neurodiversity and autistic people's strengths and gifts (Lilley et al., 2020). Further, participants often expressed beliefs around community and "looking after each other" (p.1864) when a family member or relative has an autistic child.

Newcomers comprise another growing population in Canada as evidenced by recent data reporting 437,180 immigrants in 2022 with over 40% of this total in Ontario (Singer, 2023). Although there is a lack of prevalence data on immigrant families of children with disabilities (Khanlou & Haque, 2013), recent changes to the medical inadmissibility policy of the Immigration and Refugee Protection Act (IRPA) in 2018 have facilitated the process of immigrating to Canada for these families (Government of Canada, 2022). However, despite these changes newcomers are an underserved community facing disparities in access to autism services and supports for their children (Casale et al., 2023). For example, previous research has documented barriers, including long wait times and excessive paperwork to obtain services (Ben-Cheikh & Rousseau, 2013; Rivard et al., 2019), perceived racism and discrimination from health care professionals (Dyches et al., 2004; Fong et al., 2021), insufficient outreach in rural/remote areas (Dababnah et al., 2019), and delays in accessing diagnostic services and therapies (Rivard et al., 2019). These challenges have been attributed to various factors related to language barriers (Fong et al., 2021; Kim et al., 2020), loss of social networks (Khanlou et al., 2017), income and employment instability, precarious housing and employment (Pickard et al., 2016), fragmented health and social service systems (Khanlou et al., 2017), and the lack of cultural competence (Bogenschutz, 2014). Additionally, cultural beliefs and stigma around disability as well as cultural perspectives on child development may hinder or delay families from seeking a diagnosis and obtaining supports (Bhayana & Bhayana, 2018; Papoudi et al., 2021).

Together these findings highlight the complexity of challenges experienced by newcomer families and underscore the urgent need to better understand the specific needs and priorities of newcomers in addressing these barriers. Few studies have examined immigrant families' priorities related to autism services; one exception is a study by Millau et al. (2018). Using a sample of 45 immigrant families living in Canada, researchers found that similar to families of children with autism in the general population, immigrant parents prioritized access to speech and language therapy, early intensive behavioral intervention, and school support. Importantly, culturally sensitive services that align with their traditional beliefs were also emphasized, highlighting the specific needs and preferences of immigrant families.

Consistent with previous calls for greater inclusivity in autism research and recognition of the impact of intersectionality on the lived experience of families (Lord et al., 2022), the current study sought to explore the autism service needs and priorities of Indigenous and newcomer families in Canada. Preliminary exploration comparing both groups may help shed light on service needs unique to each group as well as more general areas of need potentially applicable to other marginalized groups.

1. Methods

1.1. Participants

Participants were drawn from a large survey of 2685 primary caregivers (almost entirely parents) of children under the age of 18 diagnosed with autism in Ontario, which was offered in English and French, with the option of any other language through an interpreter. Both Indigenous and newcomer caregivers were selected based on findings from this large-scale survey (Gentles et al., 2022), identifying both groups as being largely underrepresented in the research, and worthy of in-depth qualitative study given their experience with racism, discrimination, and complex barriers accessing services. A total of 19 participants (9 Indigenous and 10 newcomer caregivers) were selected using purposive sampling to participate in an in-depth follow-up interview. This sampling technique was chosen to obtain a diverse sample in terms of income, age, caregiver relationship to the child, race, and ethnicity. For the Indigenous sample, inclusion criteria specified that caregivers self-identified as Indigenous. For the newcomer sample, inclusion criteria specified that caregivers and their families moved to Canada within the last five years. Participants were not excluded if they did not speak English or French, and instead were offered to complete the demographic form and interview in the language of their choice. However, all newcomer participants chose to complete the study materials and interview in English.

For the Indigenous sample, caregivers were mostly parents with the exception of one grandmother, whereas for the newcomer

Table 1
Family Demographics.

Demographic Information	Frequency (%)	
	Newcomer (N = 10)	Indigenous (N = 9)
Caregiver gender		
Male	2 (20.0%)	1 (11.1%)
Female	8 (80.0%)	8 (88.9%)
Family and caregiving situation		
My spouse or common law partner lives with me, and we share the caregiving responsibilities roughly equally.	5 (50.0%)	2 (22.2%)
My spouse or common law partner lives with me, and the caregiving responsibilities fall mostly to me.	4 (40.0%)	2 (22.2%)
I am a single caregiver or guardian who lives without an adult helping me, and I am primarily or completely responsible for the caregiving responsibilities.	1 (10.0%)	3 (33.3%)
I am divorced or separated, and the child's other caregiver occasionally assists with caregiving responsibilities (two days per week, or less).		2 (22.2%)
Ethno-cultural background		
Indigenous (e.g., First Nations, Métis, Inuk (Inuit))		7 (77.8%)
– Off Reserve		
Indigenous (e.g., First Nations, Métis, Inuk (Inuit))		2 (22.2%)
– On Reserve		
Black	3 (30.0%)	
South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)	4 (40.0%)	
Latin American	2 (20.0%)	
White	1 (10.0%)	
Highest level of education		
Some high school		1 (11.1%)
Some college or university		3 (33.3%)
College, CEGEP or other non-university certificate or diploma		5 (55.6%)
University undergraduate degree	1 (10.0%)	
University graduate degree	8 (80.0%)	
Family income in 2019		
< \$20,000	3 (30.0%)	3 (33.3%)
\$21,000-\$49,999	4 (40.0%)	2 (22.2%)
\$50,000-\$79,999		2 (22.2%)
\$80,000-\$109,999	2 (20.0%)	
\$110,000-\$139,999		1 (11.1%)
\$140,000-\$169,999		
> \$170,000	1 (10.0%)	
Prefer not to answer		1 (11.1%)
Gender of the child		
Boy	7 (70.0%)	8 (88.9%)
Girl	3 (30.0%)	1 (11.1%)
Age of individual with autism (years)		
1-6	6 (60.0%)	4 (44.4%)
7-12	3 (30.0%)	3 (33.3%)
13-18	1 (10.0%)	2 (22.2%)
Perceived level of child support needs		
Requires very substantial support	5 (50.0%)	3 (33.3%)
Requires substantial support	3 (30.0%)	4 (44.4%)
Requires support	2 (20.0%)	2 (22.2%)

sample all caregivers were parents. The majority of caregivers for both samples were also mothers (89% for Indigenous and 80% for newcomers). The most frequently reported family income for both groups was below \$49,999. For Indigenous families, the majority self-identified as First Nations with only one family from Métis background. No newcomer families lived in rural communities, whereas a third of the Indigenous families lived in rural communities. The mean age of children in the newcomer group was 7.0 (SD = 3.8) and 7.9 for Indigenous families (SD = 4.1). For a complete description of family and child demographics, please see [Table 1](#).

In order to ensure the confidentiality of all research participants, especially when working with small sample sizes, pseudonyms were used when presenting the study's findings.

1.2. Interview

In collaboration with our community partners, we developed a series of open-ended questions for our interview guide (please see the [Appendix](#) for an example of the interview guide). The main themes which were the focus of this study explored language and culture, and service access. Specific questions exploring both topics included “can you talk about how your language or culture has affected your ability to access autism-related services and supports?” and “what would make things easier for you to find or access autism services and supports that you need?” To ensure clarity and gather further insights, the interview guide also included prompts and follow-up questions. The interviews were conducted via Zoom at a time convenient for participants. Throughout each interview, we recorded detailed notes on the parent's tone and emphasized areas (e.g., underlining or bolding words or phrases where the participant expressed heightened emotion) to provide context. Following each interview, we completed a contact summary sheet of the participant's key responses, potential themes, and highlighted significant aspects of the interview.

1.3. Procedure

The research protocol for this study was reviewed and received approval from the Research Ethics Board at the Institution in Ontario, Canada. The researcher reached out to parents who met the study's inclusion criteria, and those who expressed interest in participating were scheduled for an interview. The parents provided their consent and completed a demographics form before participating in the interview. The average length of the interviews was 53 min and 41 min for the newcomer and Indigenous groups respectively. All interviews were conducted in 2022.

1.4. Community involvement

Recognizing the discrepancy between the research priorities of autistic people and researchers (Pellicano et al., 2014; Fletcher-Watson et al., 2018), the interview guide used in the current study was developed in collaboration with a diverse group (e.g., age, gender, immigration status, race and ethnicity) of autistic adults, caregivers, and community organization leaders from Autism Ontario. The current study incorporated community engagement during data collection by having both a newcomer and First Nations research assistant conduct the interviews for their respective groups. Additionally, one of the co-authors (GB) of this research, who contributed significantly to data analysis, is a First Nations parent.

1.5. Analysis

Interviews were first transcribed verbatim, cleaned, and uploaded onto NVivo software for analysis. Researchers involved in data analysis had background and training in qualitative data analysis and experience in the field of developmental disabilities. The data were analyzed thematically using an iterative process to create the codebook. Using a collaborative approach, our team conducted regular meetings to discuss the development of the codebook, including discussions on code definitions and revisions. The researchers first familiarized themselves with all the transcripts and then a subset of five transcripts for each group were reviewed to identify initial codes. An inductive approach was used to identify themes based on their semantic content. Following this stage, codes were added and revised based on consensus among team members. The codebook was finalized once it was established that no new codes were emerging and that codes were being applied accurately and consistently. The final stage of theoretical coding involved more in-depth analysis focusing on relationships between the initial codes. Further refinement of these codes led to the development of the final categories presented in the results section of this paper.

Throughout our analysis, criteria (e.g., credibility, dependability, and transferability) developed by Lincoln and Guba (1985) were used to ensure trustworthiness or the quality and degree of confidence and trust in the data and the interpretation of findings. Credibility was established through member checking, with interviewers actively seeking clarification from participants when necessary and verifying their data interpretations with both participants and community consultants. To ensure credibility, researchers engaged in prolonged engagement, by holding regular meetings with community members and contributing to advocacy efforts by sharing research findings and raising awareness of critical issues within the autism community. Dependability was met through taking detailed notes before, during, and after interviews, participants' willingness to engage, and other pertinent contextual information. Engaging in reflective journaling contributed to dependability by recording all research decisions, justifications, coding definitions, revisions, and theme development. Transferability was achieved by providing comprehensive descriptions, contextual information, and direct participant quotes that exemplified the emerging themes.

1.6. Positionality statement

It is important to acknowledge the positionality of the authors as this can influence the analysis and interpretation of qualitative data. All four authors acknowledge their shared background as highly educated people within academia. The first author (VF) who organized qualitative coding for this project, identifies as a cisgender, East Asian, non-autistic, second generation Canadian woman with over six years of research experience focused on health and social services access for families with children with autism. The second author (JM), who led the development of the initial study, identifies as a cisgender, caucasian, non-autistic woman who is the parent of a non-speaking autistic child, with over 20 years of qualitative research experience relating to social and health inequities and under-served populations (particularly migrant workers), and six years of research experience with caregivers of autistic children. The third author (MS) who co-led the development of the initial study, identifies as a cisgender, caucasian, non-autistic woman with more than 25 years of qualitative research experience focused on caregiving for those with various disabilities (including autism), as well as many years of frontline experience working with this population. The fourth author (GB) is Nehiyaw (Plains Cree) and a registered member of Samson Cree Nation, Maskwacis, Alberta, Canada and a parent to autistic children.

2. Findings

Various similarities and differences regarding perceived service priorities and needs were identified for newcomer and Indigenous caregivers. These findings are summarized in Fig. 1.

2.1. Service needs and priorities of Indigenous families

2.1.1. Lack of services in rural and remote areas

Caregivers living in remote and rural areas frequently mentioned the challenges finding service providers in their respective communities, with some having to travel as far as two to three hours away each time they attended therapy. Caregivers expressed frustration and highlighted the mismatch between the need for supports in their community and the availability of providers, despite having funding available to them:

We don't have the access to all the services that people seem to think we do. It's not just well okay this organization can't provide that service so we'll call the next provider. There is no next provider. I get that theoretically we are supposed to have money but you know even occupational therapists have waiting lists just as long as private places. We're a small town but there's waiting lists. It's not like Toronto where there's a lot more occupational therapists. There's much fewer here so it's not easy to find services. And there's you know a lot of kids with autism here that need the same services. (Jada, mother of an 11-year-old boy)

The challenges of living in a remote and rural area were exacerbated by barriers such as not having transportation or childcare for siblings so that caregivers could bring their autistic child to therapy. Another increasingly relevant and pressing concern related to commuting long distances for services. This created additional challenges and posed safety risks for families during extreme weather conditions, particularly for families in northern and remote communities where many Indigenous people reside:

In the winter last year, I had to stay down there a few times because the weather was so bad. There is an extra cost for sure with having to commute to Barrie twice a day but you know it's just the way it is. I don't mind doing it and I have no problem doing it because she's getting the best therapy there. But sometimes you know there's a blizzard outside and I wish I didn't have to drive. (Kaiya, mother of a 5-year-old girl)

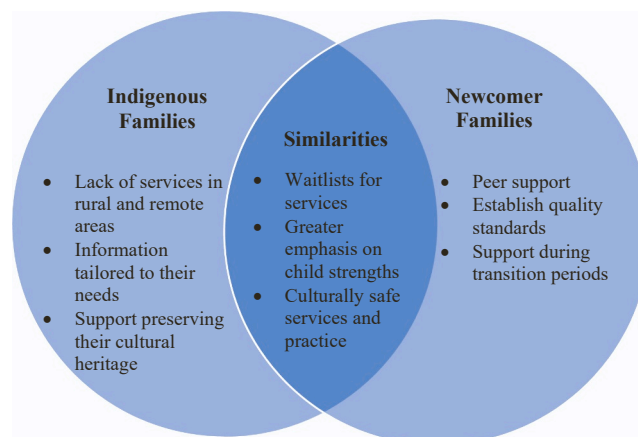


Fig. 1. Summary of the service needs and priorities of Indigenous and newcomer families.

2.1.2. Information tailored to their needs

Caregivers often expressed difficulty finding relevant information related to their autistic child and understanding their role as caregivers and how best to support their child's unique needs. Obtaining information and having more knowledge was recognized by caregivers to be a crucial step in advocating for their child and navigating the overwhelming amount of information available:

I would say the first step is somebody needs to explain exactly what autism is right? Because it's a spectrum, so it's 1000 different things and we're spinning a bunch of wheels before we can even figure out what is my child. The first step is helping us figure out what it is about our job specifically. Having somebody to take all those spectrums and put a picture together of what is our child should be the first and most important step because that releases us to be able to navigate. I have to keep navigating information that is not relevant to my son. What a waste of time and resources and frustration for my son because he needs to be understood and he's too little to communicate for himself. (Winona, mother of a 5-year-old boy)

The same parent shared important insights as to why there is a knowledge gap and why the information and research available isn't being effectively utilized by their community:

I think white communities use a central hub where all the information goes there and somebody filters it down to its appropriate place. In the Native community, we don't hub like that so whatever research information you're giving us, isn't reaching anyone [laughs]. We don't organize like you do. White people have a hierarchy. Red people don't. We're wired to think 'round table' rather than a hierarchy. I think if you guys discover some really awesome information you have to figure out a different way of getting it out because we think we're doing what you're telling us but you don't know that we don't work like this. And so we think the job is done but actually information hasn't gone anywhere and the information to help ourselves is now limited to whoever was at the table that day and you would have to be at the table with them and most of us aren't. (Winona, mother of a 5-year-old boy)

2.1.3. Support for preserving cultural heritage

In the interviews, caregivers frequently shared the importance of their culture and having mainstream services provide supports using a more holistic approach and including Indigenous content:

I know that there is not a lot of Indigenous content offered in Thunder Bay. I have noticed that in our community there doesn't seem to be a lot of Indigenous members and if they are they don't identify as such or they don't make it known. They celebrate Valentine's Day but we have nothing for National Indigenous Day. There's NOTHING for that is my point. We do special learning stuff for just pointless stuff but for important Indigenous stuff there's nothing. It's radio silence. (Marie, mother of an 11-year-old boy)

The same caregiver underscores the significance of maintaining their cultural heritage by emphasizing the importance of offering language services to their children:

We've been pushing for speaking Ojibwe for my son. It was offered to him in grade four but then there wasn't enough people who signed up for it. I keep pushing for it and it's something that is being denied to him as a cultural right for my son. [The availability] shouldn't be determined by how many people sign up for it. During the pandemic when he was at home, we were working on Ojibwe with him so he knows some Ojibwe. It was in 2020 that we got our Métis cards. My mom was raised that this part of her family didn't matter, so when my mom passed away that's when we started re-discovering our roots. (Marie, mother of an 11-year-old boy)

2.2. Service needs and priorities of newcomer families

2.2.1. Peer support

In contrast to the service needs and priorities of Indigenous families, newcomer parents frequently mentioned the need for greater support building their network and relationships with other families of autistic children. These parents often spoke about the challenges of moving to a new country and losing their support networks:

It was a challenging thing because back home I had a family who are there to help me in each and every stage because having a special needs child means you need extra help no matter how many services you get. Nothing compares and nothing matches to having family and friends around because then you can rely on them emotionally, mentally, physically, financially, everything. You've got that confidence that okay someone is there. It was a difficult decision for me to move here because I'd be leaving everyone behind. It's difficult for me to open up and that's something I've not been able to have but I miss having that support. (Maya, mother of a 15-year-old boy, immigrated from Nepal)

Difficulties meeting other families and building connections appeared to be related to time constraints but also feeling a sense of burden or stigma. Two parents shared:

I'm not comfortable to meet with other families. I feel that people don't want that extra burden. I don't feel that comfortable unless I feel they are welcoming to my son and then I kind of open up. It was difficult to interact in the neighborhood also with COVID. So my son has limited friends and wants someone to talk to. So that is something that is like a really big gap, along with him I feel that as a family also. (Maya, mother of a 15-year-old boy, immigrated from Nepal)

In Nigeria if you had a child with special needs you wouldn't talk about it. You would just be quiet and not say anything. You'd even hide it. There are many women who have children with special needs and they just don't know where to turn to for support. Having someone

that can relate to you and say 'hey, you know, this is what I did' can be very helpful. I share the things I've learned and I like to share whatever resources I find that works for me. (Zainab, mother of a 9-year-old boy)

As a result of this stigma, parents were more likely to prefer relationships specifically with other families of autistic children as they felt better understood by this community:

We need to try and connect for the children so they have more social opportunities to meet each other. It is nice to know parents who have commonality in the culture but also autism. With them being all autism parents, they would have the same journey as we have. (Anika, mother of a 13-year-old boy, immigrated from India)

2.2.2. Establish quality standards

A number of parents expressed frustration with the variability in the quality of services being delivered to their child:

I saw other services be more forthcoming providing them with information specific to their child's needs. Whereas for me the services are not really suiting my child's needs and it's very general in nature. That's when I began to understand that maybe my centre is not really providing me that much but I have heard from other parents that they do get progress updates on a regular basis. (Anika, mother of a 13-year-old boy, immigrated from India)

These parents often spoke of the need for greater transparency and accountability from service providers. One parent suggested having a system where parents can provide feedback to service providers and professionals:

Right now, everybody's working in silos. There's no regulation or audit or something about how services are doing. There's no rating system where parents can actually provide feedback and others can read about it. There has to be more transparency in terms of service providers and more regulation on how they're running their business. There is no feedback about what families are saying about them, if there was a system then service providers would be more accountable. Right now, because there is demand people will come to them no matter if they are providing a good or bad service. If there was more accountability on their side, this will help families to communicate with them better and provide a more equitable place. (Arjun, father of a 3-year-old boy, immigrated from India)

2.2.3. Support during transition periods

In the interviews with newcomers, parents often highlighted the need for services to support their child during transition periods:

I need a pathway for my child in terms of his future. Right now, my son started high school and we want to know the different options where he can explore vocational avenues depending on his strengths. I need information and supports to guide parents for high school and beyond where we can try and prepare the child to have some functional employment where he could do well and set him up for success and train him for that situation now. (Anika, mother of a 13-year-old boy, immigrated from India)

The lack of services and supports during these transition periods created a significant amount of stress for parents. In particular, parents were worried about their child's future and highlighted the need for employment supports to allow their child to live independently:

When you look at the numbers you hear that one in every five children has a disability, but then you look at the workplace and you don't see an equal representation of these adults in the workplace. So that makes me think if there really is inclusion. If they are not in the workplace, this means they will be dependent on their parents for much longer. We want them to live a life as normal as possible and being able to work and live because they are skilled. To be able to use their skills would contribute to an inclusive environment. (Zainab, mother of a 9-year-old boy, immigrated from Nigeria)

2.3. Similar service needs and priorities for Indigenous and newcomer families

2.3.1. Waitlists for services

Caregivers from both Indigenous and newcomer families most frequently expressed their dissatisfaction with the long waitlists for services in Ontario. One newcomer family shared:

We applied for funding and after a wait of one year we got the one-time funding. The wait times are just really long to get help available. If there were help available and somebody is there to guide you I think things would be much different. We are already at a stage where our son is four years and still we have not started with therapy. Those wait times are really impacting not just me but other families are in the same boat. The whole process is just too slow here. (Arjun, father of a 3-year-old boy, immigrated from India)

Despite having funding through Jordan's Principle, one Indigenous caregiver expressed:

Being an Indigenous person other than me ticking off the box saying that we're Indigenous really doesn't matter because we don't get the resources that we need. Because the waitlists are so long. (Michelle, mother of a 5-year-old girl)

The long waitlists were not only detrimental to families in terms of the impact on their child's development and potential progress that could be made, but also were costly to families contributing to financial burden. One newcomer parent described the financial impact of the lengthy waitlists:

While you're waiting on the wait list you have to look for resources to pay for out of pocket. We just started paying for him to go to therapy while we were on the waiting list and paying for everything that he needed. (Zainab, mother of a 9-year-old boy, immigrated from Nigeria)

2.3.2. Greater emphasis on child strengths

In the interviews, caregivers shared many of their child's strengths, which ranged from cooking, videogames, photography, math, science, and coding. One Indigenous caregiver shared about her child:

My son is really good at math, he's good at science. He's really independent and he doesn't require much help from most people. He is kind, he's caring. He is really good with small children. He does better with younger people like he is a gentle giant. At 11 years old he's almost 6 feet tall but he is the gentlest person with like small animals and children. (Jada, mother of an 11-year-old boy)

A number of caregivers voiced their concerns regarding service providers who they felt did not validate the child's strengths and autonomy. One newcomer parent who is also autistic described her experience:

The therapist was always saying to my child 'oh if you do something like this, then I'm going to be happy.' Well you know, he's not responsible for your feelings. He's responsible for his own and not your personal feelings and everything. So I had a big problem and I had to take him out of it. (Sofia, mother of a 5-year-old boy, immigrated from Brazil)

Caregivers often emphasized the importance of having services and professionals place a greater emphasis on the strengths of their child. These caregivers expressed the need for developing or adapting existing supports to build on their child's strengths. For example, one newcomer parent emphasized:

Why can't we focus on the things that they CAN do from an early stage? I know they can't do everything a neurotypical child can do, but why can't we focus on that skill they are good at so that their journey becomes fun and they do what they enjoy rather than what is just being offered? When they do what they enjoy, they will do better and have success. If we can make a place so that they are able to do that, I think that would be great. (Aisha, mother of a 13-year-old boy, immigrated from India)

2.3.3. Culturally safe services and practice

This theme encompassed the provision of services and supports that respects and acknowledges diverse backgrounds and preferences ensuring that all families feel valued and safe in their interactions with service providers. When asked in the interviews if service providers can do anything differently in their interactions with members of the community, caregivers frequently described needing more patience and understanding from service providers in their interactions with families. One newcomer mom articulated:

I wish they were warmer and not so cold. And that they would listen to us just a little bit and show more respect because I can hear you and I know what you are saying. Sometimes I really feel like they are always asking things to me as if my child was not there. He is there. So talk to him, interact with him, and be with him. I won't be here all the time and one day I will die. I hear that from autistic adults too that they know others are talking about us, but not to us. (Sofia, mother of a 5-year-old boy, immigrated from Brazil)

At times, caregivers felt racism or that they were being discriminated against from service providers through their tone of voice and dismissive attitudes and behaviors. When describing their interactions with service providers, one newcomer father revealed:

Sometimes I feel that because we have different accents you know they will just not answer all the questions or just end the conversation quickly. It doesn't happen with everybody but there are people who do that. Or because of our skin color some people will have this perception of you and they will try to hang up the call which was supposed to be 30 minutes but it will end in 10 minutes. So they're not spending the time to explain things, they will just say okay any questions and then bye. (Arjun, father of a 3-year-old boy, immigrated from India)

A number of Indigenous caregivers spoke about personal experiences of racism and feeling stereotyped by service providers and professionals. When asked about what service providers should know about working with people from their community, one Indigenous grandmother replied:

That we're not all potheads, I guess. That's the attitude I think a lot of people have here. And that seems to be a lot of people's attitudes—that we're all baked. (Cherie, grandmother of a 14-year-old boy)

Several caregivers shared the importance of relationship-building in particular for Indigenous communities where there is a history of mistrust in the government and people in positions of power due to a long history of colonialism, intergenerational trauma related in part to the forced separation of families via residential schools, and structural racism. For one Indigenous parent, building trust involved using accessible language and periodically checking-in with families to see how they were doing:

My experience at the centre was amazing. They sat down and explained it all and they understood how devastating it was for some parents to get the diagnosis. The service provider talked in people terms versus psychologist or clinical terms because my son's dad only has a high school education and he wasn't willing to accept the diagnosis. So the service provider was really good with sitting down and explaining to my husband that this didn't make our child less than. The service provider right up until her retirement would email me and check in if I ever needed somebody to be on my son's circle of care team or help advocate she would send me an email and say she'd be there. (Jada, mother of an 11-year-old boy)

3. Discussion

The current study sought to explore similarities and differences across Indigenous and newcomer families related to autism service priorities and needs, as these two groups were identified as research priorities in a previous study by the authors (McLaughlin & Schneider, 2019), given their under-representation in research as well as their service access barriers. Our findings revealed differences in priorities for autism services comparing Indigenous and newcomer families as well as similarities across both groups. For Indigenous families, caregivers frequently identified the need for more services and better outreach in rural and remote areas, accessible information tailored to their needs, and culturally-sensitive services which embrace and preserve their heritage. The lack of services and professionals in rural and remote areas has been identified in the literature as an ongoing challenge for Indigenous families (Horrill et al., 2018). These studies have shown that Indigenous families living in these areas often have limited access to diagnostic services contributing to delays in accessing early intervention (Burstyn et al., 2010; Leonard et al., 2011) or families simply do not get a diagnosis at all. However, the current findings extend this research by highlighting other implications of the lack of nearby services which include putting families in dangerous situations where they must commute long distances in precarious weather. This issue will likely only worsen with time as the effects of climate change become more severe and impactful, particularly for Indigenous Peoples in Canada, given they often live in geographic areas experiencing rapid climate change, and their close relationship to the land and its natural resources (National Collaborating Centre for Indigenous Health NCCIH, 2022). Indeed, prior research has demonstrated the devastating impacts of climate change on Indigenous communities exacerbating already existing health disparities for First Nations, Inuit, and Métis peoples (Ford et al., 2010; Furgal & Seguin, 2006).

The current findings also strengthen previous research which has identified barriers Indigenous caregivers experience accessing information (Jacklin et al., 2015). Although challenges finding autism information and resources are frequently reported amongst caregivers from the general population (Estrin et al., 2021; Zuckerman et al., 2014), this knowledge gap is likely greater for Indigenous families. For example, there is a severe lack of accurate data specifically on Indigenous children with autism in Canada related to prevalence rates and perspectives of caregivers regarding access to services (Di Pietro & Illes, 2014; Di Pietro & Illes, 2016; Shochet et al., 2020). A novel finding in this study relates to the reflection of caregivers regarding potential reasons for the knowledge gap and poor uptake of research amongst Indigenous families. Similar to previous research by Antony et al. (2022), the current findings emphasize the importance of Indigenous-led research and policy recommendations to inform culturally safe service delivery.

The present findings indicate the need for culturally safe services and supports which help preserve Indigenous Peoples' culture and language. Indeed, there exists some tension in regards to whether this means modifying mainstream services with Indigenous knowledge versus investing in Indigenous governed, designed, and implementation of services (Gerlach et al., 2022). For Indigenous families in the current study, caregivers prioritized having access to supports which provided a holistic approach, Indigenous content, and language services. More Indigenous-led research is needed to understand the lived experience of Indigenous people and their preferences regarding culturally safe services and supports.

For newcomer families, parents frequently identified the need for peer support, establishing quality standards for therapies and services, and support for their family during transition periods. The findings confirm previous research recognizing the importance of peer support and helping families build relationships in their communities (Baumbusch et al., 2018; Fong et al., 2021). Given that many newcomers leave behind their support networks from their home countries (Kediye et al., 2009; Khanlou et al., 2017), helping parents learn about social networking opportunities and emphasizing the importance of social relationships for families has been previously suggested (Rivard et al., 2019; Starr et al., 2016).

Another priority identified by newcomer parents included creating quality standards for therapies and services provided to families. Although previous research has shown greater dissatisfaction in the quality of therapies amongst immigrant families (Ravindran & Myers, 2013; Stahmer et al., 2019), this study has extended these findings by providing parent perspectives regarding potential solutions to address this. In our study parents suggested creating online systems to provide feedback on the quality of services delivered and spaces for parents to provide recommendations for therapies and service providers in their local community. In the current study, parents prioritized the need for services to support their children during transition periods and prepare them for future employment so they are able to live more independently. This finding is consistent with previous research on non-immigrant families where transition periods were viewed as particularly challenging and stressful for autistic adults and their parents (Cai & Richdale, 2016; Makin et al., 2017). Addressing these concerns requires greater attention to providing services and informational resources for autistic people and their families related to career and vocational training, housing, and financial supports (Sosnowy et al., 2018).

Similarities across both groups emerged for service needs related to addressing the long waitlists for services, services which place a greater emphasis on the child's strengths, and provision of culturally safe services and practice. Consistent with previous studies conducted in Canada, parents in the general population frequently report very long waitlists for autism services, and the profound stresses (both emotional and financial) that these long waits can generate (Fong et al., 2023; Khanlou et al., 2017; Rivard et al., 2019). Providing families with timely access to support programs, informational resources, and respite may help alleviate stress during this waiting period. Caregivers in the current study were often eager to share their child's strengths and expressed wishes that professionals and educators who worked with their child could incorporate these interests and strengths into therapies and learning. While these findings have been commonly observed in the general population of parents of autistic children (Lee et al., 2020; South & Sunderland, 2022), it is noteworthy that this study is, to the best of our knowledge, the first to identify this priority among newcomer parents. A number of these caregivers also shared feeling uncomfortable with certain therapies or therapists who had worked with their children, and wished there was a greater range of options available that aligned with their values.

Consistent with previous research, caregivers emphasized the importance of culturally safe services and practice. While this is important for all families, even greater efforts are needed when working with Indigenous families given the historical and current

practices of colonialism and mistrust in people in positions of power as a result. It is important for professionals to practice reflexivity, cultural humility, and awareness of their biases which inherently impact their attitudes, behaviors, and beliefs. Indeed, previous research has shown that Indigenous caregivers report feeling intimidated, unheard, or unwelcomed in their interactions with professionals (Eley et al., 2007). Similarly, newcomer parents report negative interactions with service providers including experiencing instances of racism and discrimination (Decoteau, 2017; Skrinda, 2008; Starr et al., 2016). Policies are needed which prioritize the implementation of cultural safety training and anti-discrimination measures within service organizations, ensuring that professionals are well-equipped to provide safe and inclusive services to all families they serve. This approach will promote trust, enhance the quality of care, and improve overall outcomes for families.

A limitation of the current study which warrants caution when interpreting the findings relates to the majority of respondents being women. As a result, the perspectives and experiences of fathers and non-binary people remain limited. Further, although interpreters were available for anyone who requested one, all of the participants were able to speak English. Future studies should aim to recruit non-English speaking caregivers, as their perspectives in research are extremely limited. As most of our newcomer sample comprised of families living in large, urban areas, future research should focus on recruiting newcomer families in small and rural areas. This will help determine whether the findings regarding Indigenous families prioritizing improved access to services in rural areas are a shared experience among newcomer families as well. A final limitation of the study relates to the relatively small sample size, and the lack of previous research that this study draws from, specifically studies which examine the lived experiences of Indigenous families.

4. Conclusion

The current study sought to examine the service needs and priorities of Indigenous and newcomer families of autistic children. For Indigenous families, caregivers prioritized the need for better outreach in rural and remote areas, information tailored to their specific needs, and having services that support preserving their culture and language. On the other hand, newcomer parents prioritized the need for peer support, establishing quality standards for services and therapies, and support during transition periods. Similarities across both groups indicated the need for addressing the lengthy waitlists for services, which have also been reported in the general population in Ontario, having services and professionals place a greater emphasis on the child's strengths, and culturally safe services and practice. The present findings have important implications for the design and implementation of services and supports which reflect the needs and priorities of underserved communities.

CRediT authorship contribution statement

Vanessa Fong: Writing – original draft preparation, Data analysis, Writing – review & editing, **Janet McLaughlin:** Supervision, Conceptualization, Methodology, Writing – review & editing, **Margaret Schneider:** Supervision, Conceptualization, Methodology, Writing – review & editing, **Grant Bruno:** Writing – original draft preparation, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix. Semi-structured Interview Guide

Topic	Question
About the Child with Autism	1. Can you tell me a bit about your child(ren) with an autism diagnosis?
Parent Background	2. Can you tell me a bit about your history and family situation?
Journey to Diagnosis	3. Can you tell me about your journey to seek an autism diagnosis for this child?
Service Access	4. Can you describe the autism-related services and supports you have tried to access or find, and any problems you've had with this along your journey?

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Topic	Question
Language and Culture	5. Can you talk about how your language or culture has affected your ability to access autism-related services and supports?
Jordan's Principle (for Indigenous caregivers only)	6. What has been your experience using Jordan's Principle to access services for your child?
Geography	7. Could you talk about how where you live may have affected how you access autism-related services?
Remote service access (internet, phone)	8. Can you talk about your experience using the internet or phone to access services?
Discrimination	9. How do you feel you have been treated, as a person of your background [specify relevant aspects of participant's background], by the systems [education, medical, therapy] or by specific professionals [doctors, therapists, teachers] providing autism-related services?
Service and support solutions	10. What would make things easier for you (or others in your community) to find or access the autism services and supports you need?
Research advice	11. What should researchers know or do better when studying the service and support needs of people from communities like yours?

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