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ORIGINAL PAPER

Closing Gaps: Strength-Based Approaches to Research with Aboriginal Children with Neurodevelopmental Disorders

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Abstract There is substantial literature on fetal alcohol spectrum disorder (FASD) research involving Aboriginal children, but little related literature on other common neurodevelopmental conditions such as autism spectrum disorder (ASD) or cerebral palsy (CP) for this population. As part of our work in cross-cultural neuroethics, we examined this phenomenon as a case study in Canada. We conducted semi-structured interviews with health researchers working on the frontline with First Nation communities to obtain perspectives about: (1) reasons for the lack of ASD and CP research within the Aboriginal context, (2) the potential ethical and social implications of this disparity, and (3) recommendations for change. Participants reported that the major barriers to engage in ASD or CP research are under-reporting and under-diagnosis of these conditions in Aboriginal communities, difficulties in establishing trust between community members and researchers, challenges in accessing children living under the care of child welfare services, and lack of support from universities and funding agencies to encourage community partnerships. They further perceived threats to justice as the population is denied the benefits of ASD and CP research, and stigma related to the possible over-representation of FASD in the population. The adoption of strength- and community-based practices to improve engagement and address disparities, and to create health databases with prevalence rates that are representative of all forms of disability in both Aboriginal and non-Aboriginal populations are critical steps to close these gaps.

Keywords Fetal alcohol spectrum disorder · Neuroethics · Health disparities · Indigenous peoples

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Introduction

Three of the most commonly diagnosed neurodevelopmental disabilities (NDDs) in North America are autism spectrum disorders (ASD), cerebral palsy (CP), and fetal alcohol spectrums disorders (FASD). Overall, they are estimated to affect 1–3 of every 1000 live births for the specific diagnosis; possibly as high as 1 of every 100 for the full FASD spectrum (http://canfasd.ca/media/fasd-fact-sheet/). Currently there is very little specific data on the prevalence of these conditions in Aboriginal children [1], however, a gap that is attributed at least in part to the geographical location of communities, the unique and distinct cultural beliefs about disability, poverty, language barriers, and the historical impact of colonization [2, 3]. Still, it is estimated that the disability rate among Aboriginal children is twice that of the general population [1], and reports suggest that, in Canada, Aboriginal children fall below the national averages for the population under the age of 19 for almost all measures of child health [4]. These disparities have led to calls for action from

Canadian and Aboriginal health organizations to improve access to health care and services [1, 5, 6], a call that has also been made for other similarly underserved indigenous populations, for example, in Australia [7, 8]. Identifying the prevalence of disabilities and the health needs of Aboriginal children is a critical step to achieve this goal.

In prior cross-cultural neuroethics work, we examined health research involving Aboriginal children living with ASD, CP, and FASD [9]. We retrieved a total of 52 relevant reports from a comprehensive search of five journal databases for the 30-year period between 1981 and 2011. In this literature, 51 papers focused exclusively on FASD. This focus, and the absence of research on the other two major childhood disorders, is at odds with NDD rates for the general population, and is arguably in violation of fundamental ethical principles in research that require equitable representation of all children, regardless of background [10]. The under-representation of Aboriginal children in non-FASD neurodevelopmental health research may further threaten access to the benefits of research while their over-representation in FASD research may perpetuate stigmatization. We turned to neurodevelopmental health researchers working on the frontline with First Nation communities to obtain their perspectives and gain insight on the sources and impact of this case study of cultural imbalance in research.

Methods

Participants

Researchers who have conducted research within Aboriginal communities in Canada were identified through research publications since 1981, by snowball sampling and eligible individuals to participate by e-mail.

Interviews

The interviews followed a semi-structured guide that was developed with the assistance of researchers from NeuroDevNet Inc., a Canadian Network of Centres of Excellence dedicated to helping children and their families overcome the challenges of neurodevelopmental disorders, and constructed to explore a wide range of relevant issues (see Table 1) that arose from the first phase of work (1). All interviews were conducted by the first author in English by telephone, and were about 45 min long.

Table 1 Interview questions

1. What are your overall experiences with health research, care or policy for Aboriginal children?
2. Are you aware of health research involving Aboriginal communities that focuses on autism, cerebral palsy or other developmental conditions?
3. Were you aware that there is an absence of published research in Canada on autism or cerebral palsy for Aboriginal children? Are you concerned? What do you think the source of these findings might be?
4. Why do you think it is that there is more research published on FASD than on the other conditions? What might be the benefits and consequences of this phenomenon?
5. Would you like to see more research being done on developmental disorders involving Aboriginal children? Why? In what specific areas?
6. Is there anything else you would like to mention? Recommendations?

Ethics Approval

Research ethics approval was obtained prior to the beginning of the study. Consent forms were sent electronically to participants prior to the interview and were also read over the telephone before the start of the interview to obtain verbal consent.

Data Management and Analysis

Audio-recorded files of the interviews were transferred onto a password-protected computer and transcribed verbatim by an independent contractor who completed a confidentiality agreement. Transcriptions were entered into QSR NVivo (version 10) in preparation for thematic coding and analysis. No identifying information was used or stored for data analysis.

Results

Characteristics of the Participant Respondents

Eight participants agreed to be interviewed of 21 invited, yielding a 38 % response rate. The nonetheless small pool for this qualitative study comprised of five pediatricians, two health researchers and policy-makers of Aboriginal heritage, and a social worker. Seven participants had conducted NDD health research in the past five years and all lived or worked in First Nation

communities located within three Canadian provinces: Alberta ($n = 5$), British Columbia ($n = 2$), and Manitoba ($n = 1$). All participants had 15 years or more experience working in and with Aboriginal communities. Six had conducted research related to FASD. In addition to FASD research, four had also been involved in research projects that focused on a range of other NDDs, including autism, cerebral palsy, and attention deficit hyperactivity disorder (ADHD).

Qualitative Findings

Participants reported on a range of ethical and social issues with respect to Indigenous health research and care for NDD conditions. Their experiences formed the basis for explanations as to why there is a gap in CP and ASD research. Here we synthesize: (1) the perceived reasons for the lack of ASD and CP research within the Aboriginal context, (2) perceptions about the potential ethical and social implications for the lack of ASD and CP research, and (3) recommendations for research priorities and opportunities to engage in NDD research with Aboriginal communities. Quotes illustrate the rich content of the findings. Ellipses (…) signify the removal of some parts of an excerpt for brevity. Square brackets ([ ]) indicate interviewer's comments to provide context to the quote or the substitution of a category in place of a proper noun to remove identifying material from the interview. Participant identities are protected through the use of anonymous identifiers, which are numbers followed by the letter 'P′ (participant). Anonymous identifiers (i.e., P1, P2) are provided at the end of each quotation.

Perceived Reasons for Lack of ASD and CP Research within the Aboriginal Context

To elucidate the potential reasons underlying the lack of autism and CP research, participants focused on the overall challenges they have experienced when initiating or conducting NDD research:

Unrecognized Need Although there is a substantial literature on FASD research involving Aboriginal Peoples, participants indicated that neurodevelopmental disabilities in general remain under-reported, misdiagnosed or undiagnosed in First Nation communities. They described how this phenomenon has led to a lack of awareness about the significance of these conditions in communities and, in turn, a reluctance of community members to engage in research. Three participants stated that the Aboriginal communities in which they worked in did not initially recognize the presence or impact of NDDs. We also heard differences in how some communities define and interpret disability:

> "*And then you have to define what you consider a significant disability …or is this just normal for our community here? Because if the kid is not reading at grade 6, in our society that would be a major disability, learning disability, while there it is not a big deal … if you go to the schools, they are totally overwhelmed with some of the needs there and they don't get enough funding for the interventions. There is a total lack of awareness.*" *(P1)*

Inconsistency in the reporting of ethnicity in medical records were also identified as a factor that made it difficult to conduct epidemiological research to establish prevalence rates of different NDDs for Aboriginal children:

> "*I think there are some children that are diagnosed but I don't know how they are captured. … Are they captured at the hospital? But not necessarily captured as a First Nation child living on a reserve?*" *(P1)*

> "*… identification of Indigenous status or Indigenous self declaration in health data is inconsistent… we are even further behind other countries like Australia, United States, and New Zealand in the kind of data that we have. We actually have great variability in data, and maybe some of the best data is in Northwest Territories, Yukon, and Nunavut because they are paying more attention to whether people are First Nation, Inuit or not. And it gets worse the further East you go. In the Province of Quebec there is a willful disregard for ethnic identifiers because of political reasons. So it's not something that helps health researchers …*" *(P5)*

Two participants noted that researchers are often reluctant to ask about ethnic origin:

> "*So, we see a lot of Aboriginal kids. And we made—I guess—it [ethnicity] became a very difficult question to ask from a clinical point of view because some people did not prefer to identify, some people did prefer to identify. And the issue*

of collecting that data on a database became a fairly complicated issue so prior to my time that decision was made that the question wouldn't be asked. Having said that, we see a lot of kids who are Aboriginal … So, they may be participating in studies or we may be getting data from them but we just don't know even." (P4)

"*And it's mainly the databases on wait times, access to services, and they have not put in the ethnicity question. And it was almost like there's an elephant in the room, and you don't want to ask that question.*" (P6)

Two participants cautioned that obtaining permission to access patient data is often a complex and uncertain process requiring multiple permissions from both provincial and Aboriginal health authorities:

"*But who constitutes the community and who do you consult with [for permission]? There isn't any real logic even or need to consult an individual or group of individual First Nations if the data is based on Provincial utilization and housed in Provincial institutions. But, what would TCPS2 [Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans] advise or guide in this case? They want to have appropriate community consultation but who is that with? With a group drawn from or representative of the people involved?*" *(P5)*

Mistrust of research. Four participants identified challenges of trust as a barrier to engaging in NDD research with Aboriginal communities:

"*… They are so reluctant to speak up. This is the problem. You need somebody who is courageous enough, to stand out as an advocate and say "I'm a parent of an autistic child and I'm living on reserve and that is the situation here …*" *(P1)*

"*They do not have trust and why should they? I think that there is a need to make sure that whatever we do brings Aboriginal People along with us, which is a very hard thing because of trust and colonialism.*" *(P2)*

"*Trust is always going to be an issue, especially when you are asking families to hand over their children or their data to researchers. Children, to this day, are still being stolen away from families by government agencies. Look at all the kids who are placed in foster care every year.*" *(P8)*

All participants affirmed that engagement in CP and ASD health research can only take place if the outcomes of research directly benefit the communities. Such outcomes must be focused on improving access to health care and services. Under these circumstances, they predicted that trust in non-Aboriginal NDD researchers would follow.

Accessing Children in Care for Research The high rate of Aboriginal children in foster care was identified as a significant barrier to enrolling children with neurodevelopmental conditions in health research studies, mainly due to difficulties in obtaining consent from child welfare agencies and in maintaining contact with children who experience multiple placements:

"*… the majority of the kids that come to the diagnostic service in FASD are of Aboriginal background, and the majority of them are in the foster care system. … So, you work with a child welfare worker who has to sign the consent to receive medical care or participate in research. … if the main guardian is a child welfare worker, and we know the child welfare workers change case loads every few months—there's lots of really significant barriers.*" *(P6)*

Lack of Researcher Support Other reasons cited for the lack of CP and ASD research included the lack of funding overall for Aboriginal research and a lack of support from academic universities that would allow researchers to pursue research involving community-based participatory research methods:

"*… community engagement is so difficult because it's not rewarded academically. It's very difficult for new academics… I think that if it was rewarded at an academic level then more academics would be interested in pursuing this kind of research and there would be more people who would go out to these individual communities.*" *(P7)*

Distinctiveness of FASD When probed about the reasons why FASD research is so prominent in this population, participants conjectured that it is

because FASD is unique relative to other NDDs. For example, FASD 1) involves a dual diagnosis, i.e., the mother and child dyad; 2) its origins are rooted in social, political, and historical determinants; and 3) it is highly preventable which, in principle, should make access to funding for research and services related to prevention easier than for other NDDs.

Implications of the Apparent Inattention to ASD and CP

Under-Representation and Distribution of Benefits All participants indicated that Aboriginal children with NDDs are underserved, especially those in foster care or living on reserve in rural areas where the availability of health care and specialized services is limited. Disparities in access to diagnostic assessment clinics and tertiary care (e.g., occupational therapy, physiotherapy, psychosocial services) were most frequently cited. Reasons for disparities were geographic distance from health care centers, lack of parental capacity and supports, and a lengthy and complex assessment process to diagnose NDDs, which was also often cited as a significant burden to families:

> "*... I think there's a gap in supports that way and yes, we want mothers and children and fathers even to become involved in the assessment, diagnosis, and care of a child with a disability. But if you think about the capacity of perhaps a single mother to do that or the capacity of a family to navigate those challenges or just deal with day to day life enough h... that a person has to cope with that anything added on top of that, it's just too much.*" *(P3)*

> "*We are relatively close to a big center and I try to send any kids for diagnosis at [name withheld] Hospital. Even to get the diagnosis there are so many barriers about bureaucratic forms that have to be filled out and, and stuff like that. It's very, very hard and a lot of developmental services are stretched as it is, so parents don't show up or fill in the forms…. Quite often the government says: 'Oh, but we need that speech assessment, an OT [occupational therapist] assessment,' and all this kind of stuff –otherwise we don't give the funding because it's not a complete assessment. Right, so we are waiting for over a year and then the parents forget about it or appointments and they have to fill in some very complex questionnaires. Sometimes, they don't even know the language. You know? They don't understand what all the questions are. And so they would need somebody to help them to fill in the questionnaires and send them in. In the meantime, they've moved a couple of times and their phone is disconnected ...! So there are some very practical barriers to get a diagnosis.*" *(P1)*

> "*There are lots of kids in those communities that are not diagnosed and the parents don't have the resources to get them a diagnosis and the care that they need. ... So there is a referral clinic called [name withheld] that they can go to, which is about an hour away, and will provide some services for assessment. So the next step would be now they got their child to see the pediatrician, who only comes once every two weeks, and hopefully they can get to that clinic –somebody can give them a ride on that day- now when they see me, I fill in a form that goes to the clinic. [The clinic] will then mail this big package back to the caregiver. It's huge this package! Like 30 pages long. Plus the school has to do an individual assessment of their IQ and their academic achievement. When they get the package back in [the clinic], then they will give the parents an appointment. So that is a huge hurdle for access [to care and diagnosis]. I would say that about in 5% of cases they get the information back that they need.*" *(P7)*

Participants also raised concerns about disparities in access to diagnostic services and care for children in foster homes. Two of the pediatricians voiced fears that multiple placements make it difficult to ascertain if the medical care needs of foster care children are being met in a timely and consistent manner. A third participant voiced concerns that children with complex needs have to be removed from their communities and be placed in foster care because their families are not provided with adequate resources to care for them:

"*Some parents with severely handicapped children need to give them up to foster care so the kids can attend school in Calgary. If you have very complex children and the family is not able to move into the city, for a variety of reasons, the children need to be placed in foster care. Over the years I've seen several children from reserve who needed to be placed here in ongoing care so they have access to special needs school, physio, occupational therapy, and better care.*" *(P1)*

Three participants stated that the absence of ASD and CP research could have serious implications for resource allocation by causing communities to shift attention and supports away from services for these conditions as they remain unrecognized. The participant with a background in policy-making also pointed out that the lack of basic epidemiology data about the prevalence of these conditions makes decision-makers weary of intervening:

"*… as far as autism and cerebral palsy, I haven't seen any evidence that would say there is from a health policy perspective a need to get involved.* " *(P5)*

Four participants suggested that if epidemiological data were available to show that developmental disabilities are highly prevalent in some communities, doors would open to further funding for interventions and community willingness to engage in NDD research:

"*… it [disability] has to be recognized before it actually gets investigated …. I think the prevalence data would be important because that helps us to kind of tailor responses and interventions.*" *(P3)*

"*… there's quite a high percentage of Aboriginal kids with cerebral palsy, but the research doesn't cover it. This is what's needed for change.*" *(P8)*

However, one participant who has had extensive engagement with policy makers and politicians felt that better prevalence data and increased public awareness about NDDs in Aboriginal children was not sufficient to stimulate government willingness to fund further research or improve access to health care for these communities:

"*I guess I was more naïve when I started. I kept thinking, if I just proved to them [politicians] that this works, and how good this is, they would invest in my program… but in lots of respects, the more I proved the less people listened.*" *(P2)*

Stigma The focus of research on FASD was identified as an ethical concern given the potential to perpetuate negative stereotypes related to drug and alcohol use among Aboriginal Peoples:

"*But the problem is, if you just report on a particular community it does make it sound as if you can take a leap and say therefore in all Aboriginal people there would be a high instance of FAS. And you can't do that unless you know that the prevalence of FAS is widespread in all different communities … I think it'd be really important to know why we're not seeing other disability research involving Aboriginal children. But also, what do we have to have in place so that research is reflecting equitably on everybody and not stigmatizing people by simply doing it.*" *(P4)*

Three participants voiced concerns that stigmatization may lead to biases in the diagnosis of FASD –in some cases, physicians may feel uncomfortable labeling a child with FASD, whereas in other cases, an Aboriginal child with ADHD or autism may instead be misdiagnosed with FASD because of cultural stereotypes:

"*One of the things that's interesting in terms of FASD is that—is the whole, as you know, is the whole stigma associated with FASD. For example … in the Northwest Territories, children with FASD aren't necessarily identified, partly because of stigma.*" *(P3)*

"*… you might find that there are people who are identified as having ADHD or anxiety or … a whole bunch of other kinds of behavioural things, that maybe if they were looked at another way might meet the criteria for FASD. And similarly, there might be kids in areas where we don't necessarily think of FASD, areas like higher middle class white suburban communities where nobody's ever asked the question of 'could there be FAS?'*

because it doesn't fit the profile, and the kids instead are being diagnosed with ADHD and a learning disability." *(P4)*

In contrast to these concerns, one participant reported that research on FASD does not contribute to stigmatization in the community; instead, she saw it as supportive and addressed a need that the community had identified as a priority:

"*People say we are probably discriminating against them in some way. Maybe there is a component to it [FAS], but I think many First Nation Communities have identified it in their community as a major issue … It's not [stigmatizing] as far as I know. I mean not in the community where I work.*" *(P1)*

Participant Recommendations

Epidemiological Research Six participants indicated that NDDs, including autism and cerebral palsy, were relatively common in the Aboriginal communities that they worked in. The lack of epidemiological research to establish prevalence rates was identified as a significant gap:

"*The lack of attention at least says there has to be some basic prevalence data collected and that we are falling short in that minimum area.*" *(P5)*

They suggested that, although difficult to achieve at the community level, leveraging secondary data sources, particularly health care utilization databases, could enable researchers to estimate the prevalence of NDD conditions:

"*And I really do believe that health units are privileged holders of a lot of information about disability in First Nations communities and may be a good resource for seeking out further information.*" *(P3)*

Prevention Four participants identified prevention research as a top priority for First Nation communities, especially with regard to FASD. Closely tied to prevention research is the need to better understand how social determinants of health, such as poverty, poor nutrition, and intergenerational trauma affect prenatal care. Two participants indicated that the communities they worked in were interested in pursuing prevention research aimed at developing educational curricula and programing for school aged children.

Improving Caregiver/Patient Supports and Access to Care All participants acknowledged that more research and funding are needed to improve access to supports and services. They identified needs-assessment surveys for families, research on perspectives from pediatricians on how to improve medical care and practice on reserves, and the development of culturally informed interventions as priorities. For example:

"*What is the best support to put in place in terms of the educational system? … what supports are needed for transitions to adulthood, and what works best and what is successful? … that evaluative piece I think is neglected …. I talked about needing research on sort of what interventions work. We want to make sure those interventions are also culturally appropriate and informed.*" *(P6)*

One participant also emphasized the need for more research on alternative forms of medical care delivery, such as the medical home model, which offers team based health care that is led by a physician in the community.

Mitigating Stigma Participants proposed that promoting existing resources and capacities in the community rather than highlighting gaps and dysfunction would constructively mitigate stigma:

"*… research needs to be more strength-based rather than deficit-based. Let's do research on this program that has the potential to prevent or that has the potential to ensure that children make the best possible choices …*" *(P7)*

Another recommendation emphasized the importance for Indigenous health research to encompass a wide spectrum of developmental disabilities rather than focusing on only one condition. Obtaining FASD prevalence data for non-Aboriginal children was also suggested as an approach to shift public

perception away from the stereotype that FASD is mainly an Aboriginal issue:

> "*If somebody does the research it needs to include all disabilities and not just go in and look for FASD or autism, or whatever … it has to include all kinds of disability.*" *(P1)*

Discussion

Promoting Inclusion and Access to Care

Under-representation of marginalized populations in clinical studies and data systems can mask health and social inequalities [11], which are themes at the heart of neuroethical inquiry. Participants in this small study suggest that research about disability among Indigenous populations could serve as a catalyst for developing public policies and services that address needs and protect the rights of the children to receive adequate care and live in dignity. Toward this end, they identified the need to establish the numbers of Aboriginal children living with neurodevelopmental disabilities as a key priority.

Mining health utilization databases to obtain prevalence data was one approach suggested to this address this gap, but it is not without challenges. For example, Indigenous identity is inconsistently and unreliably recorded in the vast majority of Canadian health care utilization data systems [11]. Reluctance on the part of Aboriginal patients to report ethnicity for fear of discrimination in hospitals and concerns about political marginalization from governments who are collecting the data are among the key factors that account for this phenomenon. Further, reporting requires data sharing agreements with Indigenous communities and relevant government health organizations to ensure that data are not used in a harmful way. This can require extra time and the cumbersome involvement of many institutions at multiple levels.

Another key concern that emerged from this study is that Aboriginal children with NDDs who are living under the care of child welfare services are particularly vulnerable to exclusion from research and access to medical or social services and supports. Canadian national estimates report an average of 40 % of children in care to be Aboriginal – this rate increases to 62 % in Western provinces and up to 95 % in the Northwest Territories [12]. Recent data also suggest that one in four Aboriginal children living in foster homes have an FASD diagnosis [13]. Participants in this study noted challenges in accessing this population because of difficulties in maintaining contact with children who experience multiple placements and difficulties in obtaining consent from child welfare agencies to enroll them in research. Currently, Canada has a decentralized child welfare system with over 300 provincial and territorial child welfare agencies that operate under the jurisdictions of 13 Canadian provinces and territories [14]. Further research is needed to determine how the processes for obtaining consent for children in care to participate in research vary across agencies and whether or not these variations affect recruitment. Developmental capacity, variations in caregivers, and other issues such as prior experience with maltreatment or neglect complicate the ethical involvement of Aboriginal youth with disabilities in research while under the care of welfare agencies. To address this disparity, researchers will have to approach child welfare agencies for partnership and identify the appropriate authorities representing the community in the development of the research project [15]. This should include broad consultation to develop procedures to ensure that participation in research is not a burden to social workers or the youth in care.

Beyond issues related to engagement in research, participants reported that children with complex needs are often placed in foster homes because their families are unable to provide them with the resources needed for their care within their own communities. This finding is at odds with the United Nations Convention on the Rights of the Child, which states that socioeconomically disadvantaged families must be provided with the economic and social supports necessary to safely care for their children and youth at home. Funding and research strategies are needed to identify how Indigenous families can be better served and given equal access to resources related to child welfare, such as appropriate medical, dental and social services [16]. All participants felt strongly that the outcomes of research should incorporate a direct benefit to communities that would address these disparities in access to interventions. For instance, research involving screening or diagnosis of NDDs should incorporate a strategy for intervention on behalf of children identified as having a disability. Such a strategy could include a mapping of the available services and the preparation of informative materials for families or legal guardians on how to adjust children's surroundings to enhance functioning and participation in home and community life [17].

Building Trust

Lack of trust, overall, is a major contributor to the reluctance of First Nation groups to engage with NDD researchers. This is not surprising given that the benefits of academic research for Indigenous communities are often inequitably distributed. Previous health research has been criticized for misrepresenting Indigenous peoples, appropriating their knowledge, neglecting their intellectual property rights, and failing to obtain informed consent for secondary use of their data, which have clearly resulted in harm to Indigenous participants and the wider community [18–23]. Moreover, critics argue that research often focuses on dysfunction rather than understanding Indigenous perspectives and experiences – a fact that has led to negative perceptions about Aboriginal Peoples and contributed to stereotyping [24, 25]. Together with broader legacies of colonialism, Aboriginal Peoples may be reluctant to engage with non-Aboriginal researchers, even those who have been working within the community for a long time. Participants respected this reluctance and advocated for culturally informed and strength-based approaches, which focus on understanding and building upon assets within family and community as a better way to promote trust. Several participants also made references to differences in cultural understandings and definitions of disability. This has implications for strength-based approaches as many Indigenous cultures view child development in holistic terms, where well-being is embedded in the land, family and community health and wellness across generations [18]. As illustrated in Ball and Janyst [18] by Marie Leo, an Elder from the Lil'wat Nation in the province of British Columbia: "*The idea of early childhood and ideas like disabled children, or that some children have special needs and some children are gifted—these ideas don't come from us. They are not Aboriginal ideas. They come from white people, and from cities. All children have gifts and are gifts from the Creator*".

Finally, participants acknowledged that limited prevalence data for NDDs, coupled with over-representation in FASD research, could contribute to stigmatization and assumptions that FASD is predominantly '*an Aboriginal problem*'. Here, expanding research to include a broader focus on a variety of disabilities and collecting better prevalence data for conditions such as FASD in both Aboriginal and non-Aboriginal children will help to close critical gaps.

Conclusions

This study reflects the experiences and opinions of a small sample of researchers and health professionals whose views must be interpreted with respect to their own personal and cultural perspectives. Clearly, a larger study in Canada and others transnationally are needed to fully elucidate the perceived impact of NDD research in indigenous communities and to establish future research and policy priorities [26, 27]. Nevertheless, as one participant voiced, "*As a civil society, we have a responsibility to care for children with disabilities and to watch out for them.*" *(P3)* "*Somebody has to start taking up the banner and fight. … These kids are voiceless … (P2).*

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Author's Contribution Both authors conceptualized the study and wrote the manuscript. First author conducted the interviews, analyzed the transcripts. All authors read and approved the final manuscript.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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