Disparities in Canadian Indigenous Health Research on Neurodevelopmental Disorders

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ABSTRACT: ***Objective:*** **To map the landscape of research on autism (ASD), cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD) in Canadian Aboriginal children.** ***Method:*** **The authors used a detailed search strategy to identify and access publications on ASD, CP, and FASD involving Canadian Aboriginal children, families, and communities from online databases. They analyzed these materials for the type of research, stated objectives, methodologies, and the level of engagement of Aboriginal Peoples.** ***Results:*** **The authors found a total of 52 reports published since 1981 relevant to Aboriginal children. Of these, 51 focused exclusively on FASD. They also found a near-complete failure to acknowledge community involvement in research decisions or dissemination of results in any of the publications.** ***Conclusions:*** **The focus on FASD in Aboriginal children and the absence of research on the other 2 major childhood disorders are at odds with rates of these disorders across Canadian children. The authors argue that this trend violates fundamental principles ensuring equitable representation of all children regardless of background in research and access to benefits of research in health care and perpetuates stigma in an already marginalized population.**

*(J Dev Behav Pediatr 35:*74–81, 2014) **Index terms:** autism spectrum disorder, fetal alcohol spectrum disorder, cerebral palsy, aboriginal health, neuroethics.

"Not all of our children are fetal alcohol syndrome."
-Aboriginal woman, Winnipeg, Canada.[1]

Cultural discontinuity has been linked to high rates of depression, alcoholism, suicide, and violence in Aboriginal Peoples, with the most dramatic impact on youth.[2] In Canada, major health disparities exist between Aboriginal and non-Aboriginal people, which are multifaceted in origin and largely influenced by socioeconomic and environmental factors.[3] These health disparities are especially significant for Aboriginal children who represent the poorest and the most vulnerable population in this country.[4] In almost all measures of child health (e.g., diabetes and suicide rates) and well-being (influences such as poverty and access to clean water), Aboriginal children fall well below the national averages for Canadian children.[5] Moreover, 1 Aboriginal child in 8 has a disability, double the rate of all children in Canada.[4] These disparities have led to calls for action from Canadian and Aboriginal health organizations to improve access to health care and services.[6] Identifying the health needs of Aboriginal children is a critical step to achieve this goal.

Here, we deliver an in-depth analysis of the scope of health research on Canadian Aboriginal children living with neurodevelopmental disabilities. We focus on the 3 most common disorders in North America: autism spectrum disorder (ASD), cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD). Combination of these disorders affect more than 1 million children in this region of the world. Autism spectrum disorder is now the most commonly diagnosed neurodevelopmental disorder, with an incidence of 1 child per 88 births.[7] It is characterized by problems with social interaction and communication, narrow interests, and repetitive behaviors.[8] In contrast, CP is the most common motor disability during childhood, characterized by a range of permanent nonprogressive impairments in motor and sensory development because of injury or abnormality of the developing fetal or infant brain.[9] Worldwide prevalence estimates are in the range of 1.5 to 4 children per 1000 live births.[10] Prevalence rates for FASD are less certain, with estimates that at least 9.1 children per 1000 births are affected by one of its variants: fetal alcohol syndrome, partial FASD, or alcohol-related neurodevelopmental disorder.[11–13] Alcohol teratogenesis is by far the most common and serious effect of FASD. Animal studies have shown that alcohol typically produces small neurochemical and structural changes throughout the

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brain. In humans, these changes frequently go undetected until a child reaches an age when normal functions should be maturing but, instead, appear impaired. The consequences of alcohol exposure manifest in a wide variety of mild-to-moderate impairments of both cognitive processes, such as memory, executive function, social communication, and attention span, and motor and sensory function. Childhood depression, anxiety, and other mental health conditions are also common, owing to either primary brain alterations or secondary to the neurobiological alterations. The combination of these functional deficits leads to severe adaptive problems at home, at school or work, and in society.

The combined economic burden of these disorders on society and families of any of these disorders is tremendous, even when considering that many of the economic and social impacts of neurological disorders are often under represented because they are lumped together with other conditions. For example, autism is generally classified as a behavioral disorder,[14] rather than a neurological one. Along with mental stress, raising a child with ASD, for example, is associated with a very high economic cost, including those associated with special education, social services, and lost employment (estimated at $3 million USD[15]). One study found that the lifetime costs associated with a person diagnosed with ASD is the equivalent of $4.4 million USD.[16]

We attend here specifically to research involving Aboriginal children with neurodevelopmental disorders in Canada, but our findings and conclusions have implications for indigenous communities and health researchers broadly. Research focusing on preventions and addressing brain function problems early is far more effective than dealing with issues later in life.[17] Research outcomes have positive short- and long-term impact and provide health, economic, and social benefits through enhanced diagnosis, treatment, and care for children affected with neurological disorders. Given the enormous financial burden of neurological disorders affecting children, even a limited success results in significant gains.

We use the term *Aboriginal* in this article to refer to children and adults from First Nations, Inuit, and Métis Peoples of Canada. We respectfully appreciate, however, that this umbrella term suboptimally homogenizes the diverse cultural, social, environmental, and linguistic settings of these peoples who represent some 596 bands residing on 2284 reserves, cities, and rural communities across the country, 11 major languages, and over 58 dialects.[18] We also recognize that non-Status Indians, or unregistered persons of Aboriginal ancestry in Canada,[19] may be participants in research studies but not be reported as such. In presenting our detailed analyses in the supplemental summary tables (see Tables, Supplemental Digital Content 1, http://links.lww.com/JDBP/A52), we adhere to any originally reported specificity and terminology.

REVIEW STRATEGY

We used a detailed search strategy to identify and access publications on autism spectrum disorder (ASD), cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD) involving Canadian Aboriginal children, families, and communities from the following databases: Google Scholar, PubMed/Medline, Canadian Health Services Research Foundation, Health Canada, and the library collection from the University of British Columbia, which includes scholarly journals and articles, dissertations, and theses. Publications were identified using the following string of key words: ("cerebral palsy") OR ("autistic disorder" OR "autism") OR ("fetal alcohol") OR ("foetal alcohol") AND ("adolescent" OR "child" OR "children") AND ("Aboriginal") OR ("Aboriginal") OR ("First Nations") OR ("Métis") OR ("Inuit") AND "Canada". The analysis encompassed peer-reviewed research and review articles and literature such as health reports from government agencies and nonprofit organizations, editorials, and academic dissertations. Materials from newspapers, magazines, conference presentations, booklets, brochures, and book chapters were excluded (Fig. 1).

Databases for meeting abstracts were not accessed for this review. The search was limited to the English language, and only the literature pertaining to Canadian Aboriginal Peoples was included in the analysis. All articles that met these inclusion criteria, regardless of year of publication, were included in the review. For all eligible publications retrieved, we recorded the year of publication, first author institutional affiliation, and funding sources. For research studies, we noted additional information such as the type of research (i.e., biomedical, behavioral, and epidemiological), methodologies, age of child participants, and number (i.e., sample size) of Aboriginal children who participated. We applied similar methods to health reports, academic theses, and other eligible documents by recording the name and type of

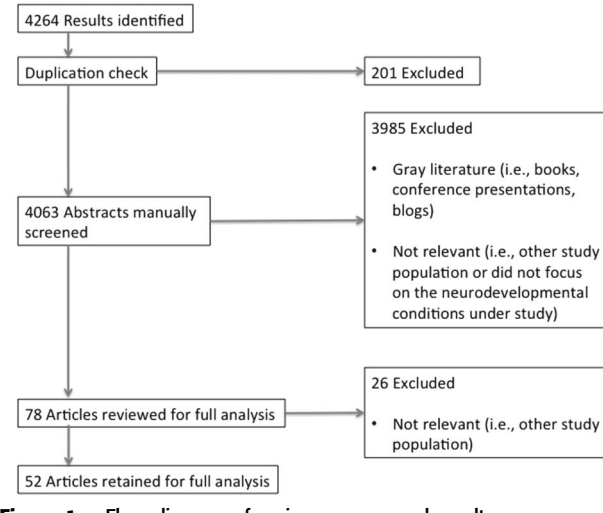

Figure 1. Flow diagram of review process and results.

the commissioning or issuing organization, funding sources, and stated objectives.

We also noted the reported level of engagement of Aboriginal Peoples by documenting Aboriginal funding sources, recruitment methods, and references to the community (e.g., consulting with elders, band councils, community engagement, or community-based participatory research) in the title, abstract, full text, and acknowledgments.

We conducted this review within the 4-month period between October 11, 2011, and February 14, 2012, and repeated it again in December 2012.

CHARACTERISTICS OF THE LITERATURE

We retrieved a total of 52 publications (Fig. 1). The focus of 51 was on fetal alcohol spectrum disorder (FASD), and we focus our discussion here. One article focused on genetic screening of Ojibway-Cree newborns at risk for developing neurological sequelae consistent with extrapyramidal cerebral palsy (CP).[20] None had to do with autism spectrum disorder (ASD).

Overall Characteristics of the Fetal Alcohol Spectrum Disorder Articles

Asante[21] published the first article addressing FASD in Canadian Aboriginal children. Over half of the articles retrieved, however, were even more recent; 31 of the 52 articles were published between 2007 and 2011. The largest cluster of authors is from the province of Alberta (Fig. 2) with one of the youngest Aboriginal populations in the country. In 2006, 31% of the Aboriginal population in Alberta was younger than 14 years compared with 19% of the non-Aboriginal population.[22]

Characteristics of the Peer-Reviewed Articles

Of the 51 FASD papers, 34 were peer-reviewed reports of research studies and literature reviews. They covered 5 main themes: prevention and/or intervention, biomedical and/or behavioral clinical research (i.e., the effects of alcohol on brain development and behavior), incidence/prevalence rates of FASD in Aboriginal communities, knowledge and attitudes of stakeholders toward FASD, and the representation of FASD in the criminal justice system.

Prevention/Intervention

Thirteen publications on prevention/intervention programs and services for Aboriginal communities, children, or parents affected by FASD were published between 2001 and 2011 (see Table 1 and Supplemental Digital Content 1, http://links.lww.com/JDBP/A52). Studies involved mixed methods: 12 publications used qualitative research (i.e., surveys, interviews, and content analyses) to assess programs and services. Five articles provided literature reviews. Four studies acknowledged funding from Aboriginal health organizations, including the Canadian Institutes of Health Research—Institute of Aboriginal Peoples' Health, the National Aboriginal Health Organization, and the Aboriginal Health Strategy Fund by Alberta Health. The remaining articles either did not acknowledge funding sources (n = 8) or were not funded by Aboriginal organizations (n = 2). Three used community-based participatory research methods.

Biomedical and Behavioral (Clinical Research)

Nine research papers were published involving biomedical or behavioral studies on Aboriginal children (aged 3–17 years) with FASD between 2001 and 2011 (see Table 1 and Supplemental Digital Content 1, http://links.lww.com/JDBP/A52). All studies included

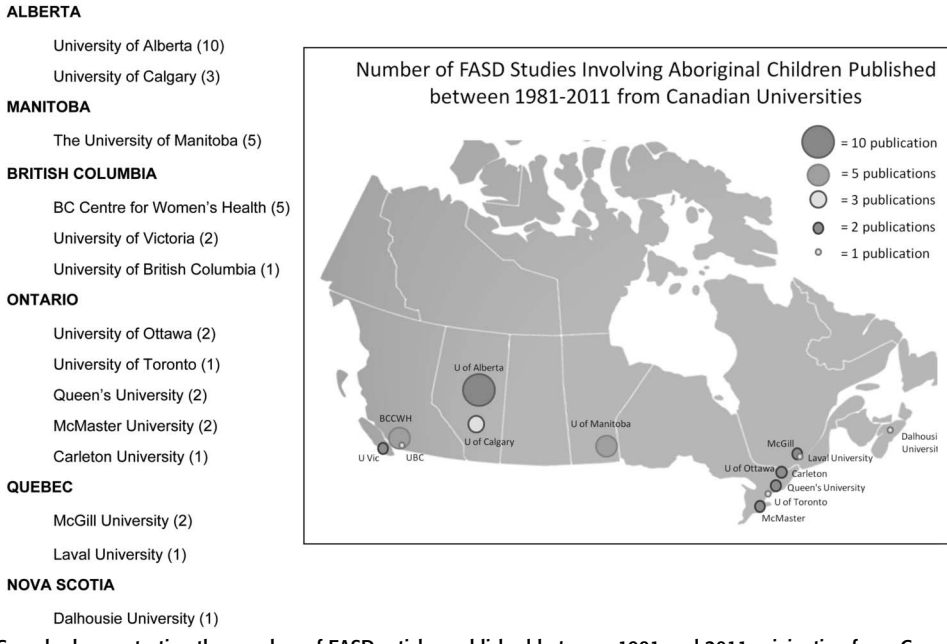

Figure 2. Map of Canada demonstrating the number of FASD articles published between 1981 and 2011 originating from Canadian universities. FASD, fetal alcohol spectrum disorder.

Table 1. Summary of Literature Reviewed

Topic	Reference(s)	Summary
FASD peer-reviewed literature		
Prevention/intervention	51–63	N = 13 research articles published between 2001 and 2011. Studies generally involved qualitative research. Three studies used community-based participatory research methods; 4 acknowledged funding from Aboriginal health organizations. See Table 1 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52, for details.
Clinical studies	23,64–71	N = 9 research articles were published between 2001 and 2011. Most studies involved behavioral and cognitive testing. Three studies[66,68,71] used neuroimaging methods. Three studies[23,69,70] also reported that recruitment took place in First Nations communities, but they did not either specify how or refer to guidelines on research ethics involving Aboriginal peoples. See Table 2 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52, for details.
Prevalence/incidence	24,31,72–77	N = 7 articles published between 2001 and 2011. Reported prevalence rates for FAS ranged from 2.8 to 190/1000 children. The percentage of women who reported drinking during pregnancy ranged from 24% to 61%. Only 1 study[24] provided an incidence rate for FAS: 7.2/1000. One study (conducted on-reserve where consent was not sought) was stopped at the request of the community. See Table 3 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52, for details.
Knowledge and awareness	25–27	N = 3 studies published between 1999 and 2009. Two studies[25,26] examined the concerns and beliefs of Aboriginal families about the prevalence of FASD in their communities. The other[27] studied the perspectives of both Aboriginal and non-Aboriginal families affected by FASD and the physicians who treat them. In 2 of the studies,[25,27] the principal investigator lived in the community and took part in its activities.
Criminal justice	28,29	N = 2 studies were published in 2008 and 2011. Bracken[28] considered the representation of Aboriginal persons in the criminal justice system and connections between the impact of colonialism and health. Dej[29] explored the discourse between childhood FASD and adult FASD and identified a shift in transition from child to adult, whereby the FASD child is perceived to be a victim in need of medical attention and full of potential, whereas the FASD adult is perceived as deviant, potentially dangerous, and hopeless.
FASD non–peer-reviewed literature		
Health reports	1,5,78–86	N = 11 reports published between 1997 and 2011 by government and nonprofit organizations reviewing prevention and intervention services in specific communities and providing recommendations for best practices. See Table 4 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52, for details.
Academic theses	30–35	N = 5 theses published between 1997 and 2008 on a range of topics including prevention, prevalence[31]; data included in Table 3 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52; and the impact of FASD on families and communities.
CP peer-reviewed literature		
Genetics	20	N = 1 study published in 2002 on the outcome of a genetic screening program involving Ojibway-Cree newborns at risk for developing neurological sequelae consistent with extrapyramidal CP.

FASD, fetal alcohol spectrum disorder; CP, cerebral palsy.

both Aboriginal and non-Aboriginal participants. Seven studies reported that Aboriginal children, broadly categorized as Aboriginal, were recruited from hospital FASD clinics. In all publications, demographic data provided on ethnicity, typically categorized participants as white, Aboriginal, or other. Although the research studies did not specifically target Aboriginal children or seek to address Aboriginal health issues, 6 of the 9 reported that most participants in FASD/fetal alcohol effects (FAE) groups were Aboriginal children. In the remaining 3 studies, approximately one third of the participants were reported as Aboriginal. Four studies recruited healthy children for control comparisons. With the exception of the study by Rasmussen and Bisanz[23] in which 1 child was identified as Aboriginal, no Aboriginal children were represented in control groups. Three studies reported that recruitment took place in First Nations communities, but they did not either specify how or refer to

guidelines on research ethics involving Aboriginal Peoples.

Prevalence/Incidence

Seven peer-reviewed articles published between 2001 and 2011 discussed incidence/prevalence rates for FASD in Aboriginal communities (see Table 1 and Supplemental Digital Content 1, http://links.lww.com/JDBP/A52). Two were literature reviews. The most common methods used to determine prevalence rates for FASD were interviews and questionnaires administered to mothers about their drinking habits during pregnancy, medical screening of children to establish or confirm a diagnosis of FASD, or both. Reported prevalence rates for fetal alcohol syndrome (FAS) ranged from 2.8 to 190 per 1000 children. The percentage of women who reported drinking during pregnancy ranged from 24% to 61%. Only 1 study[24] provided an incidence rate for FAS: 7.2 per 1000. The authors noted, however, that this rate might be an underestimation because more than half of the children identified at high risk for FASD (49 of 90 cases) could not be clinically assessed. They cited the following reasons to account for this: the community was too remote, the child could not be located, or the community did not permit screening. The authors also point out that, despite reassurances that the community of origin would not be identified, this on-reserve epidemiological study, for which consent was not sought, was stopped at the express request of the community.

Fetal Alcohol Spectrum Disorder Knowledge and Awareness

Three studies published between 1999 and 2009 investigated stakeholder knowledge and attitudes about FASD. Kowalsky and Verhoef[25] and Williams and Gloster[26] examined the concerns and beliefs of Aboriginal families about the prevalence of FASD in their communities. Oldani[27] studied the perspectives of both Aboriginal (n = 3) and non-Aboriginal (n = 3) families affected by FASD and the physicians (n = 4) who treat them. All studies involved participant interviews, participant observation, or both. In both the studies by Kowalsky and Verhoef[25] and Oldani,[27] the principal investigator lived in the community and took part in its activities.

Fetal Alcohol Spectrum Disorder and Criminal Justice

Two studies examined FASD within the context of the Canadian criminal justice system and Aboriginal Peoples.[28,29] Bracken[28] considered the representation of Aboriginal persons in the criminal justice system and connections between the impact of colonialism and health. Dej[29] explored the discourse between childhood FASD and adult FASD and identified a shift in transition from child to adult, whereby the FASD child is perceived to be a victim in need of medical attention and full of potential, whereas the FASD adult is perceived as deviant, potentially dangerous, and hopeless.

Characteristics of the Nonpeer-Reviewed Literature

We retrieved 11 health reports, 5 academic theses and 1 editorial on FASD and Aboriginal People. Between 1997 and 2011, the health reports were published both by government and nonprofit organizations (e.g., Aboriginal Nurses Association of Canada, Paq'tnkek First Nation Health, BC initiatives for Aboriginal Health, and UNICEF). Six of these were prepared and funded by Aboriginal health organizations (Table 1 and Supplemental Digital Content 1, http://links.lww.com/JDBP/A52).

Five academic dissertations for masters or doctoral degrees were produced between 1997 and 2008 on a range of topics: (1) theory and practice governing prevention efforts specifically targeting pregnant Native women, and a deconstructed problematization of FAS within Aboriginal communities[30]; (2) the prevalence of FAS and partial FASD in a First Nations community in Manitoba[31]; data included in Table 3 in Supplemental Digital Content 1, http://links.lww.com/JDBP/A52); (3) intergenerational perspectives on the difficulties of living with FAS/FAE[32]; (4) the impact of FAS on the lives of Aboriginal women, their children, and their communities[33]; and (5) the challenges faced by Northern British Columbian Aboriginal mothers raising adolescents with FASD and the adaptability, confidence, and care in their mothering roles.[34] The 1 editorial retrieved from *Canadian Medical Association Journal*[35] discusses the unpublished work of a leading expert in the field of FAS. The article, "Fetal alcohol syndrome epidemic on Manitoba reserve," was written in collaboration with a pediatrician and the head of Community Health Sciences in Manitoba and describes the landscape of the disorder in this particular region of Canada.

DISCUSSION

The Aboriginal birth rate is more than twice that of the Canadian population at large. Moreover, 1 Aboriginal child in 8 has a disability, double the rate of all children in Canada.[4] Notwithstanding the high proportion of youth with disabilities, there are only limited prevalence data available for fetal alcohol spectrum disorder (FASD), no known statistics on the number of Aboriginal individuals living with autism spectrum disorder (ASD) or cerebral palsy (CP), and virtually no relevant research on these disorders in the population. The involvement of Aboriginal people and methodology in any of these studies is spotty, at best. Only a handful of peer-reviewed research studies on FASD reported an active engagement with Aboriginal groups, and although most participants in clinical research studies were Aboriginal children, healthy Aboriginal children were not included in control groups.

What accounts for these trends and the apparent lack of research on CP and ASD in Aboriginal children in Canada in particular? On the one hand, it is possible that the general Canadian research literature does in fact include Aboriginal participants with CP and ASD but does not bother to identify them separately from other study participants. However, given that Aboriginal participants

who have FASD are clearly identified, this is an unlikely explanation. On the other hand, it is possible that CP or ASD disorders do not disproportionately affect Aboriginal compared with other Canadian children. In this case, there would be no reason for researchers to conduct studies limited to Aboriginal populations or to break down their study populations by ethnicity. Given that major health disparities exist for Aboriginal Peoples and that rates of disability are reportedly twice that of their non-Aboriginal counterparts, however, this also seems unlikely. Moreover, this line of reasoning would imply that FASD is a disproportionate focus in the Canadian Aboriginal population, because it is more widespread. The prevalence of alcohol abuse among Aboriginal people, historically attributed to the effects of colonialism[3] indeed lends support for this line of reasoning,[29,32,33,35,36] but the absent epidemiological evidence for the other disorders cannot be construed as evidence that they are actually absent disorders.

The epidemiological literature on developmental disabilities in Native American Peoples who share many common aspects of culture and history with Canadian Aboriginal Peoples sheds some light on what real incidence rates might be. For autism, data obtained from the Individuals with Disabilities Education Act indicate that the percentage of Native American children identified with autism (0.05%) is disproportionately low when compared with other racial groups.[37] However, Tincani et al[38] found that Native American/Alaska Native students were underidentified with autism compared with their non-Aboriginal counterparts. The authors speculate that geographical location, unique and distinct tribal beliefs about disability, poverty, and the historical impact of large-scale economic and political oppression delay or mitigate identification.[38] Support for underdiagnosis also comes from studies with children from the Australian Aboriginal population where culture and language create barriers to the documentation of accurate developmental histories.[39] Given these findings, it is possible that similar factors may lead to the underdiagnosis of autism in Canadian Aboriginal children, to the perception that autism is relatively rare, and consequently to the limited prioritization of relevant research for this population and related publications. Ultimately, culturally sensitive diagnostic tools for autism need to be developed before epidemiological assessments can be made. Rates for CP, at least in the state of Wisconsin, are reported to be 5.5 per 1000 Native children.[40] This rate is significantly higher than that reported for children of other backgrounds that ranged from 1.0 to 3.3 children per 1000 live births.[40] Significantly higher rates of CP have also been reported for Australian Aboriginal children.[41] Based on these data, the possibility that CP rates may be higher in Canadian Aboriginal children must be considered. Studies of the rate for FASD among Native Americans report ranges from 1.0 to 8.97 cases per 1000 births.[42–45] These numbers are significantly lower than estimates provided in the Canadian research data, suggesting widely varying prevalence rates of 2.8 to 190 per 1000 children, much higher than US national estimates (0.3–1.5 cases of FASD per 1000 live births).[11]

Overall, the incidence data would suggest that the absence of research on ASD and CP is not justified. This notable absence violates federal guidelines on the protection and representation of human subjects in research[46] and denies Aboriginal children benefits that research with non-Aboriginal children may experience. Cultural consideration and appropriateness of any intervention and access to services is thus also lacking.[38,47] The potential overidentification of FASD in Aboriginal communities is further concerning as it only further stigmatizes an already marginalized population.

CONCLUSION

Research on fetal alcohol spectrum disorder (FASD) remains a critical and valuable endeavor to improve the lives of Aboriginal children and their families living with this condition. For Aboriginal communities, culturally appropriate methodologies are needed to respectfully address the lack of baseline data for all neurodevelopmental conditions.[3,46,48–50] Moreover, the active engagement with Aboriginal groups throughout the research process must be improved to ensure that the "views of Indian, Inuit and Métis peoples are represented in planning and decision making, from the earliest stages of conception and design of projects through to the analysis and dissemination of results."[46] Ultimately, however, each community will have to decide on its own research priorities. The gaps in health research we have highlighted here are not intended to dictate what kinds of research should or should not be carried out in Aboriginal communities. Rather, our goal is to initiate discussions between academic researchers and communities that are interested in addressing disparities in public health research related to children. Aboriginal Canadians have shown leadership in FASD prevention as a priority area for public health action at the community and national level and in advancing holistic, integrated approaches to FASD treatment and prevention.[51] Similar partnerships between academic researchers and Aboriginal Peoples need to be fostered to address health questions related to autism spectrum disorder (ASD) and cerebral palsy (CP) as well. Such new knowledge and responsively tailored policies and programs will improve the health and quality of life of Aboriginal children living with and without developmental disabilities.

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