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## Discrimination Against First Nations Children with Special Healthcare Needs in Manitoba: The Case of Pinaymootang First Nation

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# Discrimination Against First Nations Children with Special Healthcare Needs in Manitoba: The Case of Pinaymootang First Nation

## Abstract

First Nations children face systemic barriers in their access to health, education, and social services ordinarily available to other Canadian children. This article summarizes the findings of a research project initiated by, and carried out in partnership with, Pinaymootang First Nation, Manitoba between 2015 and 2017. Through this partnership, we were able to document the routine delays, denials, and disruptions of services that Pinaymootang children with special healthcare needs experienced. We further described the impact that this discrimination had on children and their caregivers. Here, we consider three specific service areas: medical services (primary and specialized), allied health services (e.g., language therapy), and additional care services (e.g., medication). Our findings are drawn from formal and informal interviews with Indigenous, provincial, and federal service providers; Indigenous leadership; and caregivers of Pinaymootang children with special healthcare needs. Based on this information, we argue that discrimination is pervasive, rooted in Canada's colonial history, and actualized through three main instruments: administration of policies regulating the provision of services to First Nations populations living on reserve, chronic underfunding of services targeting this population, and geographic isolation (i.e., distance from a service hub). The article concludes with nine recommendations prepared by the project's advisory committee for future policy aiming to eliminate the discrimination First Nations children with special healthcare needs experience by way of fully (and meaningfully) implementing Jordan's Principle in Canada.

## Keywords

Canada, Jordan's Principle, Pinaymootang, First Nations, special healthcare needs, disability, children, discrimination

## Acknowledgments

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## Disclaimer

This paper summarizes the main findings of a research project completed in 2017 and conducted in partnership with Pinaymootang First Nation. The full report can be downloaded from <http://cwrp.ca/publications/3328>

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## **Discrimination Against First Nations Children with Special Healthcare Needs in Manitoba: The Case of Pinaymootang First Nation**

Canada is a settler society built upon the plundering and near extermination of Indigenous Peoples (Daschuk, 2013). Throughout the last five centuries, colonial governments have asserted control over Indigenous land; replaced pre-existing forms of Indigenous government; denied the right to Indigenous people to fully participate in Canadian political, economic, and social life; outlawed Indigenous spiritual practice; and systematically separated children from their parents and communities through the residential school and child welfare systems (Daschuk, 2013; Simpson, 2011; Truth and Reconciliation Commission of Canada, 2015).

Through such actions, colonialism has shaped the social determinants of health for First Nations people.<sup>1</sup> Social determinants are understood as “the conditions in which people are born, grow, live, work and age . . . [which] are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries” (World Health Organization, n.d., What Are Social Determinants of Health section, para. 1). Colonialism has been widely recognized as a key determinant of health for Indigenous Peoples throughout the world and in Canada (Allan & Smylie, 2015; Czyzewski, 2011; Mikkonen & Raphael, 2010; Mowbray, 2007; Paradies & Cunningham, 2009). In Canada, Aboriginal status has been identified as the most important of 14 mutually interdependent determinants of health for the overall population, the others being disability; early childhood development; education, employment and working conditions; food insecurity; health services; gender; housing; income and income distribution; race; social exclusion; social safety net; and unemployment and job security (Raphael, 2009).

The links between Indigenous identity and healthcare are shaped, in part, by a long history of institutionalized discrimination against this group, and a current public service framework that flows directly from colonial history and ideology (Czyzewski, 2011). This framework rests on three main instruments: the Constitution Act of 1867, the Indian Act of 1876, and the Numbered Treaties. Article 91(24) of the Constitution Act gave exclusive responsibility over “[Status] Indians, and Lands reserved for the Indians” to the federal government; meanwhile, Article 92 assigned responsibility for most health and social services for all other Canadians to the provinces. The Indian Act defined eligibility, acquisition, and transmission of Indian Status, which is the mechanism used by the federal state to delimit the population directly under its jurisdiction. In the Manitoban context, a series of numbered treaties were signed between First Nations and the Canadian government in the 19<sup>th</sup> century. These treaties defined the territory (reserves) where First Nations were to settle, offering in exchange “rations in times of famine, medicines, and agricultural implements” (Lavoie & Forget, 2011, p. 127). This promise was later interpreted as including access to other publicly provided services.

In combination, these three instruments have been interpreted as entailing federal responsibility to provide public services to Status First Nations people living on reserve (Lavoie & Forget, 2011). As a result, while the vast majority of Canadians receive health and social services administered and delivered by the provinces, Status First Nations people living on reserve receive services provided by the federal

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<sup>1</sup> First Nations, along with Inuit and Métis peoples, are the descendants of Canada’s original peoples and are collectively referred to as Indigenous Peoples.

government and delivered by local providers. These providers are mandated to provide services in keeping with provincial standards but are limited by strict constraints imposed by federal funding. Responsibility for services for Status and non-Status First Nations people living off reserve is the source of much jurisdictional friction between the two levels of government (Lavoie, 2013; Office of the Auditor General of Manitoba, 2013). Additionally, this division of responsibilities between the federal government and provincial governments divides the Canadian population based on their race and place of residence, engendering contradictions, duplications, inequalities, and gaps in service (Lavoie & Forget, 2011). First Nations children are caught in this system and routinely experience discrimination when they try to access health, education, and social services ordinarily available to other Canadian children in similar circumstances. Disparities between the services available to First Nations children and other children in Canada are longstanding, ongoing, and well-documented (Canadian Human Rights Tribunal [CHRT], 2016a, 2017; The Jordan's Principle Working Group, 2015; Truth and Reconciliation Commission of Canada, 2015).

Jordan's Principle is intended to be a key mechanism for eliminating this discrimination. The principle is named after Jordan River Anderson, a child from Norway House Cree Nation in Manitoba who was born with a rare and severe medical condition. Jordan's doctors approved his release from hospital when he was 2 years old. However, due to jurisdictional disputes between the federal and provincial government over payment for his out-of-hospital care expenses, Jordan never set foot outside of a hospital. He died at the age of 5 (First Nations Child and Family Caring Society of Canada, n.d.). Jordan's Principle is meant to avoid this happening again:

Jordan's Principle calls on the government of first contact to pay for the services required by a First Nations child, without service denials, delays, or disruptions. Once the child's needs are provided for, government bodies may resolve jurisdictional disputes and seek reimbursements. (First Nations Child and Family Caring Society of Canada, n.d., p. 1)

Despite endorsement by the House of Commons in 2007 and repeated calls for implementation, Jordan's Principle is yet to be fully implemented (Anaya, 2014; Assembly of First Nations, 2013; Assembly of Manitoba Chiefs, 2006, 2011; Assembly of Manitoba Chiefs & First Nations Health and Social Secretariat of Manitoba, 2016; Fontaine & Assembly of First Nations, 2008; The Jordan's Principle Working Group, 2015; Truth and Reconciliation Commission of Canada, 2015).

In 2016, the conclusion of a decade-long legal battle initiated by the First Nations Child and Family Caring Society of Canada and the Assembly of First Nations brought new hope for the implementation of Jordan's Principle. The Canadian Human Rights Tribunal's (CHRT) ruling identified inequitable funding and administration of on-reserve child welfare services as ethno-racial discrimination against First Nations children. One of several immediate remedies focused on Jordan's Principle: The CHRT (2016a) ordered the federal government "to immediately implement [its] full meaning and scope" (p. 168, para. 481). In 2017, after three non-compliance orders, the Tribunal deemed the federal government's response fragmented and insufficient (CHRT, 2016b, 2016c, 2017).

This article discusses obstacles to service access for children with special healthcare needs (SHN) in Pinaymootang First Nation, Manitoba.<sup>2</sup> We begin by introducing this community and the group of children with SHN who participated in our study. Next, the methods used for this study is presented. We then introduce the three service areas we considered (medical services, allied health services, and additional care services); the subsections discuss obstacles encountered by children with SHN in each of these areas. We argue that these obstacles translate into the denial, delay, and disruption of services for First Nations children with SHN living in Pinaymootang. We present the three factors responsible for this discrimination, which are rooted in the legacy of Canadian colonialism: funding disparities, administration of services, and geography. Finally, we conclude with a discussion of nine policy recommendations proposed by the project's advisory committee to implement Jordan's Principle in Manitoba. We also compare these recommendations with current efforts to implement Jordan's Principle in Canada.

### **Children with Special Healthcare Needs in Pinaymootang First Nation**

Our goal in this article is to understand how the discriminatory framework for services for First Nations Peoples impacts children with special needs, their families, and their communities. We focus on children from Pinaymootang First Nation, an Ojibwe community located in Treaty 2 territory, Manitoba. The majority of the Nation's members reside in Fairford reserve, which has a surface area of 7,412.60 hectares (1/15<sup>th</sup> of Winnipeg's metropolitan area) and is situated in the Interlake Region, about 250 km north of Winnipeg along Highway 6. The Band had 2,812 members in 2016, 50 percent under the age of 20 (Pinaymootang Health Centre, n.d.). Like many other First Nations throughout the country, Pinaymootang faces a number of challenges: The community's economic base has been decimated by colonial practices and, today, educational attainment is low and unemployment rates are high. At the same time, there is a sense of pride and kinship that informs the work done at the local level. Respondents described their community as a friendly and welcoming place where neighbours take care of their lots, and where individual and communal achievements are celebrated. Participants in this study also highlighted that the Nation has come a long way in the last few decades, mainly thanks to partnerships established among the Band, local service providers, and other regional stakeholders. The pride service providers take in meeting the needs of the community is evident when it comes to taking care of its most vulnerable members: In 2016, after years of lobbying with the federal government, the Pinaymootang Health Centre secured temporary funding to implement a pilot project for children with special needs and their families.

Our discussion of obstacles to accessing equitable health, social, and education services in Pinaymootang focuses specifically on the experience of a group of 12 children with SHN who were enrolled in this pilot project in 2016. Children with SHN "have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition" (McPherson et al., 1998, The New Definition section, para. 2). They require ongoing or intermittent interventions, which vary in complexity, from different service agencies and professionals (Hewitt-Taylor, 2008; Watson, Townsley,

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<sup>2</sup> The report on which this article is based was a collaborative effort (Vives, Sinha, Burnet, Lach & Pinaymootang First Nation, 2017). Lucyna Lach, Eric Burnet, Gwen Traverse and the members of a Pinaymootang based project committee played integral roles in the project summarized in the report and we are grateful for their contributions.

& Abbott, 2002).<sup>3</sup> As a group, children with SHN are particularly vulnerable to service gaps. Children are, by definition, largely dependent on adults for their well-being, and they lack the political tools to effectively advocate for changes in their living conditions. These vulnerabilities are amplified for children with SHN, who typically require multiple services over a long period of time. Not having access to services can prevent these children from receiving proper treatment for their complex medical and developmental conditions, force them to experience a poor quality of life, impact their chances of reaching their full potential, and even put their lives at risk. For children in Pinaymootang, these challenges were compounded by the intersections between being First Nations, being children, having SHN, and living on reserve. Their experiences were shaped both by the availability of federally funded services and by on-reserve conditions that stem from colonial policies and practices. Reserve communities are often rural and sometimes remote. Poverty, lack of affordable and salubrious housing, limited employment opportunities, and inadequate access to healthy food and drinking water are widespread in reserves, heightening the vulnerability of children with SHN (Reading & Wien, 2013). Pinaymootang children are exposed to all of these risk factors.

### **Methods: Pinaymootang, a Case Study**

The information discussed in this article was collected as part of a collaborative project to document service access disparities experienced by children with SHN from Pinaymootang First Nation and their caregivers. This partnership began in the summer of 2015, before the first CHRT ruling related to Jordan's Principle. Community leaders initiated the collaboration with the research team, which was facilitated by Nanaandawewigamig: First Nations Health and Social Secretariat of Manitoba (FNNSM). The terms of the collaboration were established in a Research Agreement signed in January of 2016. The governing body for the project was a 15-member advisory committee that met monthly. Members included one member of the Band Council, one regional and seven local service providers, three representatives of a major provincial Indigenous organization, and three members of the research team. The primary goal of this collaboration was to produce a policy report that the community could use in their advocacy efforts, with possible additional publications, such as this article.

We used a qualitative case study approach focusing on Pinaymootang First Nation in order to explore the context for and implications of discrimination against First Nations children with SHN in the public system of service provision. We collected information through participant observation in two sharing circles with families and one regional meeting on the implementation of Jordan's Principle in the province; one focus group; eight semi-structured interviews with local service providers and local, regional, and provincial representatives of Indigenous organizations ("key informants"); and 12 semi-structured interviews with caregivers of Pinaymootang children with SHN ("caregivers"). Key informants were recruited using convenience sampling with the project's advisory committee as an entry point. Caregivers were selected using purposive sampling from a larger group of families enrolled in a program launched by Pinaymootang Health Centre to address the needs of children with SHN in the community. Additional information about the comparability of services in nearby communities off

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<sup>3</sup> The term SHN includes a wider range of conditions than other terms more commonly used in the literature, which includes terms such as children with serious and complex medical conditions or children with severe disabilities. For example, one of the children in our sample suffered from severe eczema that required regular treatments and impacted his ability to socialize normally with other children.

reserve was collected through unstructured conversations with representatives of the Manitoba First Nations Education Resource Centre (MFNERC), Health Canada's First Nations and Inuit Health Branch (FNIHB), and Manitoba's Children's DisABILITY Services program (CDS). We conducted three separate validation sessions with caregivers, service providers, and community leadership prior to the publication of the final report. This research design responds to our objective of producing in-depth and community-based evidence with the potential of informing the implementation of Jordan's Principle in Canada. However, our conclusions regarding service disparities may not be generalizable to other First Nations communities in Manitoba or in Canada.

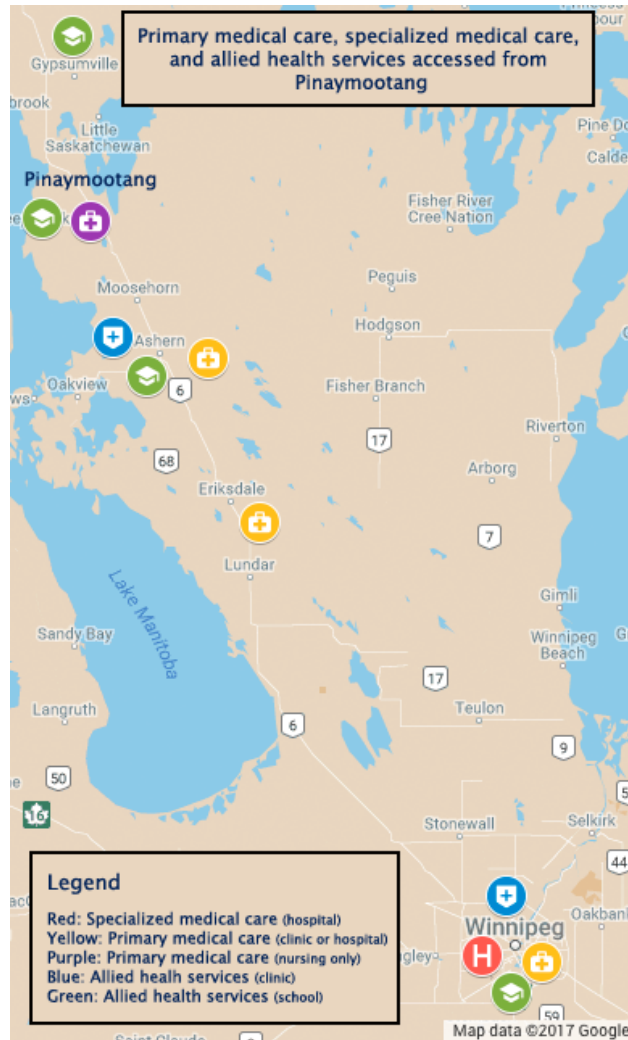
According to the CHRT's rulings (2016a, 2017), Jordan's Principle should apply to all First Nations children, regardless of their level of disability or place of residence. Our specific focus on children with SHN living on reserve reflects the priorities of our partners in Pinaymootang First Nation, who saw these children as the most vulnerable members of their community. Understanding and addressing their needs is one step towards meeting the human, constitutional, and treaty rights of all First Nations people.

### **Service Disparities Experienced by Pinaymootang Children with Special Healthcare Needs by Service Area: Medical Services, Allied Health Services, and Additional Care Services**

We interviewed service providers and caregivers to assess the availability of services in Pinaymootang according to three service areas that are typically required by children with SHN:

- a. Medical services, which for the purposes of this article are defined as those rendered or ordered by a nurse, a nurse practitioner, or a family doctor in support of their protected professional acts (with the exception of allied health services). Examples included primary care, specialized care, diagnostic services, and surgical procedures.
- b. Allied health services, which are those services delivered by healthcare professionals excluding nursing, medical, and pharmacy services (Canadian Association of Allied Health Programs, n.d.). Examples include occupational therapy, physiotherapy, speech and language therapy, and social work services.
- c. Additional care services, which include any service necessary for the health, well-being, and general functioning of a patient accessed through Health Canada's Non-Insured Health Benefits (NIHB) program. Examples include prescription medication, respite care, assistive devices such as wheelchairs or hearing aids, and medical transportation.

Some medical and allied health services were available on reserve for Pinaymootang members, while others had to be accessed in nearby off-reserve communities or in Winnipeg. Providers for these two service areas are shown in Figure 1 below. In the following sections we draw from interviews with key informants and off-reserve service providers (e.g., MFNERC, CDS) to compare these services to those that would ordinarily be available to children with SHN living in nearby off-reserve communities. Eligibility and coverage for additional care services was determined by the child's Indian Status (or her meeting the eligibility criteria to obtain it) and regular place of residence (on or off reserve).



**Figure 1.** Services accessible to children living in Fairford reserve (Pinaymootang First Nation), in nearby communities, and in Winnipeg. Original data: Google Maps (n.d.). Source: Vives et al., 2017.

### Medical Services

Medical services on reserve were provided by Pinaymootang Health Centre. However, when we conducted the interviews in 2016, the Health Centre was only funded to administer education and awareness programs (Pinaymootang Health Centre, personal communication, November 2016). There were no physicians or nurse practitioners on staff. Still, the Health Centre employed a team of registered nurses that provided medical services including basic checkups and immunization services, administration of medication, and assistance with regular treatments. For example, when one of the children in our sample suffered from severe allergies and eczema, the Centre’s nurses changed his full body bandaging and applied antibiotic ointments. The child’s mother noted that this allowed him to stay close to his family when his condition worsened.



The centre's staff also coordinated services with other healthcare providers in neighbouring communities and in Winnipeg—a key mediating role that enabled children to access specialized medical treatment. Staff advocated for patients to be placed on physicians' waiting lists and coordinated travel arrangements for medical visits off reserve. Specific cases illustrate the importance of this task. For example, at the beginning of Grade 2, staff at the local school determined that Eric, a Band member, had a cognitive disorder that needed to be evaluated and treated. Eric's father explained that the Health Centre “booked our appointments [with the medical specialists in Winnipeg] and they gave us travel on a medical vehicle to take my son over there and back, and they also provided meal tickets” (caregiver 1 interview, March 2016). Other caregivers similarly expressed that support provided by the Health Centre was essential to ensure access to services.

Having to commute regularly or to relocate off reserve to access primary medical services partially explained the disparities that Pinaymootang children with SHN experienced. As of 2016, the two closest medical facilities in the Interlake Region were Ashern Lakeshore General Hospital (50 km south of Pinaymootang on Highway 6) and Eriksdale E. M. Memorial Hospital (95 km south, also on Highway 6). Both hospitals (shown in Map 1 above) provided primary and limited emergency health services. Health Centre staff indicated that general practitioners sometimes refused to add Pinaymootang residents to their patient lists; additionally, children were removed from these lists if they missed a number of appointments within a pre-determined time period. In other words, primary medical services for children with SHN were available, but not necessarily accessible, in Pinaymootang or in nearby communities.

The situation was different for specialized medical services. Due to insufficient funding and regional labour shortages, neither Ashern nor Eriksdale hospital provided specialized medical services or assessment services. This affected all residents of the Interlake Region—on and off reserve (CBC, 2014a & 2014b). Caregivers of Pinaymootang children with SHN avoided going to local hospitals. Recounting a visit to Ashern hospital with his SHN child, a father said:

[In Ashern] they didn't want nothing to do with [my son]. They used to make us wait in the waiting room and then finally said, “Okay, now you have to go to Winnipeg.” So why waste two, three hours when we can be in Winnipeg in two or three hours? (caregiver 2 interview, March 2016)

During the interviews, participants insisted that being Indigenous was a factor that compounded the difficulties they faced in accessing medical services. Although it would be difficult to prove that these specific families experienced racist discrimination, racism targeting Indigenous Peoples is widespread in the Canadian and in the Manitoban medical systems (Allan & Smylie, 2015; Evans, White, & Berg, 2014; de Leeuw, Maurice, Holyk, Greenwood & Adam, 2012; Puxley, 2013, 2014). Furthermore, there is at least one open acknowledgement of racism towards First Nations people accessing medical services in the Interlake Region. In 2013, following a number of incidents, the Interlake Eastern Regional Authority (IERHA) apologized to Pinaymootang's Chief for “the disrespectful behaviour shown by our staff towards your health staff and community members” (IERHA letter to Chief Garnet Woodhouse, personal communication, May 9, 2013). The letter acknowledged that, although “some of this can be attributed to the stressful healthcare environment that patients and staff must deal with . . . it is also impacted by long standing systemic racism.” Caregivers mentioned perceived racism in nearby hospitals

as one the reasons they avoided them. Key informants noted that, while First Nations also experienced racism in Winnipeg (Allan & Smylie, 2015), at least specialized care was available and relatively accessible in the city.

### Allied Health Services

Our findings indicate that, of the three service areas considered here, Pinaymootang children with SHN experience the greatest degree of discrimination in their access to allied health services. Pinaymootang service providers stated that, as of March 2016, there were no early intervention services available on reserve for children between the ages of 0 and 5. Difficulties accessing assessment services further prevented most children in this age group from accessing early intervention allied health services off reserve (for a discussion on how the absence of early intervention programs affects other First Nations communities throughout Canada, see Greenwood, Leeuw & Fraser 2007; Preston, Cottrell, Pelletier, & Pearce, 2001).

Older children with SHN were expected to access these services through Pinaymootang School. In early 2016, the school was able to provide limited allied health services to students with SHN, including assessment services roughly twice a year, support for development of Individualized Education Programs, and one-on-one support from educational assistants. Caregivers and key respondents agreed that the range and frequency of fee-for-service allied health services provided through the school (e.g., speech and language therapy) was vastly insufficient to meet the needs of children with SHN in the community. Furthermore, school staff were not equipped to ensure Individualized Education Programs were followed, monitored, or adapted to children's evolving needs. Other services were not provided at all due to a lack of funding (e.g., physiotherapy and counselling). As a result, a school manager explained, children with cognitive impairments were routinely placed in regular classrooms with no additional supports:

We don't have any special places for [a child with cognitive impairments] to go or any specialized person to help him. You have a child that comes in and you tell them "Okay, don't go there, don't do that." The next minute he forgets. They're just put in the classroom, we were told, inclusion, not to separate them . . . and that's a challenge for the teacher. (school manager, Pinaymootang School, March 2016)

Conversations with caregivers and service providers on and off reserve revealed there was a sharp contrast between allied health services available for school age children living in Pinaymootang and those living off reserve in the Interlake region. The mother of Kelly, a 14-year-old girl with a neurological disability who had attended two provincial schools in nearby off-reserve communities justified her choice not to settle in Pinaymootang based on the availability of these services:

[Kelly] is able to access programs over there that she can't on the reserve . . . After finding out from the school on the reserve that they wouldn't be able to offer her *any* kind of special programming because of funding right I said, Okay. So I put her in school off reserve and then they had all kinds of programming for her . . . They have different levels of funding for different levels of disabilities with kids, and [Kelly] was a level 3, which is the highest needs. So she was fully funded, her [educational assistant] was fully funded just for her and her programming. You don't get that on reserve. (Brittany, caregiver interview, March 2016)

Other caregivers had opted to settle in Winnipeg temporarily to access allied health services for their children. A mother whose teenage daughter was diagnosed with autism moved to the city for a number of years and later returned to Pinaymootang to be close to her family. This mother could compare the range of services available at the three different school districts her child had attended with those available in Pinaymootang:

**Mother:** When we were living in the city [Annabelle] had an occupational therapist, physiotherapist and a speech therapist. All would come to the house once a month . . . Once she started school, she had all of those—[she had to] go to the school, they didn't come to the house any more, they were at the school, and it was once a month there as well. And when we moved . . . to another school and there they had a great physiotherapy room . . . We ended up moving her to another school which was her third school in the city . . . and they had the speech in the school, they had physiotherapist in the school but they didn't have the occupational therapist there. But in this school she received [these services] on a weekly basis.

**Interviewer:** Okay. And then in the school, does she have access to [occupational therapy] at all?

**Mother:** Here at [Pinaymootang] school? No.

**Interviewer:** Physical therapy?

**Mother:** No.

**Interviewer:** Speech therapy?

**Mother:** No. The specialist came out but for some reason we never get to see them. I don't know why but we never get to see them. (Jacqueline, caregiver interview, March 2016)

Comparing Kelly and Annabelle's experiences to those of First Nations children living in Pinaymootang shows that the difficulty in accessing allied health services for children with SHN was not a result of geography or remoteness, but a result of the administrative division of responsibilities between the federal government (responsible for services for First Nations on reserve) and the provincial government (responsible for services provided for all other residents of Manitoba). In fact, Kelly's school was significantly farther from Winnipeg than Pinaymootang school, and yet the range and frequency of allied health services available to her were similar to those Annabelle was able to access in Winnipeg. Administrators at Pinaymootang School blamed insufficient funding for the situation. In this context, they adopted strategies to address the needs of children with SHN enrolled in the school. These strategies focused on creating partnerships with provincial organizations, notably the federally funded MFNERC. This organization funded some of the allied health services provided through the school, sponsored the training of educational assistants and parents in Winnipeg, and provided assistive devices for students with communication impairments.

### **Additional Care Services**

First Nations children living on reserve generally access additional care services through the federal Non-Insured Health Benefits (NIHB) program. In some cases, families living on reserve may also be eligible to access certain provincially funded services. NIHB typically offers more limited coverage than provincial health insurance (Canadian Indigenous Nurses Association, 2017). Authors have further noted that NIHB funding has decreased in recent years despite an increase in the number of Indigenous people eligible, the processes currently in place to obtain services are inefficient, providers are often

unwilling to serve patients enrolled in the program, and eligibility criteria are stringent and rigid (Loyer & Small Legs, 2014). Although the NIHB program is, in general, far more restrictive than provincial insurance, it covers medical transportation, a service not covered by the provincial health insurance program for other children living in the Interlake Region (Terms of Reference Officials Working Group, 2009).

When compared to non-First Nations children living off reserve in Manitoba, Pinaymootang children with SHN were primarily discriminated against in their access to assistive devices and prescription medication. For example, one of the children in our sample was a teenage boy with a gross motor impairment. He required a wheelchair and his physiotherapist also requested an adapted tricycle as part of his treatment plan. However, NIHB criteria established that this child could only receive one mobility device every 5 years, and this device could only be manual. Thus, federal insurance guidelines forced him into a wheelchair that he would soon outgrow and ignored the advice of a medical specialist regarding a second device. The difficulties this child's family faced were compounded by the fact that there were no wheelchair accessible vehicles on the reserve; the parents had to carry their 80 kg child in their arms to help him into and out of the family vehicle each time they left the house—a physically demanding endeavour.

In contrast, the provincially funded CDS program typically referred off-reserve children with gross motor impairment to another provincial program that allowed them to borrow a wheelchair (usually electric, although manual ones were also available). Medical and allied health professionals from the child's medical team could also request that CDS cover the cost of more specialized mobility devices (e.g., an adapted tricycle). Depending on the child's specific circumstances and based on a medical referral, the program also offered a range of other services, including allied health services, respite care, after school care, funds to cover the costs of home and vehicle modifications, and summer programming (CDS, personal communication, December 2016). These services are available to all Manitoban children, with the exception of Status Indian children living on reserve because they fall under federal jurisdiction.

A second area of disparities in access to additional care services was medication. Key respondents indicated that the range of prescription medication that could be accessed through NIHB was markedly inferior to those covered by provincial insurance. For this reason, caregivers and service providers felt doctors hesitated to prescribe Pinaymootang children their first choice of medication, and settled instead for older, cheaper, and potentially less effective drugs that they believed were more likely to be approved by NIHB. For example, one of the children in our sample had from severe allergies. At first, his doctor wanted to prescribe a new medication covered by the provincial insurance program; the child's parents recounted the doctor's hesitation and final decision to prescribe the older medication instead, which the doctor thought might be less effective but was covered by NIHB. In addition, respondents found that federal policy changed quickly and often, and changes to the children's medication regimes were not always communicated in advance (see also Allec, 2000). An example came from another child in our sample who had a complex medication regime to treat his multiple health conditions. In at least two instances, his parents found out about changes to NIHB medication coverage at the pharmacy counter.

Interviewees felt helpless in the face of the limitations imposed unilaterally by the NIHB program. During the interviews, service providers insisted that there was no direct line of communication between them and the First Nations and Inuit Health Branch (FNIHB), the agency in charge of implementing the NIHB program. As for caregivers, while it is true that NIHB decisions can be appealed, the process is notoriously opaque, lengthy, and cumbersome for families (Auditor General of Canada, 2015). For example, caregivers of the child with severe allergies (introduced above) had appealed NIHB's decision to not pay for an inhaler for their child; two years later, they had not received a response and were covering the cost of the medication out of their own pockets.

We also discussed medical transportation, an additional care service typically not available for families living off reserve. This service exists to facilitate the commute to Winnipeg for medical appointments, surgeries, and other pre-scheduled medical events. Families appreciated this option, even if they rarely used it. There were several reasons for this lack of use: If using medical transportation, the round trip could take up to 14 hours (due to multiple stops), whereas with their own vehicle they could be back in 8 hours (including the time for the appointment). In addition, caregivers hesitated to travel in the medical van with SHN children. Medical transportation was simply not an option for children with severe behavioural dysregulation or heavily compromised immune systems, for whom a simple cold could quickly turn into a life-threatening condition. Instead, they chose to use private transportation.

### **Denials, Delays, and Disruptions of Services: The Impact of Service Disparities on Children and Families**

Our interviews with caregivers and service providers demonstrated that Pinaymootang children with SHN experienced denials, delays, and disruptions of services ordinarily available to other children in Manitoba's Interlake region. These children were refused services, had access to a narrower range of services than were available off reserve, or were able to access those services less frequently than off-reserve children (denial). They also experienced longer wait times for the provision of services when compared to other children off reserve (delay). Finally, some Pinaymootang children were able to access similar services to those available off reserve, but this access could be terminated suddenly and unexpectedly due to changes in policy (disruption). In all these situations, disparities and gaps in access to publicly provided health, education, and social services violate First Nations children's human, constitutional, and treaty rights (CHRT, 2016a, 2017; The Jordan's Principle Working Group, 2015).

Denial of services was most clear with children's access to allied health services, which were not available on reserve for children under the age of 5 and were rarely available for school-aged children. These denials impacted the ability of Pinaymootang children with SHN to communicate, socialize, and develop normally. For example, a child with a severe hearing impairment was unable to access American Sign Language (ASL) training until he was 4 years old, and then only because his mother decided to temporarily relocate to Winnipeg to access this service. Until then, this child was only able to communicate with his mother and in a very rudimentary way. Other children requiring counselling and speech and language therapy were also unable to access these services on reserve, something that affected their ability to socialize normally and to manage the psychological symptoms associated with their medical conditions (e.g., severe anxiety). The lack of services prevented children with SHN from reaching a quality of life equivalent to children with similar medical conditions living off reserve.

Pinaymootang children living on reserve also experienced delays in accessing services, particularly medical services. Often, these delays were rooted in differential access to diagnostic and assessment services. In our sample, this was particularly a problem for children with neurodevelopmental disorders such as autism, who were typically not diagnosed until years after they started school. For example, a child living on reserve with oral communication impairments and suspected of being on the autism spectrum was still not diagnosed at the age of 11, despite repeated efforts on the part of his family to obtain an assessment that would enable him to receive therapy. Access to early intervention is essential to support the development of children with autism and improve their social and daily living skills, decrease the frequency and intensity of autism symptoms, and improve cognitive skills (Dawson & Bernier, 2013; Lang, Hancock, & Singh, 2016; Ouellette-Kuntz et al., 2009).

Disruption of services ordinarily available to other children in Manitoba was most clear with regard to NIHB policy. Policy changes made by Health Canada unilaterally and without warning or consultation with service providers left children vulnerable to sudden changes in their medication schedule. These changes, which included cessation of coverage or replacement of a medication with a similar product, could affect supplemental and core medication. For example, parents reported changes in coverage for melatonin (a hormone used to control the sleep pattern of children with autism) and phenobarbital (a central nervous system depressant that can be used to treat children with epilepsy). While it is not possible for us to assess the impact of these disruptions on specific children, the potential adverse health outcomes that can result from failure to consistently adhere to medication regimens are well documented (Matsui, 2007; Rapoff, 2010). Changes in medications impacted patients' lives, introducing setbacks in symptom management. For example, a change in medication might result in the return of a severely disrupted sleep cycle. In addition, we encountered children who were on medications that created physical dependency; when NIHB suspended coverage for that medication without notice, caregivers suddenly found themselves without a treatment plan and without support to manage the child's withdrawal symptoms. It was clear to caregivers and service providers in the community that modifications to children's medication schedules were made by people unfamiliar with the child's condition, history, and larger medication regime in response to policy considerations and without regard for the child's best interest.

Denials, delays, and disruptions of medical services, allied health services, and additional care services limited the opportunity for Pinaymootang children with SHN to thrive and manage their medical condition. They also had a ripple effect on their caregivers, families, and Pinaymootang First Nation as a whole. Some of the children in our sample suffered from medical conditions that required qualified respite workers that could handle seizures, manage severe behavioural dysregulation, or perform cardiopulmonary resuscitation. Caregivers resented both the lack of respite care (at the time of the interviews, Health Canada did not provide long-term respite care for children in the community) and the absence of training opportunities that would allow able and willing relatives to fill in for them if needed. Without properly trained respite care, children's lives were dependent on their primary caregiver's constant physical presence. Pressure on caregivers increased due to the need to regularly commute to Winnipeg to access services.

Because of the lack of appropriate support and the demands of constant travel, caregivers of children with SHN felt overwhelmed and anxious. Some were sleep deprived because their children had irregular sleep cycles resulting from their neurological disabilities, which meant that they were up most of the

night. Others recounted sitting next to their child's crib from dusk until dawn, counting breaths to make sure their child was alive. All worried about the care of their children once they transitioned into adulthood. As caregivers devoted their time and energy to ensure their children's well-being, they became isolated. So much so that, at the beginning of this study, most did not know there were other Pinaymootang families in similar situations to theirs.<sup>4</sup> On top of all this, caregivers also found themselves under significant financial pressure. If the child lived with his or her parents, at least one of them had to give up his or her job to take care of their child—at a time when families faced additional related to their child's health needs. A critical example was that of a family with a child with a complex medical condition. The child's mother moved to Winnipeg to complete her university studies and later returned to the community to implement an ambitious employment program on reserve. As it became clear that there were no services to help her care for her son on reserve and that the school was reluctant to accept him in the classroom as a full-time student, the family's strategy shifted: The mother quit her job and the family began to rely solely on the father's income. Other caregivers in our sample (usually mothers) had similarly quit their jobs or stopped looking for paid work due to this lack of support.

In this context, families faced three possibilities, each one of them essentially flawed. First, they could stay in Pinaymootang, where they retained contact with their culture and their support networks, but their children received fewer and lower quality services. Second, they could relocate to Winnipeg, either permanently or with the hope of returning to the community. However, this would require giving up on-reserve housing in a context where the demand is extremely high and the availability low (at the time of the interviews, a family that had relocated to Winnipeg to be close to their son's medical team had been on the housing waiting list for over two years). A third possibility was to transfer custody of their child to an Indigenous child and family services agency in the hopes that they would be able to access better services through the agency. While none of the families in our study had made this decision, some mentioned that service providers outside of Pinaymootang had explicitly asked them to consider it, and the family's resistance to this possibility was a strong undercurrent in caregiver narratives. According to a 2008 study, families of First Nations children with special healthcare needs living on reserve throughout the province face a similar set of possibilities (Shackel, 2008). The emotional and physical strain they experience as a result of this impossible situation impacts their overall health and well-being (Shackel, 2008).

### **Factors Mediating Access to Services for First Nations Children: Administration, Funding, and Geography**

The denials, delays, and disruptions of services that constrained the options available to the families of Pinaymootang children with SHN are the result of a public service network grounded in colonial history and ideology. The continuation of colonial ideology is mediated by three main factors that explain the discrimination First Nations children with SHN experience: the long-term underfunding of on-reserve services; administrative practices that engendered burden, uncertainty, and risk for community members; and the intentional geographic isolation of First Nations communities. While none of these factors independently explains the challenges in accessing services for Pinaymootang children with SHN, the three factors interact in ways that perpetuate discrimination against First Nations children. In

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<sup>4</sup> Following a first meeting that brought caregivers of children with SHN together around this study, the Health Centre instituted bi-monthly support meetings intended to reduce their isolation.

this section, we explore these three factors, giving examples of the specific ways in which they manifested in the Pinaymootang context.

### **Funding: Putting FNIHB's Children Services Reference Chart to the Test**

Significant funding gaps between provincially and federally provided services have been well documented in multiple service domains (Auditor General of Canada, 2011, 2015; Canadian Human Rights Tribunal, 2016a; The Jordan's Principle Working Group, 2015; *Pictou Landing Band Council and Maurina Beadle vs. Attorney General of Canada*, 2013). For example, the Office of the Parliamentary Budget Officer (2016) recently calculated that the shortfall between provincial school funding across Canada and that of federally-funded First Nations-operated schools was between \$365 million and \$665 million in 2016. Similarly, information accessed by Member of Parliament Charlie Angus in 2016 showed "a massive gap in health services compared to what was available provincially" (Barrera, 2017, para. 5).




We documented specific funding gaps in the Pinaymootang context through interviews with advisory committee members and a focus group conducted in early 2016. Our discussions were guided by the Children's Services Reference Chart (Vives et al., 2017, p. 72). Produced in 2010 by a senior worker at FNIHB, the chart summarized all federally funded services that *could* be provided on reserves across Manitoba with funding from Health Canada and Indigenous and Northern Affairs Canada (INAC, the federal ministry that was responsible for providing all non-health services on reserve). When asked about the services actually available in Pinaymootang, respondents indicated that, in total, federal funds from these two ministries only allowed full implementation of 2 of the 14 programs listed in the Reference Chart.

Figure 2 shows all of the programs that *could* be administered on reserve with Health Canada's funding. Pinaymootang Health Centre respondents indicated that the funding they received only covered the costs of implementing 1 out of the 10 programs fully and on an ongoing basis: Public Health (Child Development Screening and Immunizations). Five other programs were partially available: Aboriginal Head Start on Reserve, Brighter Futures, Canada Prenatal Nutrition Program, Home and Community Care, and Non-Insured Health Benefits. Four programs were not at all available: Aboriginal Diabetes Initiative, the Building Healthy Communities program, the Fetal Alcohol Spectrum Disorder program, and the Maternal Child Health program.



Health Canada funded services provided by Pinaymootang Health Centre (2016)									
ABORIGINAL DIABETES INITIATIVE	MATERNAL CHILD HEALTH (0-6 YEARS)	FASD (0-6 YEARS)	BUILDING HEALTHY COMMUNITIES	HOME & COMMUNITY CARE	BRIGHTER FUTURES	NIHB	ABORIGINAL HEAD START ON RESERVE	CPNP (0-12 MONTHS)	PUBLIC HEALTH
Screening & Care	Screening & Assessment	Early Identification / Diagnosis	Mental Health, Crisis Prev After Care, Rehab. & Training	Client Assessment	Mental Health	Crisis Intervention Counseling	Parental & Family Involvement	Prenatal / Postpartum	Child Development Screening
Promotion	Home Visitation	Coordination & Integration	Family Prevention Services	Case Management	Parenting Skills	Pharmacy	Social Support	Breastfeeding Promotion, Education & Support	Immunization
Prevention / Community Projects	Case Management	Public Awareness & Education	Solvent Abuse	Occupational Therapy	Child Development	Dental Care	Education	Nutrition Screening, Education & Counseling	
Capacity Building	Health Promotion	Research & Capacity Development		Speech & Language Therapy	Healthy Babies	Vision	Health Promotion	Maternal Nourishment	
Evaluation	Integrating Culture into Care	Surveillance		Physiotherapy	Injury Prevention	Medical Supplies & Equipment*	Nutrition		
Surveillance				Access to Medical Equipment & Supplies		Medical Transportation	Culture & Language		
				Home Care Nursing Services					
				Provision of Access to In-Home Respite					
				Record Keeping & Data Collection					

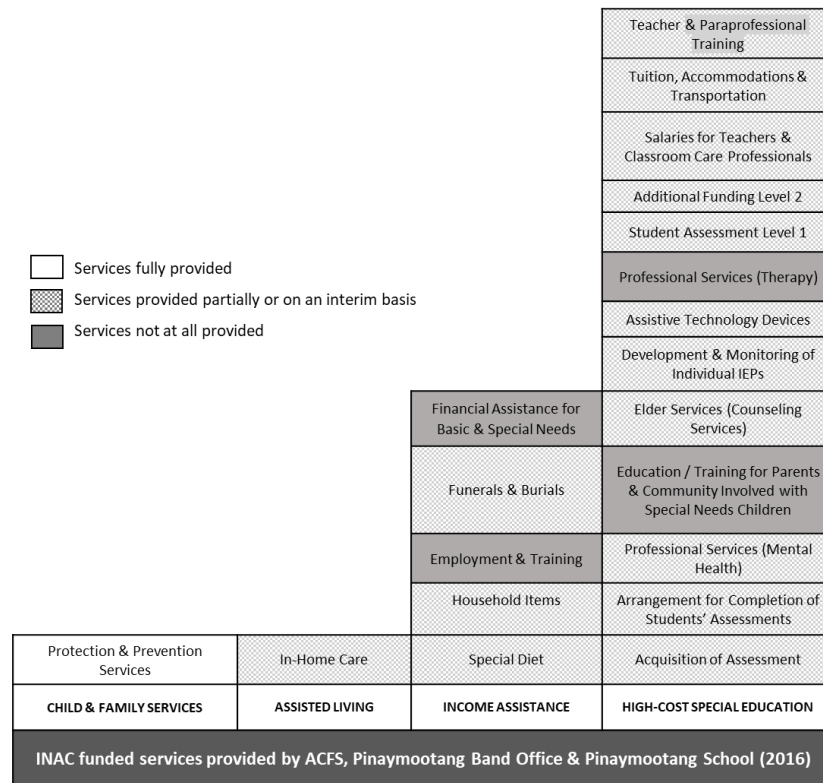
  

	Services fully provided
	Services provided partially or on an interim basis
	Services not at all provided

**Figure 2.** Health Canada funded children’s services in Pinaymootang First Nation in 2016.

Figure 3 summarizes all of the programs that *could* be funded using resources from INAC. INAC-funded services available in Pinaymootang were administered by the Anishinaabe Child and Family Services (ACFS), the Band Office, and Pinaymootang School. Respondents from these institutions indicated that the funds they received only allowed for the full and ongoing implementation of 1 of the 4 programs identified in the Reference Chart: Child and Family Services (Protection and Prevention Services). Two programs administered by the Band Office (Income Assistance and Assisted Living) were only partially available. To compensate for the lack of federal support, the Band organized fundraisers as often as twice a month. Often, funds were used to cover costs associated with the medical treatment and the relocation of families with children with SHN to Winnipeg. The High-Cost Special Education program (implemented by the school) was also only partially funded. Funding was based on the number of students with a special needs assessment enrolled in 2007 and had not been revised, even though the annual number of learning disability assessments increased from 22 to 45 between 2007 and 2016. The limitations in funding were compounded by uncertainty about cash flow timelines; many school-based services were provided only when (and if) there was funding remaining at the end of the funding period (Vives et al., 2017). Service providers explained that the lack of appropriate services at the school led some parents to keep their children with SHN at home, indefinitely. Although systematic comparison between resources in Pinaymootang and other First Nations communities was beyond the scope of our study, there are indications that the experience of other communities was similar. Education specialists at MFNERC estimated that while First Nations schools in Manitoba received, on average, \$7,000 to \$8,000 dollars yearly per student enrolled at the time (all levels of need included), the amount for provincially funded schools ranged from \$12,000 to \$22,000 per student (MFNERC, personal communication, March 2016). Further, local, regional, and provincial service providers interviewed indicated that they did not believe there to be a single First Nations community in the province where all the services identified in the services chart were available. When we

asked a senior representative from FNIHB about the discrepancy between the chart and the services available in Pinaymootang, we were told that the federal government simply transferred the funds in the amount specified and under the conditions outlined in their agreements with the Band; it was then the responsibility of the Band and local service providers to decide which of the possible programs they would provide.



**Figure 3.** Children’s programs and their components funded with INAC’s resources in Pinaymootang First Nation in 2016.

### Administration

Closely related to the funding gaps was the administration of federal funding for programs and services on reserve. Policy guidelines, eligibility criteria, and coverage can differ for on reserve services and provincially funded and administered off reserve services. Moreover, this division of responsibilities results in jurisdictional ambiguities over which level of government is responsible for providing services for First Nations children whose status or residence on reserve is unclear or called into question (The Jordan's Principle Working Group, 2015). The direct impacts of administration on Pinaymootang families were most evident when it came to NIHB. As discussed previously, NIHB standards and practices resulted in Pinaymootang children being denied equipment that would be available to off reserve children. In addition, they experienced unexpected disruptions in their regular medication and long delays in service without any response to their appeals or queries.

The focus group and interviews we conducted with Pinaymootang service providers also shed light on the indirect ways in which challenges related to federal administration of funds impacted community members. They highlighted administrative practices that limited the ability of First Nations and on-reserve service providers to meet the needs of children with SHN, which created burden, uncertainty, and risk for community service providers and Pinaymootang families. The example of the Pinaymootang Health Centre's efforts to create a program that would meet the needs of children with SHN in the community highlights these patterns of inadequate funding and support from government.

In 2010, a Pinaymootang family filed a complaint with the Canadian Human Rights Commission arguing that the services required to address their child's special healthcare needs were not available in their community. In response, Health Canada asked the Pinaymootang Health Centre to determine the costs of the child's unmet needs. The Health Centre responded with a proposal for a program designed to address the needs of 11 children it identified as having SHN, stating that it would be "unconscionable to advocate and provide services to one child, when there are numerous children and families within the community that are entitled to healthcare services and supports" (Pinaymootang Health Centre email to Health Canada, personal communication, October 31, 2014). In response, Health Canada directed the Health Centre to submit three separate funding applications in 2014. Preparation of each proposal took 20 to 60 hours, a burden that was accrued in addition to the staff's regular responsibilities. After making their submissions, the Health Centre received no news for several months; during this time, management was unable to establish a direct or consistent line of communication with Health Canada staff. The first two funding applications were denied.

The third funding application resulted in four months of temporary funding for the Niniijaanis Nide (My Child, My Heart) program, which engaged child development workers and a case manager to meet some of the needs of Pinaymootang children with SHN and their families.<sup>5</sup> Although funding for the program was announced in the summer of 2015, funds were not transferred until December, and the Health Centre was required to submit an accounting report and program evaluation three months later. Funding was later renewed for two 1-year periods, but both renewals came only weeks or days before funding was to run out. The short-term funding and short notice of funding renewal created uncertainty and risk for all involved. Service providers worried about the impact on clients if highly demanded services, such as respite care, were discontinued. One respondent suggested that, if that were to happen, "children and families would be worse off than if we'd never done anything at all." Moreover, service providers worried about clients potentially internalizing the message that "they don't matter, their children don't matter." The uncertainty around funding also impacted the hiring and retention of qualified child development workers for the program. As a manager put it, "I feel I'm playing with people's livelihoods here. If the funding is not renewed, how will [my case worker] provide for her family? Where is she going to go? And what am I going to tell her?" In other words, the administration of federal funding compounded the challenges imposed by low levels of core funding. Faced with these constraints, community service providers were burdened with the responsibility of mediating the resulting uncertainty and risk for both the families they served and the workers they employed.

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<sup>5</sup> Members of our research team formed a second partnership with the Health Centre to conceive an evaluation plan for this program. Where the *Honouring Jordan's Principle* report established a baseline for the inequalities experienced by children in the community (Vives et al., 2017), the evaluation project tracked the evolution of the Niniijaanis Niide program (Lach, Saunders, & Traverse, 2016).

## **Geography**

The third factor is the intentional geographic isolation of First Nations reserves. This isolation is rooted in the colonial governance practices and crystallized in the forced relocation of Indigenous groups to lands away from large population centres. Throughout Canada, about half of reserves are rural or remote, with poorer access to services than urban centres (Kulig & Williams, 2012). This isolation means that, today, one of the main obstacles First Nations children with SHN encounter when accessing services is geography or distance from a service hub. The direct impact of geography on families was detailed in the previous section. Limited availability of services in the Interlake Region meant that families often had to make the long commute to Winnipeg, sometimes on a weekly basis. These trips took a heavy toll on children's health and caregivers' resources. Additionally, as mentioned above, missed appointments could result in the refusal of future services.

The Pinaymootang School's efforts to address staffing challenges exemplify even broader challenges related to geography. Funding gaps combined with widespread regional labour shortages made it difficult for the school to hire and retain qualified staff. To work around this difficulty, the school (in collaboration with teachers, medical specialists, and parents) hired relatives of the children with SHN to work as one-on-one educational assistants. This decision also addressed another geographically based concern. The school was one of the community's biggest employers, and the hiring of community assistants fulfilled a perceived responsibility to provide employment in a community where opportunities were limited. However, the practice of hiring caregivers as educational assistants created an additional burden for caregivers who now had to provide care during the day as well, potentially increasing their need for respite care, which was minimally available in the community. The policy also created the expectation among parents of children with SHN needs that they would be hired, which led to tensions between the school and children's families. The legacy of colonial practices that forced First Nations to settle in rural and remote reserves thus has multiple repercussions in terms of the ability of communities such as Pinaymootang to meet the needs of children with SHN. Rurality (and, in other cases, remoteness) limits access to qualified professionals. Rurality also burdens community service providers to address these children's needs, while also providing employment for the community's members. In a context where job opportunities are scarce, conflict seems unavoidable.

### **Discussion: Moving Forward with the Implementation of Jordan's Principle in Manitoba**

In this article, we have examined access to services for children with SHN who lived on reserve in Pinaymootang, Manitoba in 2016 and 2017. We have found that these children experienced denials, delays, and disruptions in accessing and receiving medical, allied health, and additional care services. These experiences took a heavy toll on caregivers, who felt they had only three options: (a) move to Winnipeg for better services, (b) stay in the community with more limited access to services, or (c) transfer custody of their children to child and family services. The service barriers faced by Pinaymootang families arise from a colonial public service structure that creates challenges related to funding and administration of services, and geography.

Attention to each of these factors can be seen in the project advisory committee's recommendations, presented in Figure 4. The committee recommended that funding be allocated in order to close all known disparities in services and to allow First Nations communities to assess their actual needs. They

further recommended that *core* service funding be determined on the basis of these needs, in recognition of the administrative burdens associated with short-term funding and with the failure to directly link funding levels to actual needs. Additional consideration of the challenges linked to administration is evident in the recommendations around ongoing consultation with First Nations and improved communication and collaboration between and within governments. Finally, consideration of the geography-based challenges in attracting and retaining qualified staff are evident in the recommendations around supporting collaborations between First Nations and investing in short- and long-term capacity building. Both mechanisms for achieving economies of scale and sustained, purposeful investment in training are required to address the challenges to providing services in rural and remote communities.

**Pinaymootang's Study Advisory Committee:**

**Recommendations for the implementation of Jordan's Principle in Manitoba\***

1. All future decisions on the implementation of Jordan's Principle on reserve should be made in ongoing consultation with First Nations;
2. All programs aimed at eliminating service disparities should be culturally appropriate and sustainable;
3. Known and documented disparities in the services available to on reserve First Nations children and those ordinarily available to other children should be immediately and systematically remedied;
4. Budget allocations for on reserve services should be based on actual community needs, as determined by First Nations governments and service providers;
5. Funds to support the identification of community needs, and the development and implementation of programs to address those needs should be allocated as core funding (not be conditional or grant-based);
6. Funding and other resources should be allocated to support collaborations across First Nations communities. These collaborations will facilitate the sharing of resources and the training and hiring of local First Nations staff;
7. Investments in capacity building need to be made immediately. These investments should support both short-term (e.g., additional training on speech and language basics for case workers already working in communities) and long-term (e.g., funding the training of local First Nations workers in the allied health professions) capacity development;
8. Mechanisms should be put in place to improve communication and collaboration between the three levels of government (federal, provincial, and First Nations) as well as among departments within the same level of government;
9. Policy and services must be designed and implemented to address the needs of youth with disabilities and / or special healthcare needs as they transition into adulthood.

\*These recommendations build on previous ones by the Assembly of Manitoba Chiefs and Nanaandawewigamig: First Nations Health and Social Secretariat of Manitoba (2016).

**Figure 4.** Recommendations from the project's advisory committee to address the special health needs among First Nations children living on reserve.

Pinaymootang's efforts to meet the needs of children with SHN are inextricably bound to national and provincial level efforts to implement Jordan's Principle. Important advances toward the implementation of Jordan's Principle have brought new resources and opportunities for Pinaymootang. In response to the CHRT rulings, in 2016, the Canadian government committed to invest up to \$382 million to implement a variety of three-year Jordan's Principle-related pilot initiatives across the country (Health Canada, 2016). The Ninijaaanis Niide program that the Health Centre launched to address the needs of Pinaymootang children with SHN received additional funding in 2016 from this government investment. As of November 2017, the model was being adapted and implemented, to different degrees, in 40 of the 61 First Nations in Manitoba.

The provision of Jordan's Principle funding for the continued implementation and replication of Ninijaaanis Niide reflects an expanded and still evolving understanding of this mechanism. Jordan's Principle aims to ensure First Nations children have access to the services they require, but its interpretation and application have evolved over time (Churchill & Sinha, in press). For many years, the federal government used a narrow interpretation of Jordan's Principle. As recently as 2015, only cases where (a) Status First Nations children, (b) who had complex disabilities, (c) lived on reserve, (d) and required services from multiple providers were considered; additionally, (e) the government required that a jurisdictional dispute exist between the federal and the provincial governments. The 2016 CHRT ruling rejected this narrow interpretation. The Tribunal established Jordan's Principle as a mechanism for achieving "substantive equality" (CHRT, 2017, B(i)39). It ruled that Jordan's Principle applies to all First Nations children in Canada regardless of place of residence and level of disability. Further, it should do this without compounding the disadvantage imposed by the historic discrimination against First Nations through institutionalized systems and processes such as residential schools (CHRT, 2016a). It is this interpretation of Jordan's Principle that has resulted in extended funding for Ninijaaanis Niide and has also brought access to an expanded range of services (e.g. Manitoba Adolescent Treatment Centre [MATC], n.d.; St. Amant, n.d.).

These are important developments that have brought welcome and meaningful changes to Pinaymootang, but the current approach falls far short of the recommendations made by our project advisory committee, and it also replicates many of the challenges that families in our study faced in meeting the needs of their child with SHN. First and foremost, the current funding designated for Jordan's Principle will end in 2019 (Government of Canada, n.d.). Short-term funding means that the advisory committee's recommendation of core funding based on needs has not yet been realized. As of June 2018, there has been no announcement about renewing this funding and, nationally, all programs and services supported by this fund are experiencing the uncertainty and risk that comes with short-term funding. Further, investments in long-term capacity building and First Nations collaborations, which are needed to achieve economies of scale, are not possible under a short-term funding plan. Current approaches to the implementation of Jordan's Principle on a national scale thus far show fundamental administrative flaws that make it impossible to address the needs of First Nations children with SHN. These flaws reinforce the obstacles to accessing services related to funding, administration, and geography that are discussed in this article.

Because the findings reported here are from a case study of a single First Nations community, they cannot be generalized to other First Nations communities in Manitoba or elsewhere in Canada. However, based on discussions with stakeholders at the federal and provincial levels, we believe that

aspects of the Pinaymootang experience may resonate with other First Nations communities that struggle to meet the needs of children with SHN under current approaches to Jordan's Principle implementation. The evidence presented here and the recommendations prepared by the advisory committee may be useful as stakeholders seek to clarify the next phase of implementation. We believe that if these recommendations are implemented to address the needs of all First Nations children, and not only those children with SHN, they will empower First Nations communities to make decisions that improve their health and well-being, and they will begin to undermine the colonial framework that shapes their access to publicly provided services. Much more must be done, however, both to fully implement Jordan's Principle throughout the country and to erase colonialism as a social determinant of Aboriginal health in Pinaymootang, Manitoba, and Canada.

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