

HONOURING JORDAN'S PRINCIPLE:



OBSTACLES TO ACCESSING EQUITABLE HEALTH AND SOCIAL SERVICES FOR FIRST NATIONS CHILDREN WITH SPECIAL HEALTHCARE NEEDS LIVING IN PINAYMOOTANG, MANITOBA.

OVERVIEW

Authors

Luna Vives	Assistant Professor, Department of Geography, Université de Montréal
Vandna Sinha	Associate Professor, School of Social Work, McGill University
Eric Burnet	MSW, Research Assistant, School of Social Work, McGill University
Lucyna Lach	Associate Professor, School of Social Work, McGill University

In collaboration with Pinaymootang First Nation

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Grandmother and grandfather teachings

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Overview

1. Context

The feeling among families and service providers in Pinaymootang First Nation these days is distinctly optimistic. The school benefitted from a recently announced increase in funding for on reserve education that will nearly double its current annual budget, and it is a member of Canada's first Indigenous School Board, created in late 2016. The health centre has received word that the Niniijaanis Nide (My Child, My Heart) program, a pilot project to provide respite care and other supports to the families of children with special healthcare needs, will have its funding renewed for a second year. In addition, based on the strength of the first year of Niniijaanis Nide, First Nations and Inuit Health Branch (FNIHB) – Health Canada has supported Pinaymootang Health Centre in leading the development of practice standards and guidelines to improve access to services for First Nation children with special healthcare needs living on reserves throughout Manitoba. These developments bring hope to the community that has long worked for service improvements. This hope, however, is dampened by the knowledge that these developments do not challenge the underlying factors that result in Pinaymootang children experiencing denials, delays, and disruptions of services, and the fact that the new funds are not sufficient to ensure that children in Pinaymootang have access to the same range and quality of services that are ordinarily available to children living off reserve. This report is intended to draw attention to the underlying factors that drive persistent service disparities, in order to support the development of more equitable services for First Nations children in Pinaymootang and beyond.

2. Problem statement and justification

First Nations children living on reserve occupy a unique

location within the Canadian system for the provision of public services. Three factors underlie these children's experiences of accessing publicly provided services: administration (policy and program design, division of jurisdictional responsibilities etc.), funding disparities between provincially and federally provided services, and geography (or distance from a service hub). Combined, these factors result in First Nations children routinely experiencing denials, delays, and disruption of services ordinarily available to other Canadian children in similar circumstances living off reserve. Service disparities are particularly acute and harmful in the case of children with special healthcare needs, who require ongoing, complex interventions from different service agencies and professionals.¹⁰ These children's experiences are the focus of this report; although unique, they speak to a more general experience of discrimination that First Nations children living on reserve face when attempting to access services available to most Canadian children. This is a pressing social issue that violates First Nations children's human, constitutional, and treaty rights, and affects all children regardless of their level of (dis)ability.

The need to address service disparities has been highlighted by First Nations leadership, notably the Assembly of First Nations,¹¹ the Assembly of Manitoba Chiefs¹² and Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba (FNHSSM),¹³ as well as by the Truth and Reconciliation Commission of Canada,¹⁴ the United Nations Rapporteur on the Rights of Indigenous peoples,¹⁵ the Jordan's Principle Working Group,¹⁶ and the Canadian Human Rights Tribunal.¹⁷ The issue has also been raised in the House of Commons (NDP Member of Parliament Charlie Angus 2016¹⁸) and in the Manitoba Legislative Assembly (NDP Member of Legislative Assembly Wab Kinew¹⁹).

Jordan's Principle was designed to respond to service disparities affecting all First Nations children across multiple sectors, including health, social, and educational services.¹¹ Jordan's Principle is a child first principle intended to ensure that First Nations children do not experience denials, delays, or disruptions of public services ordinarily available to other children due to jurisdictional disputes between different levels of government or between departments within the same level of government.²⁰ This principle was intended to remove government red tape preventing First Nations children living on reserve from accessing services ordinarily available to children in similar circumstances living off reserve.²¹ Jordan's Principle received unanimous support in the Canadian House of Commons in 2007, and provincial and federal governments (including Manitoba) have generally expressed support for the principle. However, implementation has systematically undermined the original vision in which it applies to all First Nations children and all service sectors.²² The narrowing of the eligibility criteria and the imposition of a series of administrative hurdles have allowed the federal government to claim there are no Jordan's Principle cases in Canada.²³

In 2016, the Canadian Human Rights Tribunal ordered the federal government to fully implement Jordan's Principle and ensure First Nations children do not experience discrimination in their access to public services based on Indian Status, place of residence (on or off reserve) or level of impairment / disability.²⁴ Individual families have also fought discrimination in court (e.g., *Beadle and Pictou Landing v. Canada* 2013, *Sumner–Pruden v. Manitoba* 2016). This report contributes to ongoing conversations around discrimination in access to public services and Jordan's Principle implementation; it provides community-based evidence to inform future policy change.

3. Goals

This report focuses on Pinaymootang First Nation, an Ojibwe community 250 km north of Winnipeg. We interviewed the primary caregivers of Pinaymootang children with special healthcare needs, as well as local and regional service providers and First Nations leaders involved in

administering programs for children with special needs in the community.

Based on the information collected through these interviews, the report examines:

1. Services available to Pinaymootang children with special healthcare needs and their caregivers on reserve, in nearby communities, and in Winnipeg (Chapter 2). More specifically, we focused on three service areas: medical services, rendered or ordered by a nurse or family doctor; allied health services, delivered by healthcare professionals other than nursing, medical, and pharmacy; and additional care services, accessed through Health Canada's Non-Insured Health Benefits.
2. The impact of service disparities on children with special healthcare needs and on their caregivers (Chapter 3);
3. The role of service providers as mediators between the government and the community, as well as their efforts to access and maximize the impact of grant-based funding to address the needs of children with special healthcare needs and their families (Chapter 4).

We discuss service disparities and their impact in the context of Pinaymootang First Nation, while relating this to a larger discussion of the discrimination experienced by First Nations children and families living on reserve throughout Canada.

4. Scope and limitations

This report discusses the experiences of a group of children aged 0 to 14 with special healthcare needs (children who require ongoing or intermittent interventions, ranging in complexity, from different service providers and professionals) living on reserve, their families, and local service providers. This focus should not be interpreted as an endorsement of the federal government's continued efforts—in violation of Canadian Human Rights Tribu-

¹¹ Interpretation and application of Jordan's Principle are still evolving, due in part to a series of rulings made by the Canadian Human Rights Tribunal in 2016 and 2017. Discussion of Jordan's Principle in this report reflects an understanding based on policy and legal documents available as of March, 2017.

nal orders—to limit the application of Jordan’s Principle to First Nations children living on reserve with a disability or a short-term condition necessitating health or social services.²⁵ Similarly, our focus on children should not be construed as an indication that service disparities in First Nations communities are only experienced by children. Adults are also affected by service disparities; for the families and service providers in our study, the lack of services available to support children with special healthcare needs through the transition to adulthood and beyond was a pressing concern. We discuss the experience of children with special needs for reasons of feasibility and urgency. These children have well-defined needs that span a variety of services, and they face multiple discriminations, each one of which is a violation of their rights. Moreover, lack of access to services is particularly harmful for children with special healthcare needs who require additional supports to thrive, or even just to survive, and for whom early intervention is particularly crucial to ensure they achieve their highest potential in health, well-being, and quality of life. Understanding and addressing the needs of these children is one step towards meeting the human, constitutional, and treaty rights of all First Nations people.

5. Overview of findings

5.1 Severe funding disparities for services provided on reserve

The context for service provision in Pinaymootang at the time of data collection (early 2016) was defined by:

- Vastly insufficient base funding for both essential (e.g., diabetes screening) and supportive (e.g., respite care) programs;
- The availability of primarily short term and / or one-time additional funding, which did not guarantee program sustainability, to bridge the gap between services that could be provided with existing base funding and those needed to meet children’s needs;
- An onerous grant-based model for accessing additional funds, which put added pressure on already over-

burdened service providers;

- Obscure and lengthy decision-making processes for base and additional funding.

These factors created an environment where it was difficult for on reserve service providers to meet the needs of children with special healthcare needs and their caregivers.

5.2 Origin of service disparities

Observed service disparities were due primarily to the following factors:

1. **Administration:** a result of the distribution of responsibilities between the federal and the provincial government, including jurisdictional ambiguities, and vague bureaucratic guidelines and / or procedures for accessing services.
2. **Funding gaps:** services provided by federal and provincial ministries were not equally funded.
3. **Geography or distance from a service hub:** Pinaymootang First Nation is a rural community located 250 km north of Winnipeg.

5.3 Discrimination against First Nations children with special healthcare needs living in Fairford

Compared to children living off reserve in Manitoba, First Nations children with special healthcare needs living in Pinaymootang experienced service disparities in the three service areas studied in this report. The discrimination that children and their families faced was systemic, since it was the result of structural policies and practices that perpetuated the disadvantage of First Nations children as a group. Disparities varied across services:

- Disparities were most acute for access to allied health services such as occupational therapy, physiotherapy, speech and language therapy, and counselling. Due to funding gaps for on reserve services, allied health services were unavailable on reserve for children under the age of five living in Fairford reserve; most of these

children accessed allied health services in Winnipeg, which required regular and long commutes that put a financial and emotional strain on already overwhelmed families. Access to allied health services on reserve was limited for children over the age of five and enrolled in Pinaymootang School, where due to funding gaps the range and frequency of services was markedly inferior to those available in provincially-funded schools.

- Disparities also existed in access to additional care services. These disparities were a result of administrative factors (more specifically, differences between provincial and federal insurance policies). For example, the range of prescription medication available for First Nations children living in Fairford was narrower than that available off reserve, and the medication covered by federal insurance could (and did) change often and suddenly. Similarly, access to assistive devices for children with special healthcare needs living on reserve (e.g., wheelchair) was significantly more limited than for children living elsewhere in the province (e.g., only manual wheelchairs were eligible through the Non-Insured Health Benefits Program (NIHB), and only one device could be obtained every five years; these limitations did not exist for children living off reserve).
- Disparities existed but were less pronounced regarding access to primary and specialized medical services. These disparities were mainly due to geography (rurality) and regional shortages of qualified personnel in the Interlake region.

Combined, these disparities resulted in denial, delays, and disruptions of services ordinarily available to other children in Manitoba. Children with special healthcare needs living in Pinaymootang did not receive the services they required to properly manage their medical and developmental conditions, improve their quality of life, or reach their maximum potential.

5.4 Discrimination against caregivers of children with special healthcare needs living in Fairford

Virtually no support services were available for caregiv-

ers of children with special healthcare needs on Fairford reserve as of early 2016 (e.g., respite care, counselling, training, etc.). The few services that existed were provided through a pilot project with temporary funding from Health Canada. In contrast, families living off reserve had access to provincially-funded respite care, training, and other services that helped them take care of their children and themselves.

In the face of access disparities and an almost complete lack of support services, caregivers of children with special needs living in Pinaymootang felt overwhelmed, isolated, and frustrated. The lack of support services put an additional financial strain on families, since it required one or both of the parents to stay home to care for their child. Families of children with complex healthcare needs were faced with three possible scenarios, all of which were fundamentally flawed: staying in Fairford without access to the services their children needed, relocating to the city and moving away from their support networks, or transferring custody of their children to Child and Family Services.

5.5 Service providers' efforts to access and maximize the use of resources to address needs

Service providers in Fairford reserve have a record of excellence for their work in the community. Both the school and the health centre have invested significant efforts to partner with other organizations, communities, and service providers, and both regularly apply for grants in order to provide services to band members. The school has collaborated with the Manitoba First Nations Education Resource Centre (MFNERC) to access training services, equipment, and other resources for staff, children, and caregivers. The health centre has collaborated with the Interlake Eastern Regional Health Authority (IERHA) and nearby First Nation communities; advocated to implement a patient navigator system in collaboration with nearby medical facilities; secured short-term funding to implement a pilot program for children with special healthcare needs living in the community; and managed to guarantee the provision of allied health ser-

vices for Pinaymootang children at a Winnipeg-based provincially-funded rehabilitation clinic. Through these efforts, service providers based in Fairford reserve have become regional and national leaders in devising ways for band members to access services that could not be provided with available core funding.

5.6 Federal government offloading of burden, uncertainty, and risk onto local service providers

Local service providers bore the burden of compensating for service disparities, struggled with uncertainty about funding, and assumed the associated risks. Excessive burden was a result of the multiplicity of roles that service providers juggle in their communities (e.g., as mediators, advocates, employers, and service providers). It was also a consequence of the limitations that the grant-based funding model imposed on reserve service providers seeking to attract, train, and retain personnel, as well as design long-term strategies to address the community's needs.

Uncertainty resulted from obscure decision-making processes for the adjudication of grant-based funding, as well as the unknown timing of cash flows for both base and grant-based funding. This uncertainty prevented on reserve service providers from designing long-term strategies to address community needs and complicated, and sometimes jeopardized, short-term efforts.

In this context, on reserve service providers shouldered most of the risk of launching new programs, hiring and training personnel, and engaging families with programs and services without certainty about continued funding or even about the timing of funding receipt. All this occurred against a backdrop of strict and onerous federal regulations which allow the federal government to withdraw funding for all on reserve services as penalty for non-compliance with a broad range of guidelines and expectations.

6. Conclusions

1. Disparities in access to services due to administration,

funding gaps, and geography amounted to systemic discrimination against Pinaymootang children with special needs and their families.

2. Service disparities resulted in children's needs not being met, and overwhelmed and isolated families.
3. Service providers based in Fairford attempted to address the situation through partnership-building and grant-based funding. Thanks to these efforts, they were able to partially compensate for the lack of services in the community. While the programs and partnerships they have established improved the range and quality of supports / services available to Pinaymootang families, they did not address the problems inherent to the existing system for providing services to First Nations children living on reserve. These problems include, but are not limited to:

- funding disparities between federal (on reserve) and provincial (off reserve) programs;
- Offloading of burden, uncertainty, and risk onto local service providers, who must prepare grant applications and launch programs whose long-term funding is not guaranteed;
- Lack of local capacity and trained personnel to deliver best practice programs to these children and their caregivers;
- Lack of proper communication channels, and in particular, lack of transparency in decision-making processes;
- Absence of meaningful consultation with First Nations leadership, and no transfer of decision-making authority to local governments and service providers.

7. Recommendations

We propose that a new approach to the provision of services for children with special needs on reserve is needed. This approach builds on previous recommendations by the Assembly of Manitoba Chiefs (AMC) and Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba (FNHSSM)²⁶ to address service disparities

for all First Nations children, regardless of Status, place of residence (on or off reserve), and level of ability. Our recommendations are nonetheless focused on the specific experience of Pinaymootang children with special healthcare needs and their families.

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 aim to 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 in the Interlake region.
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 represent concrete steps towards the full implementation of Jordan's Principle in Fairford reserve, the Interlake Region, and Manitoba.

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