

# HONOURING JORDAN'S



# PRINCIPLE:



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

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# Contents

Advisory Committee Members .....	5
Acknowledgements .....	6
Acronyms .....	7
Terminology .....	8

## Overview

1. Context .....	10
2. Problem statement and justification .....	10
3. Goals .....	11
4. Scope and limitations .....	11
5. Overview of findings .....	12
5.1 Severe funding disparities for services provided on reserve .....	12
5.2 Origin of service disparities .....	12
5.3 Discrimination against First Nations children with special healthcare needs living in Fairford .....	12
5.4 Discrimination against caregivers of children with special healthcare needs living in Fairford .....	13
5.5 Service providers' efforts to access and maximize the use of resources to address needs .....	13
5.6 Federal government offloading of burden, uncertainty, and risk onto local service providers .....	14
6. Conclusions .....	14
7. Recommendations .....	14
References .....	15

## Chapter 1

### Documenting service disparities in Fairford reserve

1.1 Introduction .....	16
1.2 A history of institutionalized racism in the provision of public services in Canada .....	16
1.3 Jordan's Principle .....	16
1.4 Pinaymootang First Nation: introducing the community .....	18
1.5 Current issues between Pinaymootang First Nation and the federal government: the Fairford River Water Control Structure .....	19
1.6 Pinaymootang First Nation today: community profile .....	20
1.7 This project: objectives, brief methodology and scope .....	22
References .....	23

## Chapter 2

### Service disparities experienced by children with special healthcare needs living in Fairford and their caregivers

2.1 Introduction .....	24
2.2 Services discussed in this report .....	24
2.3 Medical Services available to children with special healthcare needs living in Pinaymootang .....	25
2.3.1 Medical services available on reserve .....	25
2.3.2 Medical services available off reserve .....	26
2.4 Allied health services available to children with special healthcare needs living in Pinaymootang .....	29
2.4.1 Allied health services available on reserve .....	29
2.4.2 Allied health services available off reserve .....	30
2.5 Additional care services .....	32

Text box 1: The Niniijaanis Niide (My Child, My Heart) Program .....	34
2.6 Factors contributing to service disparities: geography, funding, administration .....	35
2.7 Conclusions .....	35
References .....	36

## Chapter 3

### Impact of service and access disparities on children with special needs and their families

3.1 Introduction .....	39
3.2 Impact of service disparities on children .....	39
3.2.1. Denial .....	39
3.2.2 Delays .....	40
3.2.3 Disruptions .....	40
3.3 The impact of constant commuting to Winnipeg to access services .....	41
3.4 Impact of service disparities on caregivers .....	41
3.5 Stay, move, transfer custody to Child and Family Services: no perfect solution .....	43
3.5.1 Pinaymootang First Nation as a supportive but service-deprived community .....	43
3.5.2 Relocating to Winnipeg .....	44
3.5.3 Transferring custody to Child and Family Services .....	45
3.6 Conclusions .....	46
References .....	46

## Chapter 4

### Burden, uncertainty and risk: Fairford’s service providers at work

4.1 Introduction .....	47
4.2 Mediating without a voice .....	47
4.3 Burden .....	49
4.4 Uncertainty .....	51
4.5 Risk .....	52
Text box 2: The Niniijaanis Niide (My Child, My Heart) Program .....	53
4.6 Conclusions .....	55
References .....	57

## Chapter 5

### Reflections and Call for Action

5.1 A legacy of discrimination .....	58
5.2 Now is the time to end discrimination .....	58
5.3 Recommendations .....	59
References .....	60

## Appendices

Appendix A: Methodological Appendix .....	61
Appendix B: Interview Guide For Expert Interviews (Service Providers) .....	64
Appendix C: Interview Guide For Expert Interviews (Policymakers, Policy Analysts, Leadership, And Community Organizations) .....	68
Appendix D: Interview Guide For Interviews With Primary Caregivers .....	70
Appendix E: Children’s Service Reference Chart, Manitoba Region (Fnihb, 2010) .....	72
Appendix F: Terms Of Reference For The Collaboration Between Pinaymootang First Nation And The McGill-Based Research Team .....	73

<b>References</b> .....	77
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# Acronyms

<b>AANDC</b>	Aboriginal Affairs and Northern Development Canada (now INAC)
<b>ACFS</b>	Anishinaabe Child and Family Services
<b>AFN</b>	Assembly of First Nations
<b>AMC</b>	Assembly of Manitoba Chiefs
<b>CDS</b>	Children's Disability Services
<b>CFS</b>	Child and Family Services
<b>CHRT</b>	Canadian Human Rights Tribunal
<b>FNCFCSC</b>	First Nations Child and Family Caring Society of Canada
<b>FNHSSM</b>	Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba
<b>FNIGC</b>	First Nations Information Governance Centre
<b>FNHIB</b>	First Nations and Inuit Health Branch, Health Canada
<b>IERHA</b>	Interlake Eastern Regional Health Authority
<b>INAC</b>	Indigenous and Northern Affairs Canada
<b>MFNERC</b>	Manitoba First Nations Education Resource Centre
<b>NDP</b>	New Democratic Party
<b>NIHB</b>	Non-Insured Health Benefits Program, Health Canada



# Terminology

## Pinaymootang First Nation and Fairford Reserve

Pinaymootang is a First Nation group consisting largely of the descendants of Ojibwe people who migrated to Manitoba's Interlake Region in the 15th century from what is now Ontario. The Nation has a total population of 3,258<sup>1</sup> people. Fairford, Manitoba, is the First Nations Reserve (#06379) where a large number of Pinaymootang First Nation's people reside (1,271<sup>2</sup> of the Nation's members). Fairford reserve is located on Treaty 2 territory in Manitoba's Interlake region, and is classified as Zone 2 according to Indigenous and Northern Affairs Canada (INAC)'s geographic categories, meaning that it is "between 50 and 350 km from the nearest service centre to which it has year-round road access".<sup>3</sup> Although Pinaymootang refers to the First Nation and Fairford to the reserve, we use both terms interchangeably throughout the report, in keeping with common practice.

## Special healthcare needs

"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally".<sup>4</sup> These children's needs may include,

- Medical services, rendered by a nurse or family doctor or ordered by a nurse or family doctor in support of their protected professional acts (with the exception of allied health services). Examples from our study include primary care, specialized care, diagnostic evaluation, and surgical procedures;

- Allied health services, delivered by healthcare professionals other than nursing, medical and pharmacy<sup>5</sup>. Examples include occupational therapists, physiotherapists, speech and language pathologists, and social workers;
- Additional care services, refers to any service, specialized equipment, or assistive device necessary for the health, wellbeing, and general functioning of a patient and accessed through Health Canada's Non-Insured Health Benefits Program. Examples include prescription medication, respite care, assistive devices such as wheelchairs or hearing aids, and medical transportation. Examples of additional care services from this report include:
  - Assistive devices: "specialized equipment or devices that can help people with disabilities with their daily activities in communication, self-care, mobility, hearing, vision, (and) environmental control".<sup>6</sup> Assistive devices include mobility aids such as wheelchairs or walkers, gastrostomy tubes for feeding, and hearing aids;<sup>7</sup>
  - Prescription medication: pharmaceutical medication that requires a medical prescription and that helps improve or manage a specific medical condition;
  - Specialized medical equipment: equipment or devices that are medically necessary to ensure a patient can eat, breathe, or perform other basic functions. This equipment often requires trained medical personnel for installation, operation, cleaning, and changing. (e.g., tracheostomy tubes);<sup>1</sup>

<sup>1</sup> Because specialized specialized medical services are necessarily accessed through provincially-funded facilities, much medical equipment is provided by Manitoba Health. In Pinaymootang, only medical equipment accessed through Pinaymootang Health Centre or prescribed by a doctor for at-home use would be covered by Health Canada.



- Respite care: a “reprieve, a short interval of rest, temporary relief, and as an interruption in the intensity of a caregiving activity”;<sup>8</sup>
- Medical transportation “to access medically required health services not provided on the reserve or in the community of residence”.

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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.<sup>10</sup> 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,<sup>11</sup> the Assembly of Manitoba Chiefs<sup>12</sup> and Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba (FNHSSM),<sup>13</sup> as well as by the Truth and Reconciliation Commission of Canada,<sup>14</sup> the United Nations Rapporteur on the Rights of Indigenous peoples,<sup>15</sup> the Jordan's Principle Working Group,<sup>16</sup> and the Canadian Human Rights Tribunal.<sup>17</sup> The issue has also been raised in the House of Commons (NDP Member of Parliament Charlie Angus 2016<sup>18</sup>) and in the Manitoba Legislative Assembly (NDP Member of Legislative Assembly Wab Kinew<sup>19</sup>).

Jordan's Principle was designed to respond to service disparities affecting all First Nations children across multiple sectors, including health, social, and educational services.<sup>11</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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.<sup>22</sup> 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.<sup>23</sup>

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.<sup>24</sup> 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-

<sup>11</sup> 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.<sup>25</sup> 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)<sup>26</sup> 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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# Chapter 1

## Documenting service disparities in Fairford reserve

### 1.1 Introduction

This chapter sets the stage for the report, which focuses on the specific experiences children with special needs, their primary caregivers, and service providers have on Fairford reserve. First, we introduce the policy context that enables discrimination against First Nations children living on reserve. A second section briefly discusses Jordan's Principle, a mechanism intended to eliminate service disparities and allow First Nations children living on reserve to access the same services that would be available to other Canadian children in similar circumstances. The discussion then turns to the challenges and strengths members of Pinaymootang First Nation face, as described by research participants. The last section sets out the objectives, scope, and methodological approach used in the report. The chapter aims to stitch together the larger policy context at the national level with the daily experiences of members of Pinaymootang First Nation, and explain the origins of the current project.

### 1.2 A history of institutionalized racism in the provision of public services in Canada

First Nations children experience denials, delays, and disruption of services ordinarily available to other Canadian children in similar circumstances. These service disparities violate First Nations children's human, constitutional, and treaty rights. The need to address service disparities has been highlighted by First Nations leaders, notably the Assembly of First Nations<sup>27</sup> and the Assembly of Manitoba Chiefs,<sup>28</sup> as well as by the Truth and Reconciliation Commission of Canada,<sup>29</sup> the United Nations Rapporteur on the Rights of Indigenous peoples,<sup>30</sup> the Jordan's Principle Working Group,<sup>31</sup> and the Canadian Human Rights Tribunal.<sup>32</sup> This issue has also been

raised in the Canadian House of Commons by NDP MP Charlie Angus<sup>33</sup> and in the Manitoba Legislative Assembly by NDP Member of the Legislative Assembly Wab Kinew.<sup>34</sup>

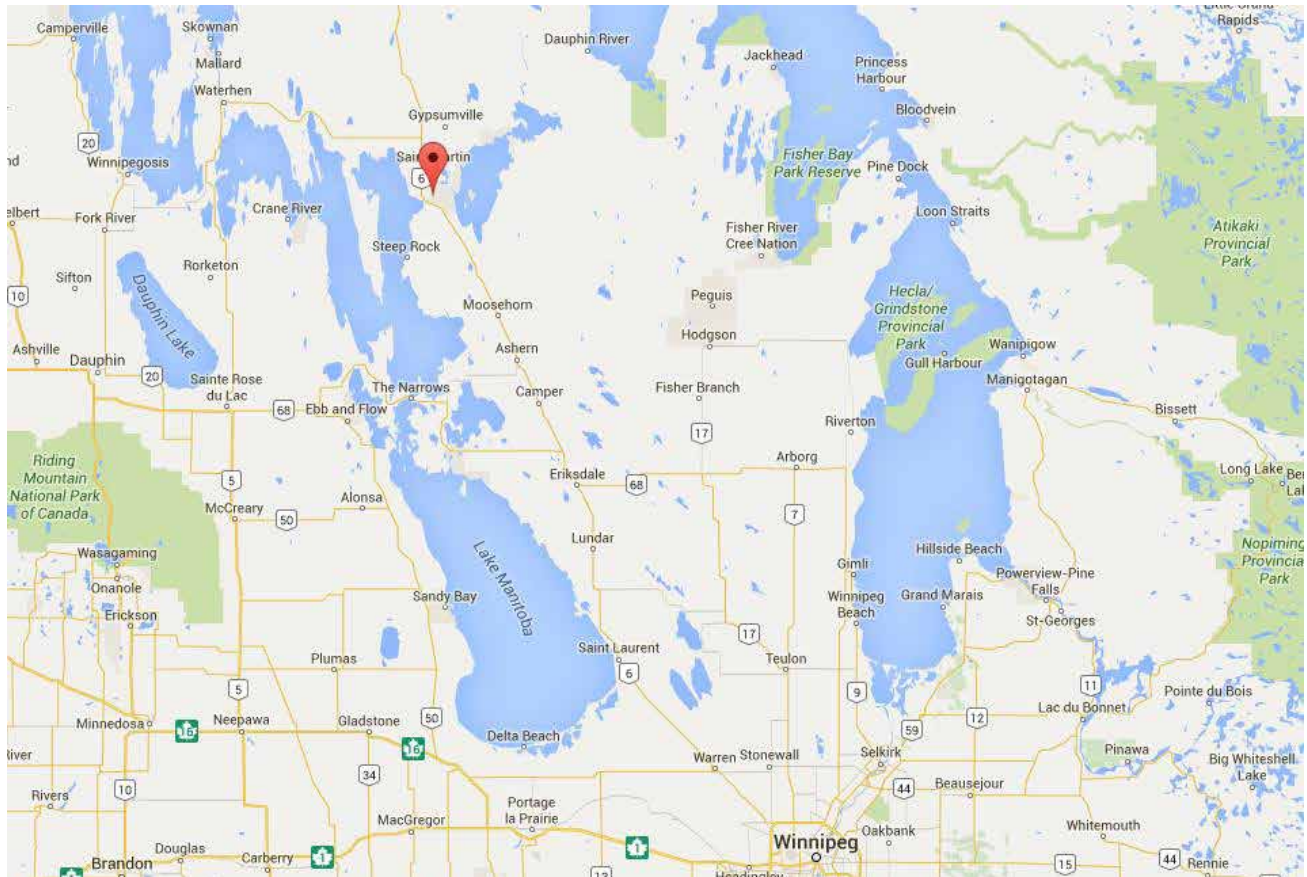
From a policy perspective, the discrimination against First Nations children is the result of three main factors. The first factor is the administrative organization of service provision in Canada: while services for First Nations peoples living on reserve are provided by the federal government, public services for most other Canadians are provided by provincial and territorial governments. This two-tiered system engenders jurisdictional ambiguities over which level of government is responsible for providing services for First Nations children living on reserve. It also means that access to on- and off-reserve public services may be governed by very different guidelines and procedures. The second factor leading to service disparities is the funding gap between provincially and federally provided services, with the latter routinely being allocated significantly less resources than the former. Finally, with about half of reserves being far from urban centres some service disparities are due to geography or distance from a service hub.<sup>35</sup> Combined, these three factors result in First Nations children experiencing denials, delays, and disruptions of services ordinarily available to other children in Canada.

### 1.3 Jordan's Principle<sup>III</sup>

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

<sup>III</sup> 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.





Map 1: Fairford reserve in the Manitoba Interlake Region. Map data 2016 Google.

disputes.<sup>36</sup> The Principle is named in honour of Jordan River Anderson, a child from Norway House Cree Nation—a First Nations community about 600 km from Fairford. Jordan was born with special healthcare needs and died without ever having experienced life outside of a hospital because of a jurisdictional dispute between the federal and provincial governments over who would pay for his out-of-hospital care.<sup>37</sup>

Jordan's Principle was unanimously endorsed by the House of Commons in 2007.<sup>38</sup> The Principle's goal is to remove government red tape preventing First Nations children living on reserve from accessing services ordinarily available to children off reserve in similar circumstances. Jordan's Principle states that when a dispute regarding a service ordinarily available to other children emerges between the provincial and the federal government, or between two ministries or departments within the same level of government, the service must be provided immediately by the ministry

or department of first contact; the dispute should be resolved at a later date through a separate mechanism. As originally endorsed in the House of Commons, Jordan's Principle applied to all children regardless of level of (dis)ability and across service sectors.<sup>39</sup> However, the Principle has never been fully implemented; the federal government has gradually narrowed the eligibility criteria, effectively eliminating any potential cases.<sup>40</sup> Until 2016, Jordan's Principle was interpreted by the federal government as applying only to children with multiple disabilities needing services from a variety of providers. This interpretation focused on permanent or acute temporary medical disability, and contravened the original spirit of Jordan's Principle, which was to ensure that all First Nations children living on reserve had access to the services they required.

In 2016, in a ruling on First Nations child welfare, the Canadian Human Rights Tribunal (CHRT) concluded that jurisdictional ambiguities and gaps, combined with

the severe underfunding of public services on reserve, result in access disparities and discontinuities of care that violate First Nations children's rights under the Canadian Human Rights Act and amount to racial discrimination. As one of several immediate remedies, the CHRT ordered the federal government to "cease applying its narrow definition of Jordan's Principle and to take measures to immediately implement [its] full meaning and scope".<sup>41</sup> At the time of writing, the Canadian government has expanded its interpretation to include on reserve First Nations children with disabilities or "interim critical conditions", but has not yet fully complied with the CHRT order to implement Jordan's Principle.<sup>42</sup>

This report documents the obstacles faced by First Nation children, their families and community in Manitoba when trying to access services ordinarily available to non-First Nations children. Our hope is that sharing the experiences of Pinaymootang families and service providers will inform future policy development, and help lead to a Canada where racial discrimination has no place in the provision of public services.

## 1.4 Pinaymootang First Nation: introducing the community

Fairford reserve is the land allocated by the Canadian government to Pinaymootang First Nation within Treaty 2 territory. The reserve has a surface area of 7,412.60 hectares (1/15th of the Winnipeg metropolitan area) and is situated in the Manitoba Interlake Region, about 250 km north of Winnipeg along Highway 6.<sup>43</sup> The band has 2,812 members, with 1,233 living on reserve and 1,579 residing elsewhere.<sup>44</sup> The majority of the members are Status Indians, a controversial legal category defined by the Canadian government to identify the descendants of the country's pre-colonial populations.<sup>45</sup>

The ancestors of today's Pinaymootang First Nation's members were Ojibwe people who migrated west from Ontario starting in the early 15th century. Their presence in the Interlake region of Manitoba is well documented by 1842, when the Fairford Anglican Mission was cre-

ated.<sup>46</sup> During this time and until the signing of Treaty Number 2 in 1871, members of the band relied on local resources for their needs. According to Belanger, during this period "[f]ish were plentiful, sap was available for sugar production, small game animals such as rabbits were abundant, and from local gardens a variety of vegetables were grown".<sup>47</sup> Unlike other groups in the area, Pinaymootang had limited contact with non-Native settlers and its members were only partially dependent upon trade with non-Native settlers for their survival.<sup>48</sup>

That changed in the second half of the 19th century with the signing of the first four numbered treaties between the Crown and Indigenous populations in the territory that is Manitoba today.<sup>49</sup> The Nations in the Interlake region and parts of Parkland and Westman (Dauphin River, Ebb and Flow, Keeseekoowenin, Lake St. Martin, Lake Manitoba, Little Saskatchewan, O-Chi-Chak-Ko-Sipi, Pinaymootang, and Skownan) entered Treaty Number 2 with the Crown in August 1871 at Manitoba House.<sup>50</sup> These communities exchanged land rights and the promise of peace, law, and order for limited reserve land, an annual monetary compensation (\$5 per band member, in 1871 to present), farming tools, and education. By signing Treaty Number 2, members of Pinaymootang First Nation agreed to abandon their seminomadic lifestyle and settle in Fairford reserve. What followed, however, were centuries of oppression. The new settlers interpreted Treaties with Indigenous populations as a tool for conquest and control. From this colonial mindset followed assimilationist, colonialist, and genocidal<sup>51</sup> federal policies that have shaped the provision of services on reserve and continue to manifest in discriminatory policies and practices today. These include, but are not limited to:

- The Indian Act of 1876, which set the terms of the relationship between Canada's original populations and the Crown. The Indian Act established the category "Status Indian" for descendants of the country's First Nations, and defined the circumstances under which Status could be obtained and lost. Changes were made to the Indian Act in 1985 to eliminate gender bias on the transmission of Indian Status, but the

Act has remained a controversial piece of legislation.<sup>52</sup>

- The Constitution of Canada, which since 1876 gives the federal Parliament and government exclusive authority over “[Status] Indians, and lands reserved for the Indians”.<sup>53</sup> By doing so, the Constitution makes Status Indians legally distinct from other Canadians. This has crucial implications for the provision of public services, where “[r]esponsibility for services to First Nations children is often shared by federal, provincial / territorial, and First Nations’ governments; in contrast, funding and delivery of these same services to most other children in Canada falls solely under provincial / territorial jurisdiction”.<sup>54</sup>

In combination, the Indian Act and the Constitution form the foundation of the policy framework that exists today.

The context for children and families living on reserve is also shaped by a long history of mass, government sponsored removal of children from their homes and communities. The Residential School System (1892–1996) was designed with the explicit goal to “kill the Indian in the child”<sup>IV</sup> by removing Indigenous children from their families, their communities, and their culture. Indigenous children were forcibly removed from their families and taken to boarding schools administered by Catholic and Roman Anglican churches, where they were forced into Canadian white mainstream culture, values, religious beliefs, and language.

Psychological, physical, and sexual abuse were common at these schools, and neglect of residential school students was endemic. Residential schools have resulted in the disruption of traditional cultural practices, the near disappearance of traditional social structures, institutions, and language, the fragmentation of communities, intergenerational trauma, substance abuse, and increased incidence of mental health problems and suicide among Canada’s Indigenous populations.<sup>55</sup> The Truth and Reconciliation of Canada has described this system as “cultural genocide”.<sup>56</sup> As the residential school system was phased out, the provincial child welfare system became responsible for the mass removal of Indigenous children from their homes and communities. This is reflected in



Image 1.1: the Fairford River Water Control Structure.  
Source: Wikimedia Commons.<sup>61</sup>

the “Sixties Scoop” (the widespread removal of Indigenous children from their families by the child welfare system from the 1960s into the 1980s<sup>57</sup>), and the current overrepresentation of Indigenous children in the foster care system,<sup>58</sup> both of which are important subtexts to this report. Most significantly, the systematic targeting of Indigenous children by Child and Family Services agencies continues to manifest itself into parents’ lack of trust in the Canadian government, and in particular of federal services and programs.

## 1.5 Current issues between Pinaymootang First Nation and the federal government: the Fairford River Water Control Structure

The relationship between Pinaymootang First Nation and the federal government has been fraught with tension, as illustrated by the history of interactions between Pinaymootang First Nation and the federal government surrounding the Fairford River Water Structure, a provincially-managed dam located in Fairford reserve.

<sup>IV</sup> Sir John A. Macdonald elaborated on this in an intervention at the House of Commons in 1883: “Indian children should be withdrawn as much as possible from the parental influence, and the only way to do that would be to put them in central training industrial schools where they will acquire the habits and modes of thought of white men” (Truth and Reconciliation Commission of Canada, 2015, p. 2).

The reserve is located in Manitoba's Interlake Region, between Lake St. Martin, Pineimuta Lake, and Lake Manitoba. Between 1960 and 1961, the Government of Manitoba built the Fairford River Water Control Structure to regulate the level of Lake Manitoba upstream from the reserve. Since 1967 the provincial government has operated the dam and caused extensive seasonal flooding on the reserve in order to protect other areas of southern Manitoba. To compensate for these floods, the federal government gave Pinaymootang First Nation 5,772 acres of land in 1979. In 1998, the band took the Government of Canada to court for the first time, arguing that, by allowing the provincial government to flood the land, the Crown had neglected its treaty obligation to protect the band from harm.<sup>59</sup> The ruling concluded that the Crown could not be held responsible for the band's losses, since the dam was operated by the Government of Manitoba.<sup>60</sup> This allowed seasonal flooding to continue.

The seasonal flooding has systematically destroyed important components of Pinaymootang's formal and informal economies. Since 1960, traditional trapping lines, fishing spots, and hunting grounds have disappeared. An existing muskrat population was displaced as a consequence of the dam's operation, causing the closure of a small fur industry. Lands formerly used to grow hay for a 200-cow operation that provided work to the Nation's members have been converted into a marsh. Moreover, the intentional flooding of some of the reserve's land for the last five decades has impacted the community's insufficient and largely inadequate housing stock (Band Councillor, interview, February 9, 2016).

During the great flood of 2011,<sup>v</sup> the province used the Fairford River Water structure to protect the more populated areas along Red and Assiniboine Rivers. The Government of Manitoba intentionally raised the water level of Lake Manitoba 0.73 m over normal operating range<sup>62</sup> forcing the evacuation of entire First Nations communities in the area. In Fairford, 40 of the existing 300 housing units were flooded.<sup>63</sup> A group of ten plaintiffs filed a class action lawsuit against the provincial and federal governments following the 2011 flood, on behalf of nearly 4,000 total evacuees (CBC News, 2017).

They argued that the way Manitoba operated the dam in 2011 was detrimental to the bands' land, residents' livelihoods, and the Nation's treaty rights. Although the lawsuit was overturned in 2014, an appeal was granted and has given the case new life in 2017.<sup>64</sup> At the time of writing, the Government of Manitoba was reviewing the case and considering its next course of action.<sup>65</sup> The flood has nevertheless had a profound and lasting impact on First Nations communities in the Interlake region: in early 2017, there were still 2,016 First Nations evacuees from the area living in temporary accommodations.<sup>66</sup> Replacement housing in Fairford was not finished in early 2017.<sup>67</sup> As the province designs a new Outlet Channel to control water levels in Lake Manitoba that puts the community at the centre of a variety of potential dam structures,<sup>68</sup> Fairford reserve remains highly vulnerable to future flooding. This vulnerability highlights the concrete ways in which colonialism affects the everyday lives of Pinaymootang band members.

## 1.6 Pinaymootang First Nation today: community profile

The band's population is young when compared to the overall Canadian population: approximately 50% of Pinaymootang's members are under the age of 20.<sup>69</sup> This is consistent with Statistics Canada's observation that the growth rate for First Nations in Canada is much higher than for the non-Aboriginal population (29% compared to 8% between 1996 and 2006<sup>70</sup>). The proportion of young people in Pinaymootang stands in contrast with the aging of the overall Canadian population, and has important implications for the provision of health and social services in the community.

Due to existing social and structural factors that are a direct result of Canada's colonial history, Indigenous children in Canada are at an increased risk of having their health compromised. The infant mortality rate within the Indigenous population is significantly higher than

<sup>v</sup> In May 2013, exceptional environmental conditions led to the most severe flood ever recorded in Manitoba. Communities along the shoreline of Lake Manitoba were severely impacted as its flood-level waters, along with those of multiple swollen tributaries, interacted with severe winds on May 31 (Manitoba 2011 Flood Review Task Force, 2013).

in the rest of Canada.<sup>71</sup> First Nations children are more likely to develop chronic health conditions and present higher frequencies of physical, cognitive, and mental impairments.<sup>72</sup> For example, while 4.6% of Canadian children between the ages of 5 and 14 were diagnosed with a learning disability in 2006, the rate for First Nations children was 1.5 times higher.<sup>73</sup>

The high frequency of disease and disability among First Nations children is rooted in Canada's history and ongoing legacy of colonialism. Today, Indigenous children are more likely to be exposed to pollutants and environmental hazards, including inadequate and / or crowded housing, and are less likely to have access to safe drinking water and affordable nutritious food.<sup>74</sup> The historical, political, and socio-economic factors surrounding the lives of Indigenous children in Canada have resulted in many First Nations children being born and raised in conditions of extreme social disadvantage. Immediate and intermediate social determinants of health experienced by First Nations children in Canada are the result of past and current systemic racism and widespread discrimination against Indigenous populations in Canadian society; in the case of First Nation communities, these are further compounded by the lack of self-determination of local governments.<sup>75</sup> <sup>VI</sup> Higher risks of poor health, combined with increased difficulties to access public services,<sup>76</sup> means that First Nations children often carry these conditions as they transition into adulthood regardless of their level of (dis)ability.

Pinaymootang demonstrates the types of impacts that these historical and structural factors have on First Nation communities throughout Canada. The employment rate in Fairford for self-identified Aboriginal individuals (26.7%) is significantly lower than the average for all self-identified Aboriginals in Manitoba (50%) and for the total population of the province (63.1%).<sup>77</sup> This is consistent with information provided by community members and service providers during interviews. Low participation rates in the labour market are a result of lack of employment opportunities in the community. There are no private enterprises; the few sources of revenue and employment are all small and band-operated (Pinaymoot-

ang School, Pinaymootang Health Centre, Pinaymootang Band office, gas bar, etc.).

Education attainment figures for Pinaymootang First Nation further depict a community struggling to succeed. For example, in 2011, 48% of the residents of Fairford reserve between the ages of 25 and 64 who self-identified as Aboriginal had no certificate, diploma or degree, compared to 37% of the overall self-identified Aboriginal population of Manitoba and 17% of the total population (Aboriginal and non-Aboriginal combined).<sup>78</sup> With dire population and employment statistics like these, it would be easy to view Pinaymootang as only an impoverished and hopeless place. Band members interviewed for this project did not see their community this way, and described Pinaymootang First Nation also as a place of great beauty where people joined forces to overcome common challenges. They took pride in the community's rich and diverse spiritual life: Band members are predominantly Christian (Anglican, Pentecostal, and Apostolic), with some embracing traditional spirituality or a combination of Christian and traditional beliefs. The main language spoken is English, but many are fluent in Salteaux (the local dialect of the Ojibwe language). Respect for elders and the strength of extended family relations give testimony to the vitality of traditional culture. Families are large and close-knit: relatives often step in to support each other when the need arises. When that is not enough, community members organize fundraisers, silent auctions, or collect money at church to help families who, for example, need to relocate to Winnipeg to access medical services.

This sense of pride and kinship informs into the work done at the local governance level. Band members emphasized that Pinaymootang has come a long way in the last few decades, mainly thanks to the strong collabor-

<sup>VI</sup> Self-determination would allow First Nations government to make decisions regarding community wellness and health programs in their communities to an extent that does not exist today, particularly given the lack of meaningful consultation in current decision-making processes (Auditor General of Canada, 2015; Ladner, 2009). Research suggests that "band level measures of community control over the delivery of health, education, child protection and policing services, and the achievement of a degree of self-governance" are associated with lower suicide rates in First Nation communities (Hallett, Chandler, & Lalonde, 2007, p. 3).

ration and the creation of partnerships between the band, the health centre, the school, and other regional stakeholders. Service providers take pride in their successful efforts to meet the highest quality standards. For example, the health centre was fully accredited by Accreditation Canada in 2014; this is an exceptional achievement that demonstrates the team's outstanding performance and highlights the excellence of the services provided by the Centre. Socially, respondents described Pinaymootang as a friendly and welcoming place where neighbours take care of their lots, and individual and community achievements are celebrated.

## **1.7 This project: objectives, brief methodology and scope <sup>vii</sup>**

In 2015, Pinaymootang First Nation decided to come forward to share the difficulties children with special needs and their families were experiencing accessing the services they needed. The Nation partnered with a research team based at McGill University to document the experience of Pinaymootang First Nation families and service providers, establish access disparities, and link their experience to larger provincial and national discussions on the implementation of Jordan's Principle. By doing so, Pinaymootang leadership wished to contribute community-level experience to the development of policy that would lead to the end of discrimination against Indigenous children in the Canadian system for public service provision.

This partnership began officially in January 2016 with the signing of a Research Agreement between the McGill-based team and Pinaymootang leadership. This research agreement recorded the conditions for the collection, analysis, ownership, and distribution of the data, and formally established the project's governing body (the Advisory Committee). The terms of governance for this project were based on the First Nations Information Governance Centre's OCAP™ Principles.<sup>79</sup> The project's Advisory Committee included representatives of Pinaymootang Band Council, the health centre, the school, and the band office; as well as representatives of regional and provincial Indigenous organizations and all the members

of the research team. The Advisory Committee acted as the main governance body for this project. All decisions related to this project were discussed with and approved by the Advisory Committee, including those regarding data collection and the structure, content, and dissemination strategy of this report. In recognition of the band's governance and ultimate leadership over this project, Chief and Council reviewed and approved the research agreement, were kept up to date with the evolution of the research project, and reviewed and approved the final report.

The core of the data discussed in this report was collected between January and September 2016. During this period, we collected information from different stakeholders:

1. Service providers based in Fairford: we conducted seven structured interviews with leaders and service providers in the community to establish the range and level of service accessible to children with special needs living in Fairford and their families on reserve, in nearby communities, and in Winnipeg;
2. Families: we conducted 12 semi-structured interviews with the primary caregivers of band members with special needs, under the age of 14, to understand their experiences accessing services, and the impact that access disparities had on the children and caregivers;
3. Representatives of local, regional, and provincial Indigenous organizations: we conducted three semi-structured interviews with one Council member, the representative of a regional Aboriginal child and family services organization, and a provincial Indigenous organization. These interviews allowed us to deepen our understanding of the policy context at the provincial and federal level and connect the experience of Pinaymootang families and service providers with that of other First Nation communities throughout the province;
4. Representatives of other Indigenous organizations as well as of federal agencies involved in the provision of services in Pinaymootang First Nation. These were

<sup>vii</sup> For a more detailed discussion of the project's methodology, please refer to Appendices A–D.

five short unstructured interviews conducted over the phone that focused on a specific area of policy.

We have focused on children with special needs for strategic reasons: given the limited resources available to carry out this project, it seemed reasonable to focus on a group of children with a well-documented and long-standing need for services across a variety of sectors. This does not mean we endorse the federal government's efforts to apply Jordan's Principle exclusively to First Nations children living on reserve with "disabilities and those who present with a discrete, short-term issue for which there is a critical need for health and social supports".<sup>80</sup> The discrimination against children with special healthcare needs is particularly harmful given their dependency on multiple services to thrive and survive. All First Nations children are entitled to the same rights and services as any other Canadian child, regardless of their place of residence and level of (dis)ability.

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# Chapter 2

Service disparities experienced by children with special healthcare needs living in Fairford and their caregivers

## 2.1 Introduction

In this chapter, we explore the disparities between the services available to children living in Fairford and their caregivers and those available to other children and families in similar circumstances in the Interlake region. In keeping with the rest of the report, we focus on children with special healthcare needs, defined as those who require ongoing, complex interventions from different service agencies and professionals,<sup>81</sup> and we use the children and caregivers experiences as a foundation to draw attention to the types of disparities that also impact other members of the Pinaymootang community.

The chapter begins with a brief definition of the services discussed in this report (medical services, allied health services, and additional care services) and the locations where Pinaymootang families access them. The second section of the chapter focuses on medical services, accessed both on and off reserve. A similar section focused on allied health services follows. The discussion on access disparities for additional care services (section 2.4) does not have such a clear geographic dimension, and instead focuses on how differences between provincial and federal insurance policies impose service disparities on children with special healthcare needs living in Fairford, compared to other children in similar circumstances living off reserve in the Interlake Region. In the final section, we examine the factors contributing to the service disparities described throughout the chapter.

## 2.2 Services discussed in this report

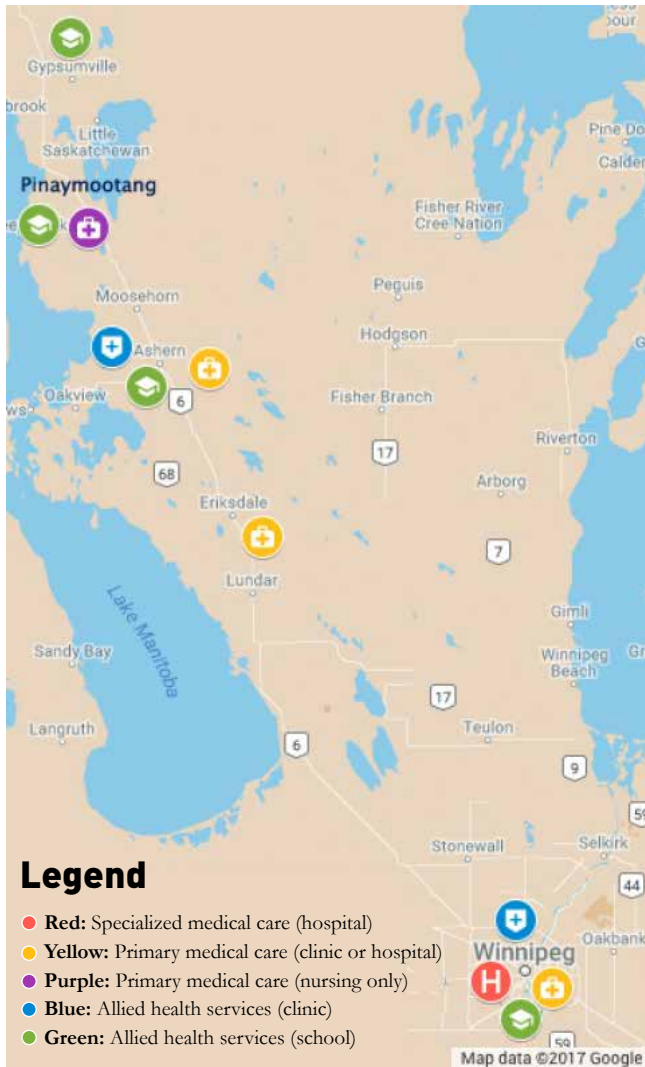
The discussion in this report focuses on three service areas typically required by children with special healthcare needs:

- Medical services, rendered by a nurse or family doctor or ordered by a nurse or family doctor in support of their protected professional acts (with the exception of allied health services). Examples from our study include primary care, specialized care, diagnostic evaluation, and surgical procedures;
- Allied health services, delivered by healthcare professionals other than nursing, medical and pharmacy<sup>82</sup>. Examples include occupational therapists, physiotherapists, speech and language pathologists, and social workers;
- Additional care services, refers to any service, specialized equipment, or assistive device necessary for the health, wellbeing, and general functioning of a patient and accessed through Health Canada's Non-Insured Health Benefits Program. Examples include prescription medication, respite care, assistive devices such as wheelchairs or hearing aids, and medical transportation.

In this report we also address, in less detail, the services that primary caregivers of children with special healthcare needs require to be able to care for those children. These services include qualified respite care (defined as a “reprieve, a short interval of rest, temporary relief, and as an interruption in the intensity of a caregiving activity”<sup>83</sup>), training for family members (e.g, CPR), stress management workshops, professional mental health support, and peer-to-peer support.

Medical services and allied health services accessible to children with special healthcare needs living in Pinaymootang were administered by service providers on reserve, in nearby off reserve communities, and in Winnipeg (see Map 2.1 below). Obstacles to accessing these





Map 2.1: Primary medical care, specialized medical care, and allied health services available to First Nations children living in Fairford by category and place of access.

services that were experienced by Pinaymootang families residing off reserve are discussed below and in Chapter 3, when we discuss the impact of service disparities on children with special healthcare needs and their caregivers.

## 2.3 Medical Services available to children with special healthcare needs living in Fairford

On reserve, medical services for children with special healthcare needs are primarily provided by Pinaymootang Health Centre, Pinaymootang School, and Pinaymootang Band office. Anishinaabe Child and Family Services

(ACFS) also provides services in Fairford, either directly or in collaboration with Pinaymootang Health Centre or the band office. ACFS' main role is to support First Nations families and protect First Nations children, both on and off reserve. ACFS may investigate cases where a child's safety and wellbeing are suspected to be at risk, and if no other options are available, the agency may place children with relatives, in foster care, or in adoption.

First Nations communities in Manitoba struggle to provide even basic services with the resources made available by the federal government.<sup>84</sup> In this context, First Nations governments are encouraged to prioritize those services considered essential (e.g., immunization) over supportive services (e.g., physiotherapy).<sup>85</sup> Pinaymootang First Nation's experience is consistent with the experience of other bands throughout Manitoba.

### 2.3.1 Medical services available on reserve

As of March 2016, the health centre was officially funded to administer only education and awareness programs.<sup>86</sup> Despite this formal arrangement, in early 2016 the Centre relied on a team of nurses and provided a range of services including basic checkup and immunization services, the administration of medication, and assistance with regular treatments. For example, nurses at the health centre treated Eric, who had severe eczema breakouts. These treatments allowed him to stay close to his family when his condition worsened.

**In the summertime [Eric's] eczema got really, really bad. We had to keep him wrapped up at the health centre almost every day [or go to] Ashern almost every day just for them to change his wrappings.... They had to put antibiotics and antibiotic wrappings on him...from head to toe. (Eva, caregiver interview, March 2016).**

The Centre's staff also coordinated services with other healthcare providers in neighbouring communities and in Winnipeg—a key mediating role that allowed children with special healthcare needs living in Fairford to access medical specialists. Justin was one of the patients who

benefitted from the referral system developed at the Centre after it was clear the school could not provide the needs assessment he required to access other services. Justin's father's described this experience:

**[Justin] started grade two and then we were called into the school, me and his mother or one us at least because they wanted to talk us and they told us...he's going to be need to be taken to a specialist.... Our appointments were booked by the health centre and they gave us travel on a medical vehicle to take my son over there and back, and they also provided meal tickets (Chris, caregiver interview, March 2016).**

For Justin, as well as for other children with special healthcare needs, the services provided by the health centre were crucial to ensure follow up and referrals. However, these children had to leave Fairford to access virtually all the medical services they required.

### **2.3.2 Medical services available off reserve**

Children with special needs living in the community could also access some services at provincially-funded facilities off reserve, both in nearby communities and in Winnipeg. Within the Interlake region, the main facilities families accessed 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 provided primary health services but no specialized medical care.

Caregivers of children with special healthcare routinely bypassed these two hospitals on their way to Winnipeg. As William, father of a child with a life-threatening condition, explained, stopping at one of these hospitals could be a waste of precious time.

**[In Ashern] they didn't want nothing to do with him. They used to make us wait in the waiting room in Ashern and then finally said "Ok, no, you have to go to Winnipeg." So why waste two, three hours there when we can be in Winnipeg in two**

**or three hours? (William, caregiver interview, March 2016).**

Even when services were available and accessible, caregivers found that medical personnel were not always prepared to serve children with special healthcare needs. For example, Julia (the mother of a boy with epilepsy) was horrified when a physician in Ashern told her to put her convulsing infant in a crib and wait for the seizures to pass.

**The first time [Danny] had [a seizure] they wouldn't do nothing for him [at the hospital in Ashern]. He had three seizures in one night, and all they did for us at the hospital—we were there for an hour and all they did, they gave him Tylenol and they left us in the room for an hour. ... I got really mad at that Doctor because I asked him "What are you going to do if he had another seizure and what if it'll be worse?" He's like "Oh kids like that, you just turn the light off and leave him". I was like, "You can't do that, he's just a baby! He can hurt himself; he can choke on his own spit!" And I got so frustrated I told this nurse, and she's like "You know, he won't do nothing for you. My suggestion to you is to go to Winnipeg." (Julia, caregiver interview, March 2016).**

Families also shared experiences of perceived racism in nearby hospitals. Caregivers referred to experiences in nearby hospitals where children were denied diagnostic services (e.g., X-rays) and later found to have fractured bones, lack of care for a child with pneumonia, and increased waiting times. For example, the parents of a child with a special medical condition took their son to Ashern hospital because he had a fever. After one day of waiting in the hallway to be seen, the boy was placed in a room that, according to the parents, was colder than the other rooms and had a cold draft. After a day in that room the doctors found that the boy had pneumonia. The parents believed that they would have been treated differently if they had been white.

Parents' perceptions of racism at Ashern hospital are backed up by a history of mistreatment and discrimination. In 2012, Pinaymootang Health Centre requested the intervention of the Interlake Eastern Regional Health Authority (IERHA) to address "incidents of discrimination and abuse within the [Ashern] Lakeshore Hospital that had been reported but had gone unaddressed for several years [...] [and] respond to the community's concerns of safety and professionalism" (Pinaymootang Health Centre, briefing note, March 2014). A year after Pinaymootang Health Centre made this request, an elder was refused care by Ashern Hospital staff and Pinaymootang Health Centre staff who intervened were verbally abused and insulted in the process. The then director of the IERHA wrote a letter to Pinaymootang First Nation's Chief at the time, Garnet Woodhouse, apologizing for "the disrespectful behavior shown by our staff towards your health staff and community members on April 18th [2013]".<sup>87</sup> The letter went on to say that although "some of this can be attributed to the stressful healthcare environment that patients and staff must deal with [...] I believe, and as I said at our meeting, that it is also impacted by long standing systemic racism". The discrimination against First Nations patients alluded to by the former IERHA director is a widespread phenomenon in Canadian health facilities.<sup>88</sup> It is also a reality in Manitoba, as shown in the case of Brian Sinclair. Sinclair was an Aboriginal man who died at the Winnipeg Health Sciences Centre of a treatable bladder infection, while waiting in the Emergency room, while medical staff ignored him because they assumed he was drunk.<sup>89</sup>

Pinaymootang's Health Centre staff suggested that the lack of culturally appropriate training and language barriers were also factors explaining families' experiences in nearby hospitals. Medical facilities in rural Manitoba faced significant challenges to attract and retain qualified personnel.<sup>90</sup> Labour shortages meant that many of the physicians in the Interlake region were new to Canada. For example, in 2016, three of the four physicians working in Ashern had been in Canada for less than two years. These physicians and other staff who are working under shortage conditions are under high stress, and some who agree to remain on call are called in every day.<sup>91</sup> Re-

spondents felt that cultural differences and language barriers were significant, and that the high turnaround of staff at the hospital meant medical personnel never got to know their patients. The situation was similar at the local pharmacy.

As a result of limited services offered in nearby hospitals, lack of specialized care, experiences of racism, and difficulties communicating with the personnel, caregivers of children with special healthcare needs who needed to see a doctor often went directly to Winnipeg. While they also experienced racism and discrimination at institutions in Winnipeg, caregivers noted that at least specialized care was accessible and available if they travelled to the city.

In Winnipeg, children who were diagnosed with a special healthcare need either during pregnancy or shortly after birth started receiving services immediately following their diagnoses. The cost of these services was covered by Manitoba Health. This was the case of Scott, diagnosed with rare heart condition before birth and born at the Children's Hospital in Winnipeg, who underwent three open-heart surgeries during the first year of his life. It was also the case of Lukas, 4, diagnosed during a routine pregnancy ultrasound with a life-threatening birth defect. According to William,

**[Lukas] was born in the ambulance on the way to Winnipeg.... So they had him out there [in the Neonatal Intensive Care Unit] and that night they said, you know, he was not going to live through the night. "We're going to call you guys to come down here and you guys can say your good-byes and we're just going to let him go".... We were expecting him to go anytime and then three days later he was living and the doctor said "Ok, we have to perform the surgery, to help release some stress on his chest." So they did the surgery, and they didn't expect him to make it through the surgery either. But they had no choice but to do it so they said, "Well, brace yourself again for the worst, he might not make it through the surgery." So they did the surgery, he made it through and then it was slow...day by day then...they told me and my wife "Ok he's on a 100% oxygen, he's get-**

**ting all his [pain] meds, keep him comfortable”.... He was on life support, he was in his little incubator with the little tube going down his throat, two at the top ...for a month and a half (William, caregiver interview, March 2016).**

Samantha and William described life-threatening situations that could be managed because provincially-funded specialized care was available and accessible to their children. Assessment, evaluation, diagnosis, and treatment all happened while Scott and Lukas were hospitalized without their caregivers having to request them.

Once they left the hospital, medical emergencies inevitably meant a trip to Winnipeg for children with special healthcare needs. These trips could be very stressful. Parents often recounted leaving their homes in the middle of the night with three hours of driving ahead of them. This was the case of Irene, mother of Ellen, a child with a life-threatening injury that was undetected at the time of birth. Ellen had been discharged after 40 days in the Neonatal Intensive care Unit at Winnipeg’s Children’s Hospital following a very difficult delivery. She had trouble breathing but, at the time, doctors dismissed the mother’s concerns and sent both home.

**She was only home for three months, but there was one time in July...we were sleeping so it was probably like four in the morning, then all of a sudden you’d hear her trying to, having a hard time [breathing] and slowly turn purple....She slept right beside me. I could hear her trying to—her gasping.... And suddenly everything, I didn’t—just panicking, running around, trying to get... in the car, take us to the hospital (Irene, caregiver interview, March 2016).**

Irene found herself rushing to the hospital in Winnipeg with her daughter in her arms: Ellen could not hold her head up, and would stop breathing and turn purple when in the car seat. Because of the severity of Ellen’s condition, she remained in the hospital for over a year and Irene wound up temporarily relocating to Winnipeg.

Other families of children with special healthcare needs

also relocated to Winnipeg temporarily in order to access services for their children and themselves. Five of the families we interviewed made this decision at some point or another, although in all cases they either moved back to Pinaymootang or were planning to do so. For the most part, these were families with children with life-threatening conditions. The impact of commuting and relocation on children and families is discussed in greater detail in Chapter 3.

Other families whose children had special healthcare needs that were not life-threatening stayed in Pinaymootang, and had a hard time connecting with medical services provided in Winnipeg. The first obstacle for access was getting a referral. According to respondents from Pinaymootang Health Centre, children from the community born in a hospital in Winnipeg were automatically assigned a pediatrician in the city. However, a child who missed a certain number of appointments would be taken off of the patients’ list (the exact criteria for removal varied depending on the clinic or hospital). As will be discussed in Chapter 3, it was time consuming and costly to commute to Winnipeg for a medical visit, and the commute posed particular challenges for those families who had other children or additional family responsibilities. As a result, children commuting from Pinaymootang often missed doctor’s visits and, as a result, were taken off of pediatricians’ patient lists. Without an assigned pediatrician, obtaining a referral to see a specialist or have a needs assessment done became a major obstacle.

Those caregivers that stayed in the community or who had moved back to Pinaymootang travelled to Winnipeg to see specialists as frequently as once every other week. This was the case of Andrew, diagnosed with a severe neurological disorder shortly after birth and then with autism at the age of seven. Throughout his short life Andrew had been followed by neurologists, child development specialists, physiotherapists, occupational therapists, speech and language therapists, ophthalmologists, and other medical staff—all in Winnipeg. Even when the family was willing to commute frequently, Andrew had been unable to consistently access these specialists, and his family considered that he was falling through the many cracks in the system.

## 2.4 Allied health services available to children with special healthcare needs living in Pinaymootang

### 2.4.1 Allied health services available on reserve

As of early 2016, no allied health services for children under the age of five (usually referred to as early intervention) were offered on reserve. Children who required occupational therapy, speech and language therapy, physiotherapy, or any other allied health service and were not yet attending school had to access these services off reserve.

Pinaymootang School, which is band-operated, was the main on reserve provider of allied health services for children with special healthcare needs over the age of five. In early 2016, there were 295 students registered in grades 1 to 12<sup>viii</sup> and a staff of 60 (including 21 teachers, 24 educational assistants, and 3 administrators).<sup>92</sup> The school was able to provide special needs students with assessment services roughly twice a year, to support development of an Individualized Education Program, and to offer one-on-one support from educational assistants. However, school staff were not equipped to ensure these plans were followed, monitored, or adapted to children's evolving needs.

Some additional allied health services (e.g., occupational therapy, speech and language therapy) were available through the school; allied health professionals were hired on a fee-for-service basis roughly twice a year. These professionals visited Pinaymootang for two or three days at a time and were not usually able to see all the children who required service. Other services like physiotherapy or counselling were not provided at all due to a lack of funding. Neither service providers nor caregivers were satisfied with the frequency, quality, and range of allied health services available through the school.

School staff pointed to insufficient base funding as the reason for a lack of adequate services for children with special healthcare needs. This argument is backed by existing research: the funding formula for First Nations

schools throughout Canada had not been revised since 1996, and is subjected to a two per cent annual increase cap of the school's overall budget.<sup>ix</sup> As a result, First Nations' schools were not able to keep up with the increasing costs associated with the use of technology in the classroom or augmenting classroom activities to meet the functional diversity of the student population.<sup>93</sup> Funding specifically earmarked for the High-Cost Special Education Program at Pinaymootang School was based on the number of students with a special needs assessment enrolled in 2007. While funding has remained stable, school staff indicated that the number of assessments for Levels 1 (mild learning disabilities), 2 (moderate learning disabilities) and 3 (profound learning disabilities) at the school had doubled between 2007 and 2016 (increasing from 22 to 45). When asked about services available for these children with special needs at the school, a senior manager indicated that due to insufficient funding:

**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 "Ok, 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 (Pinaymootang School Manager, interview, March 2016).**

Funding that was available could sometimes be compromised by Indigenous and Northern Affairs Canada (INAC)'s administrative practices. For example, the Auditor General of Canada (2011) pointed to several inadequacies in INAC's funding mechanisms for programs and services on reserve. One issue in particular was a mismatch between when funding was needed and when it was made available. Funding disparities and funding uncertainty impacted students with special healthcare needs the most, since allied health services and structural upgrades / maintenance to make the school more accessible

<sup>viii</sup> There are 306 full-time equivalent students enrolled at the school. These include 295 children in grades 1–12 and 22 students in daycare and kindergarten.

<sup>ix</sup> This cap has been lifted recently (Fontaine, 2015).

to children with functional diversity were usually put on hold when funding was compromised.

Caregivers sorely resented the lack of adequate allied health services on reserve. The mother of a child with autism voiced the frustration of several respondents:

**At the school here the speech language pathologist comes in four times a year, which is in my opinion a disservice to them. They need somebody regularly, not four times a year. What can they accomplish in three to four times in a ten-month school period? Nothing in my opinion. And they have one, one [special education teacher]...who's trained in speech language support, that's it. .... And the other thing that burns me. Once they reach grade four, that's it. Then what happens? ....They don't get services anymore, the speech language services, they don't get that beyond that grade (Brittany, caregiver interview, March 2016).**

In order to be better positioned to address the needs of the student body, the school developed a partnership with the Manitoba First Nations Education Resource Centre (MFNERC) and hired educational assistants to work one-on-one with students with special healthcare needs. These initiatives are discussed in detail in Chapter 4.

#### **2.4.2 Allied health services available off reserve**

Occupational therapy, physical therapy, speech and language therapy, and professional counselling were offered through hospitals in Ashern and Eriksdale, although they were virtually unavailable to children living in Pinaymootang.<sup>94</sup> Children over the age of five could access allied services available in neighboring communities by enrolling in off reserve schools. Those Pinaymootang children who were registered in off reserve schools had access to a full range of allied health services, including occupational therapy, physiotherapy, speech and language therapy, and counselling at least once a month or as needed. One of these children was a 14-year-old girl with a neurological disability who had attended two provincial schools in nearby off reserve communities.

**[Kelly] is able to access program 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 "Ok". 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 three, which is the highest needs. So she was fully funded, her EA was fully funded just for her and her programming. So, you know, you don't get that on reserve. It's very obvious that you don't get that on reserve (Brittany, caregiver interview, March 2016).**

Kelly's experience accessing a wide range of services through a variety of specialists through the school, from kindergarten to grade eight, contrasts with the experience of students with special needs who stayed in Pinaymootang, discussed above. However, the decision to enroll a child in an off reserve school had drawbacks: parents mentioned racism in nearby schools, the lack of community, the absence of cultural references that were relevant for First Nations students, the daily commute, and the lack of familiarity with school personnel in off reserve communities. This was a challenge particularly for children with special healthcare needs who were easily upset by a change in routine. For that reason, some parents did not consider this option viable.

More allied health services were available to children with special healthcare needs in Winnipeg. Parents who were forced to access services in the city were faced with two possibilities: commute often or relocate to the city. Allied health services were usually accessed through the Winnipeg Rehabilitation Centre.<sup>x</sup> Service providers in Winnipeg provided children living in Pinaymootang with access to the full range of medical services and allied health services available to other children on site. As shown in previous quotes, the frequency with which children had to travel to Winnipeg varied, but in all cases commuting put

<sup>x</sup> This arrangement was formalized in the summer of 2016, when the Winnipeg Rehabilitation Centre agreed to take on all Pinaymootang Band members.

stress on already overburdened families. From a clinical perspective, seeing children in their natural environment and providing advice for caregivers in this setting is generally considered a more effective approach.<sup>95</sup> In no case were these services provided remotely (i.e., telehealth) to Pinaymootang families at the time of data collection. Families accessing allied health services in Winnipeg faced the same obstacles discussed above for access to specialized medical services (financial cost, time commitment, access to referrals, and discrimination).

Families who relocated to Winnipeg usually accessed occupational therapy, physical therapy, and speech and language therapy through the school at least once a month, sometimes as often as once a week. The following quote is from a mother who moved to Winnipeg to be able to access services for her child and returned to Fairford years later to be able to be close to their family. Her experience illustrates the comparison of services available for children with special needs in Fairford and Winnipeg:

**When we were living in the city [Annabelle] had OT, 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...she was going to school at [name of first school] and then we moved to St. Vital area where she went to [name of second school], and there they had a great physiotherapy room...**

**We ended up moving her to another school which was her 3rd 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 she in this school she received [these services] on a weekly basis.**

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

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

**I: PT [physical therapy]?**

**M: No.**

**I: Speech therapy?**

**M: 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).**

In the city, caregivers were able to access additional training provided by the province. Several parents had attended workshops on parenting children with autism. Another, Samantha, had relocated to the city to be able to attend three months of training on American Sign Language (ASL) not available in Fairford. Her son, Scott, was profoundly deaf, and Samantha was concerned there was nobody he could communicate with in Fairford. Following this experience, at the time of the interview Samantha was considering a permanent move to the city so that her child could receive the services he needed, particularly further ASL training.

**I told [my family] I would move to Winnipeg for three months...to get my [American Sign Language training], and for my son to get his ASL going and everything...so we moved to Winnipeg for those three months.... The occupational therapist and speech therapist [at the Manitoba School for the Deaf in Winnipeg] have been trying to get us to go back. They want him to go back to try and help his communication a little bit.... That's the only reason we're moving, it's because of my son, my son's needs, to help him to learn, like how to live, you now? .... Once he's starting school, at [the Manitoba School for the Deaf], there's a lot of deaf kids there, and they'll probably use ASL, and all the teachers there, they do ASL, and you know? (Samantha, caregiver interview, March 2016).**

As these experiences demonstrate, access to allied health services was determined by the location where families accessed services (in Fairford, in nearby communities, or in Winnipeg).

## 2.5 Additional care services

In contrast to medical services and allied health services, access to additional care services was determined by children and families' place of residence rather than the location in which they sought to access services (children with Indian Status living on reserve were only eligible for federal insurance, while all other children were, generally speaking, covered under the provincial insurance plan). Factors linked to administration explained disparities in additional care services. In particular, the distribution of jurisdictional responsibilities, policy design, and policy implementation (including decision-making mechanisms) were at play here. Funding gaps for additional care services also paved the way for these service disparities. For families ordinarily residing on reserve, Health Canada's Non-Insured Health Benefits (NIHB) program was the only means of accessing additional care services. In this study we consider additional care services all services accessible to First Nations children living on reserve through Health Canada's NIHB program. This includes:

- **Assistive devices:** “specialized equipment or devices that can help people with disabilities with their daily activities in communication, self-care, mobility, hearing, vision, (and) environmental control”.<sup>96</sup> Assistive devices include mobility aids such as wheelchairs or walkers, gastrostomy tubes for feeding, and hearing aids<sup>97</sup>;
- **Prescription medication:** pharmaceutical medication that requires a medical prescription and that helps improve or manage a specific medical condition;
- **Specialized medical equipment:** equipment or devices that are medically necessary to ensure a patient can eat, breathe, or perform other basic functions. This equipment often requires trained medical personnel for installation, operation, cleaning, and changing. (e.g., tracheostomy tubes).

First Nations children living on reserve are discriminated in their access to all three, because NIHB's policies differ from provincial standards. NIHB typically offered more limited coverage than provincial health insurance for all three but included medical transportation to Winnipeg

(something the provincial health insurance program did not cover<sup>98</sup>). For example, a child living on reserve with a gross motor impairment who requires a wheelchair to move around the community was eligible for only one mobility device every five years, and this device could only be manual. Once a child received a manual wheelchair they stopped being eligible for similar devices (e.g., an adapted tricycle for physical therapy). NIHB did not cover the costs of making a family vehicle or home wheelchair accessible.<sup>99</sup> In contrast, children living off reserve in Manitoba were eligible for the Children DisABILITY Services (CDS) program, funded by Manitoba's Department of Families. For a child with a gross motor impairment, CDS referred children to the Manitoba Community Wheelchair program, administered by the Society for Manitobans with Disabilities and funded by Manitoba's Department of Health. Through this program children could borrow a wheelchair (usually electric, although manual ones are also available). Those requiring more specialized mobility devices (e.g., an adapted stroller) were referred to CDS by their therapy professional. CDS offered a range of others services for Manitoban children living off reserve, including allied health services (based on referral, typically from a development pediatrician), respite care, after school care, home and vehicle modifications, and summer programming (based on a comprehensive family assessment completed by CDS staff).<sup>100</sup>

With prescription medication, beyond the more limited federal coverage, respondents found that federal policy changed quickly and often, and that changes were not consulted with, or necessarily communicated to, First Nations service providers.<sup>101</sup> As a result, physicians serving Pinaymootang patients were not always informed about of which medication would be covered under the program. Caregivers and service providers felt doctors off reserve hesitated to prescribe children with special healthcare needs from Fairford their first choice of medication, and settled instead for cheaper but potentially less effective options that they believed were more likely to be approved by NIHB. Caregivers were shock to find a child's medication changed when they went to renew their prescription at the pharmacy. When this happened, caregivers wondered if anyone was paying attention to



how the many different medications children were taking as part of their treatment might interact with each other.

Caregivers were aware they could appeal NIHB's decisions. However, the process is notoriously opaque, lengthy, and cumbersome for families.<sup>102</sup> Nurses at the health centre would advocate with doctors, communicate changes to NIHB policy, and support families throughout the appeal process, but the process was still unpredictable. One family had appealed a NIHB's decision refusing to pay for an inhaler ("puffer") for her asthmatic son, but never received notice of the resolution:

**One time they were going to give [Eric] a new puffer because his asthma was so bad.... I got the nurse to help me to send those [documents to NIHB] and with what needed to be filled out, and I sent them away and I never heard back from [Health Canada] (Eva, caregiver interview, March 2016).**

Due to the scope of this study and the size and recruiting methods used here, we were not able to systematically compare access to medical equipment on and off reserve. However, respondent interviews suggested that service disparities exist here as well. This suggestion is also reflected in the broader national discussion around services for First Nations children. During a parliamentary meeting of the Indigenous and Northern Affairs Committee on May 10, 2016, MP Charlie Angus reported accounts that included a doctor paying for a medical bed for a dying child out of his own pocket, children dying from preventable illnesses because of a lack of medical supplies, and Health Canada telling doctors to re-use catheter equipment (which can lead to infections and kidney disease).<sup>103</sup>

The last additional care service considered in this report is medical transportation. This was a service not available under provincial insurance policy, and thus residents of neighbouring communities off reserve were not eligible for it. When we asked First Nations and Inuit Health Branch (FNIHB) personnel to indicate the most important service they provide to First Nations communities, they indicated that this would be medical transporta-

tion.<sup>104</sup> This seemed to tacitly reflect an understanding of both the severe limitations of services provided on reserve and the geographic barriers involved in accessing services off reserve. Medical transportation allowed families to go to medical appointments in Winnipeg using the Centre's medical van or opt for a \$94 reimbursement to cover their gas expenses for a return trip to Winnipeg. In addition, families who had to attend scheduled appointments early in the morning or went to the city for a multi-day treatment had their accommodation and meal expenses covered by the health centre with Health Canada funds.

Still, most families we interviewed opted to travel in their own vehicle. There were several reasons for this. Respondents indicated the round trip could take up to 14 hours, as opposed to 8 (including the time for the appointment) if they made their own travel arrangements. Beside the inconvenience, caregivers hesitated to travel in the medical van with children who exhibited behavioural dysregulation or had severely compromised immune systems. Travelling by car also helped minimize the need to stay in the city overnight. Some families complained that accommodations provided by NIHB were barely appropriate: they were dirty, noisy, and too small to accommodate more than one person. If they had relatives in the city, caregivers generally preferred to stay with them.

The provision of additional care services was not dependent on place of access, but on place of residence. This meant that to be eligible for the provincial insurance plan, families had to relocate off reserve. However, as discussed in the following chapter, relocation was not a problem-free option.

## **Text box 1: The Niniijaanis Niide (My Child, My Heart) Program**

In December 2015, Pinaymootang Health Centre secured funding through Health Canada's Health Service Integration Fund Program to launch the Niniijaanis Niide (My Child, My Heart) Program (previously called Children with Complex Needs Program). With it, the health centre aimed at addressing the unmet needs of all children with special healthcare needs living in the community.



### **In its current form**

The program has evolved to serve 27 children aged 22 months to 14 years residing in Pinaymotang. These children's needs are numerous, diverse, and ongoing. Multiple and overlapping diagnoses include developmental disorders, sensory and mobility impairments, congenital organ defects, neurobehavioural conditions, life-threatening physical injuries and medical conditions, etc. These children require specialized medical care off reserve, but also on reserve care. This is where Niniijaanis Niide (My Child, My Heart) Program Child Development Workers come into play. Workers provide qualified respite care, and draw on resources and information from a wide variety of sources and fields of expertise to support caregivers and help children thrive. At the onset of the program, budget limitations meant that the caseworkers needed to rely on Internet resources to learn some of the basic occupational therapy and speech and language therapy skills their cases called for. The Child Development Workers also employed their own personal resources to fulfill their professional duties. With time, they were able to acquire additional skills by attending trainings with the Winnipeg Rehabilitation Centre for Children such as the Guiding Language Development workshop (in person) and seminars on challenging behaviour and autism (via telehealth). They also attended a two-day certification on early autism intervention through Dr. Richard Solomon's Play Project.

### **Room to grow**

The opportunities to grow and expand the program are numerous. Funding applications for an adapted vehicle, as well as for ASL training, have been submitted. The success and expansion of the program depends on the development of local capacity, both as a means to better address the unique needs of children living in the community and to overcome the difficulties in attracting and retaining qualified personnel in the Interlake Region. Pinaymootang Health Centre also envisions a partnership with Ashern Hospital to implement a larger patient navigator model for all First Nations in the area, and to work on initiating additional programs for children with special healthcare needs living on reserve who are transitioning into adulthood.

## 2.6 Factors contributing to service disparities: geography, funding, administration

Our findings indicate that service disparities existed in all service categories, although the extent of these disparities varied. Also, although there were often multiple, interacting factors which contributed to service disparities, we found that they could be grouped into three primary factors: geography, administration, and funding gaps.

1. Administration: Some service disparities resulted from federal decisions around the administration of health and social service programs. For example, the failures of communication around NIHB decisions; restrictions in service availability / eligibility (e.g., limits on mobility assistance devices in comparison with what was provided through provincial CDS); the onerous nature of the NIHB appeals process; and the uncertainty about the timing of education fund transfers, all qualify as administrative factors that contributed to service disparities for Pinaymootang children, and resulted in First Nations children having access to markedly inferior services.
2. Funding gaps: There is voluminous evidence of the underfunding of on reserve health and educational services, and these funding gaps resulted in service disparities for Pinaymootang children with special needs. For example, the Office of the Parliamentary Budget Officer recently calculated that the shortfall between provincial school funding across Canada and that of INAC-funded First Nations schools was between \$365 million and \$665 million in 2016.<sup>105</sup> In Pinaymootang School, insufficient funding for the special education program caused some services ordinarily available at schools off reserve to be rarely available (e.g., speech and language pathology) or completely unavailable (e.g., counselling).
3. Geography: Distance from a service hub affected children's ability to access certain services (e.g., specialized medical care), which were usually centralized in Winnipeg, and had an impact on the availability of ser-

vices (such as allied health services) in neighboring off reserve communities. Service disparities due to rurality had a similar impact on children living in Fairford and nearby communities such as Ashern. In this sense, disparities based on rurality did not constitute a clear form of discrimination based on children's Indian Status or on reserve residence.

These factors are directly linked to Canada's colonial history. Administration and funding disparities are both a manifestation of discrimination in Canadian policy and the origin of service disparities for First Nations children living on reserve. For example, funding disparities for First Nations schools are a result of discrimination in the allocation of public resources, while they also contribute to the service disparities experienced by First Nations children. The geographic location and the concentration of Pinaymootang members on Fairford reserve are also manifestations of the systemic racism that has dominated the relationship between First Nations and the Canadian government since colonization. This racism shaped the terms of Treaty Number 2, forced the settlement of First Nations peoples in lands that were deemed less desired by colonizers and / or were resource-poor, and allowed for the passing of policies limiting the freedom of movement of Status Indians in the past (e.g., the Pass System). All these factors have resulted in the settlement of Pinaymootang members in a rural area with reduced access to some of the services children with complex healthcare needs and their caregivers require.

Table 2.1 (pp. 39) summarizes our findings of service disparities for all three categories considered (medical services, allied health services, and additional care services), including the main factors leading to discrimination.

## 2.7 Conclusions

Based on the experience of children with special needs living in Pinaymootang and their families, we conclude that service disparities exist for all service categories (medical services, allied health services, and additional care services), although the intensity of and reasons for the disparities varied.

Service disparities were most acute in regards to allied health services. Early intervention allied health services for children aged 0–5 were not at all available in Fairford. Due to labour shortages in nearby off reserve communities that resulted in difficulties accessing these services in the Interlake Region, most children under the age of five in our sample had to commute to Winnipeg up to twice per month to access these services. Unclear policy seemed to indicate that children over the age of five were expected to have access to allied health services through the band-operated school (this was common practice, although not required in existing policy).

Service disparities also existed in the provision of additional care services (specialized equipment, assistive devices, prescription medication, and medical transportation) accessed through Health Canada’s NIHB. Federal and provincial policy differed, which meant that children with special needs living on reserve had inferior access to these services. In addition to inferior coverage, respondents were concerned that federal policies often change unexpectedly, without consultation or communication with First Nations service providers. The only recourse for First Nations children with special healthcare needs to be eligible to the wider range of services provided by provincial health insurance was to leave the reserve. Medical transportation was exceptional in this general pattern of inferior coverage for residents on reserve: it was not a service covered by provincial insurance. However, its existence seemed to point to an acknowledgement, on the part of Health Canada, of the inferior services available to residents on reserve, and of the geographic barriers they encountered to access services elsewhere.

Service disparities also existed in regard to medical services, although these disparities were not as acute as in the areas discussed above (allied health service and additional care services). Pinaymootang Health Centre offered nursing services at the time of data collection. Access to primary medical services within the Interlake Region was not easy; although exacerbated in the case of First Nations children, access obstacles were the result of regional labour shortages that affected children living off reserve too. Similarly, specialized medical services were

hard to access for First Nations children living on reserve as well as children living off reserve, since these services were centralized in Winnipeg. Here, existing service disparities were not as stark as in other kinds of services required by children with special healthcare needs, but they were compounded by experiences of racist discrimination both in nearby medical facilities and in Winnipeg.

The range of services available to respondents in Fairford, in nearby communities, and in Winnipeg is likely to increase in the near future, as a result of the federal government’s obligation to eliminate racist discrimination against First Nations children in the context of a recent Canadian Human Rights Tribunal (CHRT) case. The Niniijaanis Nide Program (featured in Textbox 1) is an example of the way services on reserve may become more available in the near future. This program is part of INAC and Health Canada’s efforts to closing the funding gap between provincial and federal services. At this stage, it is impossible to know what the effort will mean for children with special needs, their families, and their communities, although the resources allocated so far will not be enough to equalize funding.<sup>106</sup>

Despite the existence of difficulties accessing medical services for the overall child population in the Interlake Region due to personnel shortages, evidence collected as part of this study highlights the ongoing discrimination experienced by First Nations children with special healthcare needs. This discrimination is based on their belonging to a racialized group (“Status Indians”) and on reserve residence.

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**Table 2.1: Medical Services, Allied Health Services, and Additional Care Services Available on and off Reserve**

<b>Medical Services: primary and secondary healthcare services and basic emergency services</b>			
<b>Access: on reserve</b>	<b>Funded by</b>	<b>Level of access</b> (compared to children in off-reserve neighbouring communities)	<b>Main factors leading to service disparities</b>
Services accessed through Pinaymootang Health Centre	Federal gov. : Health Canada / FNIHB	Less than children residing in off reserve neighbouring communities for primary care (e.g., no physician in the community at time of interviews).	Administration Funding disparities
<b>Access: off reserve</b>	<b>Funded by</b>	<b>Level of access</b> (compared to children in off-reserve neighbouring communities)	<b>Main factors leading to service disparities</b>
Services accessed in neighbouring communities	Province: Manitoba Health	Less than children residing in off reserve neighbouring communities for primary care. <b>Additional burdens:</b> - Commute to neighbouring communities (100 to 200 km round trip) - Difficult access due to shortages in medical personnel in nearby medical facilities - Racism, communication barriers	Funding disparities Geography
Services accessed in Winnipeg	Province: Manitoba Health	Equal to children residing in off reserve neighbouring communities for specialized medical care. <b>Additional burdens:</b> - Longer commute to Winnipeg (480 km round trip) - Racism <b>Additional services provided:</b> - Medical transportation services (NIHB funded)	Geography *Access may require permanent relocation.
<b>Allied Health Services: occupational therapy, physical therapy, speech and language therapy, counselling</b>			
<b>Access: on reserve</b>	<b>Funded by</b>	<b>Level of access</b> (compared to children in off-reserve neighbouring communities)	<b>Main factors leading to service disparities</b>
Early intervention services (0-5 years): N/A	Federal gov.: Health Canada	Not available on reserve.	Funding disparities
Services accessed through Pinaymootang School (children over 5)	Federal gov.: INAC	Less than children residing in off reserve neighbouring communities (services provided through the school are less and are offered less frequently than those offered in provincially-funded school, for example occupational services were offered twice a year in 2014–15 and four times a year in 2015–16, compared to once a month at Gypsumville school).	Administration Funding gaps
<b>Access: off reserve</b>	<b>Funded by</b>	<b>Level of access</b> (compared to children in off-reserve neighbouring communities)	<b>Main factors leading to service disparities</b>
Neighbouring non- First Nations communities	Province: Manitoba Health, Manitoba Education and Training	Less than children residing in off reserve neighbouring communities. - For children under 5: due to lack of personnel, Pinaymootang children typically access services through Winnipeg-based providers. - For school-aged children: Pinaymootang children must be enrolled in a provincially-funded school to access these services.	Administration Geography
Winnipeg	Province: Manitoba Health, Manitoba Education & Training	Equal to other children of any age residing in Winnipeg. <b>Additional burdens:</b> same as for medical services accessed in Winnipeg (see above).	Geography *Access may require permanent relocation.
<b>Additional care services: specialized equipment, assistive devices, and prescription medication</b>			
<b>Access:</b>	<b>Funded by</b>	<b>Comparative level of access</b>	<b>Main factors leading to service disparities</b>
For children and families on reserve	Federal gov.: Health Canada (Non-Insured Health Benefits Program)	Less than children in neighbouring communities covered by provincial insurance and eligible for the provincial Children with DisABILITY Services	(CDS) program. Administration
For children and families on reserve	Province: Manitoba	Health Insurance, Department of Families	Equal to all other children in the province.



# Chapter 3

Impact of service and access disparities on children with special needs and their families

## 3.1 Introduction

In the previous chapter we established that there are disparities in the services available and accessible to Pinaymootang children compared to those in neighbouring communities. Service disparities had a profound impact on children and caregivers. Children in our sample suffered from a variety of medical conditions, ranging from neuro-behavioural disabilities and rare chromosomal abnormalities to severe allergies. They required regular specialized medical care not available in the community, and some had to be hospitalized frequently in Winnipeg for monitoring and treatment. In all cases, the children whose cases are discussed in this report required allied health services and additional care services on an ongoing basis.

We interviewed caregivers to learn about the consequences that service disparities had on their children and themselves. Caregivers spoke at length about this, but also about their children: they felt that although social workers, doctors, and nurses saw them as clients defined by a diagnosis, there was another story that needed to be told. During the interviews, parents laughed when describing their children. A girl with autism liked to play with the language and trick her mother into saying “Under where?” (Which sounds like underwear). Others enjoyed reading, playing outdoors, writing stories, dancing, doing their nails, or spending their free time learning math. All loved their parents dearly and were loved in return. Beyond their diagnoses, these children were just like any other: they had caring families who were struggling to provide for their needs in a very complex structural context. The children, like their parents, liked to be surrounded by their relatives and friends in the community.

In this chapter we engage with caregivers’ narratives with

two main objectives. First, we document the obstacles Pinaymootang children and their families encountered when trying to access the health services, treatments, and equipment they required. Second, we discuss the impact that service and access disparities had on children, their caregivers, their families, and their community.

## 3.2 Impact of service disparities on children

The combination of administration, funding disparities, and geography resulted in Pinaymootang’s children with special healthcare needs experiencing denials, delays, and disruptions of services ordinarily available to other children in Manitoba.

### 3.2.1. Denial

Denial of services was most clear for children’s access to allied health services, notably occupational therapy, physiotherapy, speech and language therapy, and counselling, which were virtually unavailable on reserve. Early intervention allied health services (for children 0–5) were not at all provided in Fairford, and were barely available for school-aged children due to budget shortages. However, these services were available in nearby non-First Nations communities, both in hospital settings in Ashern and Eriksdale and at provincial schools. As noted in the previous chapter, children with special healthcare needs living in Fairford were rarely taken in as patients to receive allied health services at nearby hospitals, and caregivers of children with the most severe medical conditions were reluctant to register them at schools off reserve.

Denial of allied health services ordinarily available to other children in similar circumstances living off reserve had a significant impact on Pinaymootang children with special

healthcare needs. For example, a child with a severe hearing impairment was unable to access ASL training until he was four, and only because his mother decided to relocate to Winnipeg to access this service. Until then, this child was only able to communicate with his mother in a very rudimentary way. Other children requiring counselling and speech and language services were also unable to access them on reserve, something that affected their ability to socialize normally and manage the psychological symptoms associated with their medical conditions (e.g., severe anxiety). Denial of equal additional care services (for example, an adapted tricycle) further discriminated against Pinaymootang children with special healthcare needs, and prevented them from reaching a quality of life equivalent to children with similar medical conditions living off reserve.

### 3.2.2 Delays

Pinaymootang children living on reserve also experienced delays in accessing 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 they started school.

Due to the small sample size in our study, we cannot draw any conclusions about whether children living on reserve experienced longer diagnostic delays than children off reserve. This is particularly the case for autism screening and assessment, which is a complex and time-consuming process with diagnostic delays prevalent across the province. While we are unable to answer the comparative question, the impact of delayed diagnosis and assessment services clearly resulted in delays in treatment. For example, a child living in Fairford with a clear oral communication impairment and suspected of being in the autism spectrum was 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.

In the case of children with autism, access to early intervention is essential to their development and the development of social and daily living skills. Early intervention is

cited as important to develop communication skills, lessen the frequency and intensity of autism symptoms, and improved cognitive skills.<sup>107</sup> According to Dawson and Bernier, early intervention strategies can vastly improve how someone with autism functions, turning a diagnosis that can result in “a lifelong condition with very poor prognosis to one in which significant gains and neuroplasticity is expected, especially when the condition is detected early and appropriate interventions are provided”.<sup>108</sup>

Delays in access to services translated into a de facto denial of early intervention for children with autism living in Fairford reserve. Delays or denials of access to and provision of early intervention services would be harmful for some children.

### 3.2.3 Disruptions

Disruption of services ordinarily available to other children in Manitoba was most clear when it came to Health Canada’s Non-Insured Health Benefits Program (NIHB) policy. Policy changes made by Health Canada unilaterally and without warning or consultation with service providers made 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.<sup>109</sup> Caregivers believed some of the substitute medications were less effective, particularly in the context of larger treatment plans. Changes in medications impacted patients’ lives, including introducing setbacks in symptom management. For example, a change in medication might result in the return of a severely disrupted sleep cycle.



Caregivers raised several issues with medication changes. First, changes to insurance coverage seemed to respond to policy preferences, not to the specific needs of children. Second, changes were not made by a child's medical team, but by people who were not familiar with the child's condition, history, and larger medication regime. Third, and related to this, changes to one medication were made in isolation to the rest of the overall treatment plan: When families learned of policy changes at the pharmacy counter (showing a lack of communication between the parties involved that is problematic on its own), they were not informed of how the new medication could potentially interact with other drugs their child may be taking. Fourth, some of the medications children were on created physical dependency. Some families in our sample were not informed when a drug that created dependency was about to be removed from the child's treatment plan, and they received no support to manage the child's withdrawal symptoms. Finally, caregivers were frustrated by the lack of an efficient mechanism to challenge these sudden changes of coverage.

### **3.3 The impact of constant commuting to Winnipeg to access services**

Families could sidestep service disparities related to geography by accessing services off reserve. However, this often meant frequent commuting, which is time-consuming, and comes with high financial and emotional costs. Commuting could also potentially put children with special needs at risk: children with autism suffered during the long trips, and others with compromised immune systems risked being exposed to diseases during the commute in the medical van. This was a major concern for Irene, mother of Ellen, who lives with a life-threatening spine injury. After Ellen was discharged from the Neonatal Intensive Care Unit, she had bi-weekly medical appointments in Winnipeg. The commute terrified Irene, who had to hold Ellen's head in the car or she would turn blue and stop breathing. Irene considered taking the medical van to be able to keep a closer eye on Ellen, but the baby's immune system was so weak that the health centre staff discouraged her from doing so.

**[T]hey didn't want to put her in the medical van with the others, all the other people who have to come in [to Winnipeg].... What if there's someone with a cold, that's something big. 'Cause when she gets a cold now, she's already on the highest settings on her machine, and we almost lost her a couple times, and she [just] had a cold. (Irene, caregiver interview, March 2016).**

Not all families could commute to Winnipeg as often as was needed, resulting in their children losing their place in a patient list or losing access to treatment altogether. To avoid service disparities, families of children with severe medical needs considered moving to Winnipeg. Relocation made them the responsibility of the province and eliminated service disparities due to geography, funding gaps, differences in insurance coverage, and jurisdictional ambiguities—but the trade-off was a difficult loss of social supports and connection to the community, discussed below.

### **3.4 Impact of service disparities on caregivers**

As of early 2016, there were no support services for family members caring for a child with special needs in Fairford.<sup>XI</sup> This resulted in stressed, overwhelmed, exhausted, isolated, and frustrated caregivers who were forced to give up any employment they might have to take care of their children, without training or support beyond that which their families could provide. The lack of respite care services in the community was particularly problematic, as emphasized by this respondent from a provincial First Nations organization:

**Respite is a huge issue especially when you talk to the families. You see the exhaustion. It's almost like they're scared to leave [their children] with people, like they're not socialized to be with other people. And so it creates a hard position for parents to be in, where they can never get a break (FNHSSM, interview, February 2016).**

<sup>XI</sup> This changed with the implementation of the Niniijaanis Nide (My Child, My Heart) Program in January 2016.

Some of the children in our sample had complex medical conditions that required respite workers to be able to respond to complex events, like a seizure, severe behavioural dysregulation, or cardiac arrest. Caregivers resented not just the lack of respite care, but the absence of training opportunities that would allow able and willing relatives to be trained to handle these kinds of situations. Without respite care or specialized training, children's lives were literally dependent on their primary caregiver's constant physical presence, as explained in this fragment from our interview with Julia, the mother of a child with epilepsy:

**My biggest struggle is [that] sure I get the help that I need and I've started to get some more of it. But...I can't really trust him with anyone. If I were to let him stay with someone else and if he were to have a seizure they wouldn't know what to do. And then they would freak out, and I'm at work so there's no one really there to [make sure he's ok] (Julia, caregiver interview, March 2016).**

Because of the lack of support, caregivers of children with special needs felt overwhelmed and anxious. Most respondents were sleep deprived: some could not sleep because their children had irregular sleep cycles related to their neurological disabilities and were up most of the night; others sat next to their child's crib from dusk until dawn, counting breaths to make sure their child was not dying; and many lost their sleep worrying about the care of their children once they reached adulthood.

Caregivers who devoted all of their time and energy to their children's wellbeing faced severe isolation. This isolation was particularly apparent at the beginning of the research, as we learned that many of the families in very similar situations we met were not aware of each other, even though Pinaymootang First Nation is a small community. Indeed, parents so strongly expressed their feelings of isolation at the first community meeting held to discuss the research project that the health centre instituted bi-monthly meetings for parents of children with special needs. A nurse and mother of a teenage girl with autism talked about the impact these gatherings had on her and other caregivers needing support:

**Well you know what, the parents, like the families aside from the children, they need outside support. You know the parent support meetings that are conducted bi-monthly. They need that. It gives them time to talk to other parents about their issues. Because you know what? You have to parent a child with a disability to know what it's like. You know—yeah, you can have children but you know what it's like to have one that has a disability? They are very different, it's very stressful, you have to learn to really cope you know... and to have other parents who can relate.... They need somebody that they can talk to, they need you know coping skills for stress, those kinds of things. (Brittany, caregiver interview, March 2016).**

Brittany's reflections speak to the absence of professional counselling and other forms of support for caregivers, in the community and elsewhere. Caregivers had to cope on their own, often with little help than their relatives and friends. Some parents, like Jacob, turned to traditional Ojibwe ceremonies, or to the church, for support.

**[W]hen I go to ceremonies I get a lot of, um, help from there. To help me keep focused. And when I can't go I'm very very stressed out, eh? Because I need the...I need those teachings to help me stay on track. And I pray for my son, and that's the reason I went to ceremonies is to, to help out my son (Jacob, caregiver interview, March 2016).**

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 their job to take care of their child—and this at a time when families faced increased expenses to provide for their child's needs. The situation was even more difficult for single mothers, who had to give up their jobs or stop looking even for occasional work. For example, one participant who returned to Fairford after years of studying and working in Winnipeg had started an employment and training program for youth living on reserve. This participant had to give up her job after her son was born with special needs.

From then on, any kind of employment was out of the question due to a lack of support. Other mothers faced similar situations. As a result, many families depended on income assistance, their relatives' financial support, and, at times of particular hardship, on the money collected through silent auctions in the community.

Finally, caregivers were also frustrated by the service disparities they encountered: they knew of the services that were available off reserve, both to children with special needs and to their families. They felt the federal and provincial governments treated them as second-class Canadians and some were determined to fight to end that discrimination. The experience of discrimination affected their sense of wellbeing and mental health. Two families in the community had launched legal cases to access services for their children.

### **3.5 Stay, move, transfer custody to Child and Family Services: no perfect solution**

Given the situation, families faced three possibilities, each one of them essentially flawed: they could stay in Fairford without services; relocate to Winnipeg temporarily or permanently to access services; or transfer custody of their child to Anishinaabe Child and Family Services (ACFS). Families of First Nations children with special healthcare needs living on reserve throughout the province faced a similar set of possibilities.<sup>110</sup> This impossible situation made families feel trapped, and the emotional and physical strain negatively impacted their overall health and wellbeing<sup>111</sup>.

#### **3.5.1 Pinaymootang First Nation as a supportive but service-deprived community**

The first possibility families faced was to stay in the community. Ten out of twelve families in our sample were living in Fairford at the time of the interviews. They felt safe and supported, and found that they were better able to take care of their children when surrounded by their relatives. In Fairford, they remained part of their church or spiritual community, stayed close to the land,

were able to stay in their homes, and did not have to deal with the administrative challenges associated with having their files transferred to the province to access housing, healthcare, or income assistance (if needed). Caregivers were also happy not to see their children grow up in Winnipeg. The housing that was accessible and available to Pinaymootang families in the city tended to be concentrated among the poorest and most violent in Canada, and caregivers feared that, if they moved to the city, their children would get caught in that spiral of poverty and racialized violence.<sup>112</sup>

However, on reserve caregivers faced other challenges. Pinaymootang First Nation reflected the difficult on-reserve living conditions that exist throughout the country, including poverty,<sup>113</sup> lack of adequate housing,<sup>114</sup> and access disparities beyond health, including social and education services<sup>115</sup>. The community faced an urgent housing crisis: 125 people were on the waiting list to access one of 321 community homes.<sup>xii</sup> Unemployment was high, and lack of supports for caregivers meant that families with children with special needs depended on one person to stay at home full-time to provide care for the child. Thus, children and caregivers who stayed experienced “[poor] quality of life, isolation, and deterioration of health”.<sup>116</sup> Despite all this, the reserve was home to these families: they wanted to stay. When asked if they had considered relocating to Winnipeg, families explained that, for them and their children, Pinaymootang was a better place:

**I: Have you ever considered leaving the community?**

**M: No, never. I know there are better options for children with complex needs in the city, but I like the reserve setting because it's quiet and it's homey (Martha, caregiver interview, March 2016).**

**I've been actually told [to move to Winnipeg] a couple of times already but the thing is I wanted**

<sup>xii</sup> Pinaymootang's total band membership includes 3,250 members, with 1,252 living on reserve (Pinaymootang Band Office, personal communication, March 6, 2017). This means that in order to provide all on-reserve members with housing, each of the 321 homes would need to accommodate approximately 4 people. However, in order to house the totality of all band members, each home would need to accommodate more than 10 people.

him to grow up out here in the same way I was brought up, that's what he's doing right now.... It's really nice and peaceful [in Fairford]. My grandma, she was like that and she actually got to meet [Danny] last summer at a powwow. And he loves it. He loves watching the dancers and it was amazing to see how he was. She taught him how to pray and how to do smudging, she taught him how to do that and I found that after he did that so calm and peaceful and he liked that (Julia, caregiver interview, March 2016).

This sense of community and safety—both physical and cultural—motivated caregivers to stay in Fairford. However, as the quotes above demonstrate, respondents were acutely aware of the trade-offs in terms of the lack of services for their children if they stayed on the reserve.

### 3.5.2 Relocating to Winnipeg

The second option was to move to Winnipeg.<sup>xiii</sup> Two of the families interviewed were living in Winnipeg, and a third was planning to relocate to the city within a few months. Their children had particularly complex and potentially life-threatening medical conditions which required frequent specialized care. Two of these children had to be in the proximity of a fully-equipped hospital, while the third required frequent medical care and ASL training to be able to communicate. While relocating to Winnipeg might remove obstacles to access services, it meant families were put in an unfamiliar context that lacked social supports. It also forced families to engage with complex bureaucratic procedures to have their files transferred from the band to the provincial government.<sup>117</sup> As Allec<sup>118</sup> observed,

**Moving off reserve is not necessarily a trouble free option. Challenges facing families who choose this option include access to housing, employment, education, and family support services. Interviews with provincial officials indicate that the additional cost to the Manitoba Government for social and health programs can be substantial when a family moves off reserve to access services not available on reserve. For example, when a family moves to Winnipeg to access children's special services and**

**doesn't have financial means of support, they likely will need to access the provincial Income Assistance program to cover basic food and housing costs. As a matter of policy, INAC would not reimburse the province, as the family is considered living off reserve.**

In this type of situation, families become vulnerable to jurisdictional disputes in which they can be denied supports and services by both federal and provincial governments.<sup>xiv</sup>

This was the experience of the two families living in Winnipeg at the time of the interviews, who had not had any income for some time during the transition beyond that given to them by their families and raised by the community to support them. Remarkably, both had succeeded in negotiating the bureaucratic requirements that followed their relocation to the city while spending 12-hour days at the Intensive Care Unit in the Children's Hospital. Despite this, they felt neither they nor their children belonged in the city, and they planned for their return:

**We'll we're hoping in the next year...we're already enquiring about trying to get a house, we're trying to find a house in Ashern even, so we can be closer to the kids, be close to friends and family, because I don't want my son growing up in Winnipeg because [Winnipeg] is the murder capital of Canada so you have to think—it has a lot of bad areas, bad seeds around and I don't want my kids to grow up like that (William, caregiver interview, March 2016).**

<sup>xiii</sup> For a broader discussion of the experience of medical relocation for First Nations people in Canada, see Lavoie et al. (2015).

<sup>xiv</sup> "Another interviewee offered an even more extreme example of the extraordinary efforts taken to ensure First Nations children's access to services. She explained that if a First Nations child who lives on reserve requires a serious procedure, such as an organ transplant, he may have to relocate to a city to in order to be near, or in, the hospital while he waits for an organ donor, undergoes surgery, and completes recovery. The parents of such a child must move to the city with their child for this time period—but this can mean leaving jobs in their home community. Because these families are ordinarily resident on reserve, but temporarily living off reserve, they can become subject to jurisdictional ambiguity around income support, housing and other services. They may be denied both those services regularly available to First Nations people living on reserve and those for low-income families living off reserve. The interviewee indicated that, as a result, the family may have to rely on fundraising efforts and on band resources for support." (The Jordan's Principle Working Group, 2015, p. 80)

Several of the families we met, in fact, had moved back and forth several times: to Winnipeg to access services, then back to Fairford to be close to their families. This was a difficult situation to come to terms with, as families felt that staying in Fairford without access to services and moving to a life of poverty in the city both constituted threats to their children's wellbeing. Bitterly, one mother said: "In Winnipeg we're alone...but there's nothing [in Fairford] for my son, no services, at all." (Samantha, caregiver interview, March 2016).

For families who were torn between staying in the community and relocating to Winnipeg to access services, housing shortages on Fairford reserve were a primary consideration. They knew that once they gave up their homes on reserve, they would be on a waiting list for years before being assigned a new one, which would bar their return to the community. That is why William, quoted above, was looking for a home in Ashern; without available housing in Fairford, he was looking for the closest alternative.

### **3.5.3 Transferring custody to Child and Family Services**

Finally, caregivers could request to have custody of their child transferred to a mandated Child and Family Services agency (in the case of Pinaymootang First Nation, ACFS) in the hope that the agency would place the child in a medically approved foster home where he or she would be able to access services. This situation is similar to that found elsewhere in the country. This has been documented in a number of evaluations of federal programs serving children with disabilities living on reserve.<sup>119</sup> In the case of Pinaymootang children, the regional manager of ACFS corroborated this: all medically approved homes were in the city, which meant that children had to be relocated far away from the community, and families transferring custody rarely got to see the children.

Transferring custody to ACFS (a First Nations Agency managed by Manitoba's Southern First Nations Network of Care) was not a decision that any of the families in our sample made. However, a few reported that they had been encouraged to transfer custody of their child by a social worker (usually during a major health

crisis at the hospital). This possibility was a strong undercurrent in caregivers' narratives, and one that they resisted. Families associated transferring custody of their child with past and current abuses of Indigenous children in the child and family service system. They linked child and family services (CFS) with residential schools and the centuries-long concerted effort on the part of the Canadian government to erase Indigenous culture. One respondent summarized the general feeling that getting involved with CFS carried risks that outweighed any benefits:

**CFS is a big red flag for Native people.... I met with families and parents who went through CFS, and that's a big headache and a hassle.... it's more stress than anything. I know a woman who got her kid taken away just because she couldn't be there beside her kid in the hospital, and yet she has other kids, four kids at home, and that one kid, you know, and then she couldn't be there all the time so CFS took away her kid! (William, caregiver interview, March 2016).**

In general, caregivers preferred to stay away from CFS out of fear that their children would be taken away. Racism and mistrust resulting from the residential school and child welfare system also played a role in caregivers' reluctance to access services even when they were available. For example, at one point Irene felt forced to authorize a tracheostomy<sup>xv</sup> to be done on her daughter, who was hospitalized with a life-threatening spinal injury and had a social worker from CFS following her file. Irene did not want to authorize the procedure, but feared the CFS worker would interpret her refusal to go through with it as a lack of interest and proceed to remove the child from her care. Following the procedure, the same social worker tried to convince Irene to transfer Ellen's custody to CFS, and later the same worker threatened to take her child away after learning that Irene had reached out for mental health support to deal with anxiety. Based on the collective experience of interactions between First Nations families and CFS and on her own experience dealing with this particular

<sup>xv</sup> A tracheostomy is "an opening surgically created through the neck into the trachea (windpipe) to allow direct access to the breathing tube and is commonly done in an operating room under general anesthesia" (John Hopkins Medicine, n.d.)

social worker, from then on Irene went out of her way to hide her difficulties from the agency. Other caregivers who might benefit from CFS support (for example, accessing food during times of need) also tried to pass unnoticed by hiding their difficulties. Perceptions were a bit better when it came specifically to the ACFS agency, but even so, families were reluctant to put their children under ACFS care, even if that meant children would be able to access the treatment they needed. An ACFS representative interviewed for this report confirmed that families tend to be “leery” of all child welfare agencies for fear their children will be taken away.

### 3.6 Conclusions

Access to medical services, allied health services, and additional care services for children with special healthcare needs living in Fairford and their caregivers was more limited on reserve than in nearby off reserve communities. For children, service disparities meant denial of services, notably allied health services; delays accessing medical treatment, mainly due to difficulties accessing diagnostic and assessment services; and disruption of services, in particular prescription medication, due to sudden and unexpected changes in Health Canada’s NIHB program guidelines. Even though many children in the larger Interlake region experienced access issues, children in Fairford experienced these additional access issues, resulting in more “hoops” and difficulties for their caregivers to get them the services these children required. In these ways, Pinaymootang children were discriminated against because of their Indian Status and place of residence—a situation that violates these children’s human, constitutional, and treaty rights. As the CHRT concluded in 2016, this discrimination has no place in contemporary Canada and must end.

Little attention had been paid to services for caregivers of children with special needs living on reserve. According to our data, caregivers in Fairford did not have access to training to support their children’s development (such as ASL training or behavioural interventions) and received no support for themselves (i.e., respite care, counselling services). They were overwhelmed, exhausted, isolated, and forced into situations of financial dependency; moreover, these

caregivers did not feel fully competent to respond to their children’s needs, particularly during a medical crisis (e.g., a violent seizure). Parents (and, in particular, mothers) felt that the absence of qualified personnel in the community put a burden on them to always be physically present for their children. In many cases, the only services respondents had access to were provided through the new, temporarily funded program *Ninijjaanis Nide*. These services included 2–4 hours a week of one-on-one attention by a case worker from the health centre. This respite was vital, yet insufficient. By being denied support services equal to those available off reserve, caregivers’ rights are violated as well.

Given the discrimination that First Nations children with special needs and their caregivers face on the basis of Indian Status and place of residence, families faced a difficult decision: they could stay in their community with virtually no access to services for their children or themselves; they could relocate to Winnipeg, leaving their communities and safety nets behind; or they could transfer custody of their child to a CFS agency and hope that this way they would be able to access the services they required to manage their medical condition and achieve a better quality of life. Each one of these options is fundamentally flawed, and not one of them serves the best interests of Pinaymootang children.

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# Chapter 4

Burden, uncertainty, and risk: Pinaymootang's service providers at work

## 4.1 Introduction

The focus of this chapter is on the role of local service providers and community leadership, who, together, are intermediaries between the federal government and community members (including the families of children with special healthcare needs). In this role, they act as service providers, as well as advocates, knowledge translators, and employers. Drawing from interviews conducted with staff from the school, the health centre, the band office, the regional CFS agency, and with representatives of First Nations organizations and FNIHB, we explore Pinaymootang Band's efforts to access and maximize the impact of both core and additional (grant-based) funding to meet the needs of children with special needs and their families. Respondents' defined their professional lives in terms of the families they worked for, yet, as we found, their work was profoundly shaped by federal funding agencies. As we elaborate in this chapter, three elements characterized our respondent's relationship to federal funding: burden, uncertainty, and risk.

The impact of these elements of the federal funding relationship was magnified by service providers' close ties to the community. Service providers based in Fairford were part of the social networks caregivers depended on: many were not just nurses or school staff, but also family members: parents, sisters, aunts, cousins, and life-long friends of the community members they served. Even service providers who were not based in Fairford had a deep personal connection with the community: for example, both the health centre's Head Nurse and the school Principal (who both lived off reserve) had spent several decades working in Fairford. As a result, service providers felt a responsibility towards their client population that went beyond a strict interpretation of their job description.<sup>120</sup> <sup>1</sup> As

one service provider put it, "when I see these families in the community, I want to walk to them and give them a hug." At the same time, service providers and community leaders became the face of the federal government vis-à-vis other band members—a position that came with a high price. A representative from a provincial First Nations organization reflected on the position that people who are both community members and professionals find themselves in (here referring specifically to Councils in Manitoba):

**how demoralizing it must be for Chief and Council to have to make those decisions when it's people you work and deal with on a day to day [basis]. There's things that prevent me from not sleeping well at night from just little interactions, but to actually be responsible for life and death of people, you have to pick and choose.... and for them to [have to] play those games, to write two proposals [to maybe be able to address existing needs].... it's a lot of work when your day to day is always crisis management at the community level (FNHSSM, interview, March 2016).**

The situation she described can be applied to other service providers in First Nations communities, as will be discussed in this chapter.

## 4.2 Mediating without a voice

A 2.5 X 1.5 m chart produced by FNIHB (reproduced in Appendix E) hangs on the wall of the Pinaymootang Health Centre and encapsulates the challenges faced by service providers in the community. Printed in bright colors, the chart (reproduced in Appendix E) summarizes the services funded by the federal government (Health Canada and INAC) that could be accessible to children living in First Nations communities in Manitoba. These services in-

clude preventative programs such as the Aboriginal Diabetes Initiative, the immunizations program, NIHB-funded additional care services, and the high-needs program for special needs students funded by INAC and administered at band-operated schools, among others. The chart gives the impression that on reserve First Nations people have access to an impressive range of services. But, as the small print at the bottom of the chart notes, “not all programs and services may be available in each community.” Service providers and advocates we spoke with were certain there is no community in the province where all the services depicted in the chart were available, and noted that some (e.g., mental health services funded by Health Canada) were not available at all in the province. In Fairford, federal funding only allows for the full implementation of one out of the ten programs funded by Health Canada that is presented on the chart.

In a context defined by deep and chronic funding shortages, jurisdictional ambiguities, and the lack of clearly defined provincial standards<sup>121</sup> the broad range of services depicted on the FNIHB chart served to construct an assumption of First Nations’ responsibility for service disparities. Local service providers felt that anyone walking into the health centre was led to believe that those services should be available to them, and if they were not, it was due to incompetence on the staff’s behalf. A manager at the centre expressed her frustration about this: “If somebody from outside [the community] came in, it would look like all these services are offered. The sad reality is that all these services are not offered. [The poster] is deceiving.”

Service providers concerns that they would be blamed for service gaps seem to be given credence by statements made by federal officials in other venues. For example, when asked by our research team about the limited services available in Fairford, an FNIHB official noted that the FNIHB is simply a funder, and has no say over the allocation of funds to specific programs.<sup>122</sup> Insinuated in her comments was that regardless of well-documented shortfalls in federal funding,<sup>123</sup> responsibility for the range and quality of on reserve services lies with First Nations. This argument featured explicitly and prominently in a CHRT case on First Nations child welfare that has spanned almost a de-

cade (FNCFCSC vs Canada, 2007–2016).<sup>124</sup> The complainants—the First Nations Child and Family Caring Society of Canada and the Assembly of First Nations—alleged that on reserve child welfare services were “flawed, inequitable, and discriminatory”<sup>125</sup> according to Section 5 of the Canadian Human Rights Act and the CHRT upheld this allegation in 2016. In the intervening years, the federal government sought to have the case dismissed on the grounds that Aboriginal Affairs and Northern Development Canada (AANDC) (renamed INAC in 2015) only provided the funding, not the service, and was therefore not responsible for any inequities that might exist. The complainants were able to demonstrate that the control that the federal government exerts over child welfare services proves its role goes well beyond that of a mere funder, and that AANDC “(...) controls the provision of those services through its funding mechanisms to the point where it negatively impacts children and families on reserve”.<sup>126</sup>

In the case of Pinaymootang, the displacement of responsibility for service disparities caused by federal funding shortages was sometimes accompanied by pressure to reallocate resources against policy guidelines. For example, reflecting on discussions with the federal government, one respondent said:

**It was like everybody was putting the blame on the First Nation where they would say, “Well, the First Nation that gets funding to provide the service and it’s up to them to decide how they want to... handle their funding dollars”. They were making it sound like we were not doing our jobs. So my argument came to be, “Hey, you’re telling us to provide respite care for long-term services through our Home and Community Care program, when in fact [you] told us Home and Community Care is only for short-term care, and these children are long-term care. How can you sit there to tell us, okay use your program for long-term care? Your policy states short-term care!” (Health Centre, interview, November 2016).**

In this situation, the federal expectation that First Nations would repair the disconnect between limited federal funding and the needs of the community was so entrenched,



that it even superseded expectations that First Nations comply with program guidelines. First Nations service providers could be asked to allocate funds in violation of policy guidelines even if, as will be discussed below, this put service providing organizations, and the entire community, at risk of losing part or all of their funding.

Service providers' role in mediating between limited federal funding and community needs was further complicated by the lack of effective communication channels and a pervasive mistrust that characterizes federal–First Nations relation. That mistrust finds its way into everyday administration and management, as one respondent described when she reflected on the obstacles she faced when trying to produce a comparable data set of funding sources at federal and provincial levels in Manitoba:

**I sent out a template for [the province] to fill out to put the side-by-side comparison. They never responded, they never did anything... After so many attempts to engage the province to just demonstrate comparability...nothing. It felt like it's them against me, and I didn't understand that. I just assumed "Oh, great, we can work together and I can inform you based on what I know. (FNHSSM, interview, March 2016).**

Whenever an urgent need that the community could not address because of strict policy guidelines, lack of effective communication channels became a source of frustration for service providers. Calls and emails went unanswered, sometimes for months; and when service providers received a response, sometimes it was not to address their concern, but to ask them to provide socio-demographic information about the community or submit a separate grant proposal. In respondents' experience, communication with the federal government was unilateral. When asked if it was easy to communicate with INAC regarding a specific program in Pinaymootang, the person in charge of administering the program replied: "No. You're talking to a machine, leaving a message and waiting for them to call back. If the case is urgent you can expect to hear back in 24 hours."

Representatives of provincial First Nations organizations such as Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba (FNHSSM) echoed frustrations with the pace and nature of communications with the federal government. Moreover, they indicated that even when they were allowed to participate in policy development/revision activities, they felt their presence was not always welcome. They felt they were there only so the government could claim they have consulted the Indigenous community. Most "collaborations" felt superficial and respondents had the impression their voices were often ignored.

In this context, service providers were mediators without a voice. The expectation was that they would negotiate any challenges or tensions tied to the gap between community needs and federal funding / resources, and that they would do so without the direct engagement or support of federal officials. For Fairford service providers, this expectation resulted in additional burden, uncertainty and risk, all of which complicated their efforts to provide for the needs of Pinaymootang children.

### **4.3 Burden**

Service providers experienced burdens that stemmed from the juggling of multiple responsibilities within the community. These responsibilities went beyond administering programs. For example, the school, health centre, and band office were the primary employers in the community, meaning that, in addition to providing for the health, education, and social welfare of the community, it fell on them to ensure the livelihoods for many families in the community. The school, the health centre, and the band office played a key role mediating between community members and funding agencies. On the one hand, this mediation involved communicating and educating agencies; on the other, it involved applying for temporary funding through an onerous, obscure, and time-consuming grant-application process to compensate for the lack of core funding. Finally, as members and residents of Pinaymootang First Nation, employees of service providing agencies carried the emotional burden of addressing the needs of other community members who were often their relatives.

The burden and contradictions inherent to being at once a service provider and a major employer in the community was particularly evident in Pinaymootang School which, in March 2016, hired 24 band members as educational assistants. They worked one-on-one with high-needs children, some of whom were diaper-dependent, unable to communicate effectively, or exhibited severe behavioural dysregulation. The school had difficulty hiring and retaining qualified personnel because of widespread regional labour shortages and budget constraints. To adapt to this context, the school hired educational assistants from within the community (sometimes these were children's parents). This helped the school deal with labour shortages, gave the children the undivided attention of an educational assistant, and alleviated the financial burdens put on families of children with special healthcare needs, many of whom were forced to give up paid employment to care for their children. But the practice of hiring parents as educational assistants also created an additional burden for caregivers to provide care during the day, potentially increasing their need for respite care (which was minimally available in the community, if at all). The policy also created the expectation from parents of children with special healthcare needs that they would be hired and led to tensions between the school and children's families.

Service providers also had an added role as mediators, negotiators, advocates, educators, and knowledge translators with provincial agencies that might or might not be aware of the particularities of service provision on reserve. For example, it was common for service providers working in provincial facilities (including physicians, nurses, and bureaucrats) to be unfamiliar with Jordan's Principle; it thus fell upon Fairford's workers to explain differences in funding for services on reserve and the imperative to ensure equal access to services. It fell on service providers in Fairford to keep up to date with Health Canada's NIHB program, as well as inform medical professionals of the changes and organize follow-up with the children. This included mediating with physicians, assisting families who wished to appeal NIHB's decisions not to cover certain medications, and making sure that the pharmacy filled the prescriptions appropriately and in a timely fashion. Recently, their roles even extended to ensuring that a local

pharmacy filled prescriptions in an appropriate and timely fashion. This had become a problem following the sale of Ashern's pharmacy to a multinational conglomerate. After a number of mistakes and failures to provide Fairford patients with the prescribed medication, the health centre threatened to take their business elsewhere. This was immediately met with an apology and an offer to compensate the community with an at-school breakfast program sponsored by the pharmacy.

First Nations service providers in general, and providers based in Fairford in particular, also experience burden related to a labour-intensive grant-based federal model for accessing additional funding to compensate for the lack of appropriate base funding. Depending on the grant requirements, a proposal might take anywhere between 20 and 60 hours to put together. In a community where the resources were stretched thin and where qualified personnel was already overburdened, submitting a grant added significant burden, and payoff on this investment was never certain. This is especially true given the lack of transparency in the selection process. An example of this is the history of the Niijaanis Niide program, discussed in Box 4.1 below. In 2014 and 2015, staff at Pinaymootang Health Centre repeatedly sought funding opportunities to compensate for the lack of permanent funding to launch this program, which was deemed as sorely needed in the community. The proposal directly addressed the most urgent needs of children with special healthcare needs living in Fairford and their caregivers. In addition to this program, the Centre submitted two related applications: one to implement a patient navigator system for First Nations patients at Ashern Lakeshore Hospital, and another one to provide services to young adults with disabilities (the children that were growing out of the Niijaanis Niide program). These other applications were not successful. The experience of the health centre surrounding these efforts attests to the persistent strain created by competing for grant money in a service-based setting already strained by staff shortages. In total, the five grants submitted to fund different programs required 4–6 weeks of full-time labour to complete, of which only one was ultimately successful. This experience supported the generalized feeling among service providers that funds were a moving target and the proposal process

was at odds with respondents' immediate duties toward the community.<sup>xvi</sup>

Additional burdens were placed on service providers in this system. For example, respondents often felt emotionally responsible to provide the services that community members required through the only channels that were left to them in the context of insufficient core funding and unreliable additional funding: the creation of informal networks to access additional resources. Respondents described a context where accessing services or not depended on informal relationships and on the willingness of individuals within other organizations to support specific agendas. Combined, all these burdens resulted in widespread reports of stress and burnout among local service providers.

#### 4.4 Uncertainty

Service providers providing essential services dealt with two main sources of financial uncertainty that are comparatively uncommon for similar organizations working outside of First Nations communities: dependency on grant-based funding to address the community's needs and uncertainty around timing of fund transfer. Reliance on grant-based funding to provide essential as well as supportive services in the community is problematic for a number of reasons. Most clearly, not knowing if, how much, and for how long funds would be available made it impossible to plan even short-term service strategies. In the cases of the funding proposals discussed above, success was uncertain, but uncertainty accrued even when proposals were successful. For example, funding for the Ninijjaanis Nide program was approved, but initially, only for one year, with the possibility of extension to two years after submission of evidence of program effectiveness. Even as the Director of the health centre was being asked to spend an increasing amount of time and energy presenting the nuts and bolts of the program to audiences of providers across Canada (and preparing a three-day conference to train on-reserve service providers across Manitoba to implement similar programs in their own communities), renewal of the program was uncertain. The uncertainty around funding increased the challenge of attracting and retaining qualified personnel, in a context of wider regional and off reserve staff shortages in both health<sup>127</sup> and education<sup>128</sup>, and

First Nations' smaller budgets for staffing purposes. As one 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?"

This problem was compounded by uncertainty over the timing of fund transfer. Once funding was announced, months could go by before the band received funds. In some cases, the band was expected to document use of the funds and program effectiveness within an unreasonable short period of time. For example, funding for the Ninijjaanis Nide Program for children with special needs was announced in the Summer of 2015. Cash was not transferred to Pinaymootang's local government until December, with the program starting in January 2016. The federal government required Pinaymootang Health Centre to submit an accounting report and evaluation of the program by March 31, 2016—three months later.

The example of Pinaymootang First Nation is not unique in this respect; delayed timing for provision of program funds, as well as burdensome (and in some cases, pointless) reporting requirements are widespread throughout First Nations' interactions with INAC across Canada.<sup>129</sup> Over the long term, funding gaps and uncertainty of funding (with the resulting postponement of services that are deemed less essential) has led to the deterioration of band-operated schools throughout Canada. By 2011, 47% of First Nations needed a new school, and 74% of First Nations' schools were in need of major repairs.<sup>130</sup> At the time of data collection, Pinaymootang School was in need of major maintenance work, including work to make the school accessible for children with gross motor impairments.

Uncertainty regarding funding for services steeped into respondents' sense of professional identity and relations with other community members. Service providers had the responsibility of communicating the uncertainty of funding or programs to families: they had to encourage caregivers to identify their needs, while simultaneously warning them

<sup>xvi</sup> Eventually, Pinaymootang School was one of 12 Band-Operated schools whose funding was increased thanks to this initiative.

## **Text box 2: The Niniijaanis Niide (My Child, My Heart) Program**

### **Context and background**

In 2010, a family from Pinaymootang filed a complaint with the Canadian Human Rights Commission. The family argued that the services required to address their child's complex healthcare needs were not available in their community. The case led Health Canada to contact the Pinaymootang Health Centre in order to determine the costs of the child's needs that were not covered under the existing funding model. Pinaymootang Health Centre responded with a proposal for funding that encompassed the needs of 11 families of children with special healthcare needs, 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 health care services and supports."

### **Burden**

Throughout 2014 and 2015, the health centre was directed by Health Canada officials to submit proposals for the same program to three separate funding opportunities. The health centre submitted three applications to fund the program: two (unsuccessful) applications to Health Canada's First Nations and Inuit Health Branch's Home and Community Care Program and First Nations Chronic Disease Prevention & Management Framework, and one (successful) to Health Canada's Health Service Integration Fund (HSIF). The preparation of these proposals was in addition to the staff's regular responsibilities and amounted to an estimated 20 to 60 hours per proposal.

The services provided through the Niniijaanis Niide (My Child, My Heart) program combine assessment, care, and treatment practices from several different disciplines, each normally the responsibility of a specialist. This places enormous pressure on the program's child development workers, case manager, and health centre director, who are responsible for meeting the needs of the children and their families while following best practices and ensuring a safe and appropriate delivery of services.

### **Uncertainty**

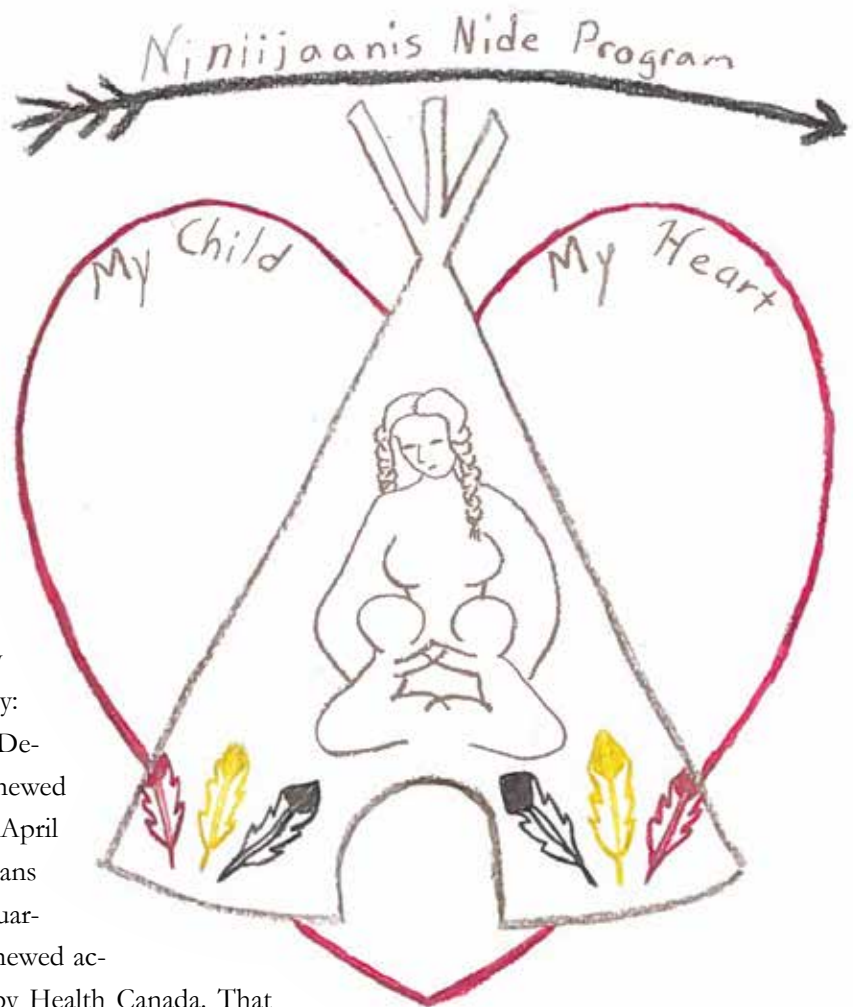
The health centre received no news for several months after submitting a grant application and did not have a direct line of communication to Health Canada staff. Different representatives from Health Canada made sporadic contact with the health centre and it was unclear if each representative was aware of the other com-

munications taking place between the Ministry and local service providers. Faulty communication and the lack of transparency involved in the selection and fund renewal processes prevented the health centre from devising and implementing a short-term strategy to address the needs of community members, which impacted the hiring and retention of qualified child development workers for the program, and made the sustainability of the program uncertain beyond the end of the fiscal year.

### **Risk**

Funding for the Niniijaanis Nide (My Child, My Heart) program is temporary: it was initially granted for four months (December 2015 to April 2016) and later renewed for two additional years (April 2016 to April 2017, and then until April 2018). This means that the program's sustainability is not guaranteed and depends on funding being renewed according to a decision made unilaterally by Health Canada. That

means services for children with complex healthcare needs and their families in the community could be discontinued if budget priorities change. This creates a risk both to the service providers and to the families involved in the project. Gaining the trust of families in need only to become the bearers of bad news if funding is not renewed has the potential to damage ongoing relationships between service providers and community members. Child development workers hired for the program risk being left without a job once and if funding for the program is discontinued after March 2018. For families, establishing new routines and getting vulnerable children used to a certain standard and availability of care only to see it taken away risks the emotional wellbeing and development of children and their families.



that the ability to meet their needs could be temporary due to funding. Similarly, workers had to put energy and time into developing programming, creatively meeting families' needs with limited resources, and extending available funding as far as possible, while also knowing that they might soon be out of their job. Uncertainty not only made it hard to manage service providing organizations and address the needs of children with special needs and their families, it also made it difficult to build relationships of trust with community members. Moreover, service providers worried about the clients potentially internalizing the message, delivered through the cessation of needed services, that "they don't matter, their children don't matter."

## 4.5 Risk

Service providers in Fairford faced risks that were primarily related to losing the trust of community members, potentially harming clients if support services were discontinued, and meeting the accountability requirements defined by the federal government, in particular in the context of the First Nations Transparency Act, which imposed strict reporting requirements on First Nations governments.

Some of the risks that service providers struggled with flowed from the uncertainty around program funding and continuity. There was the personal risk assumed by taking on positions that were only temporarily funded. There was also the risk of betraying the trust of community members. Service providers felt they would bear the brunt of blame in their community should they have to discontinue highly demanded services that had just been made accessible to children and families, for example respite care. They felt that their efforts to provide services might actually harm clients if these services were suddenly taken away, once they had learned to rely and benefit from them. They wondered, for example, what would happen to a child who had begun to receive speech and language therapy if funding for the "My Child, My Heart" program was discontinued, and if this child would retreat back into severe anxiety and isolation from their peers now with the knowledge that a fair chance was being denied to them. A respondent believed that, if that were to happen, "children and families would be worse off than if we'd never done anything at all."

A more tangible risk had to do with service providers' acrimonious relationship with the federal government. Respondents resented the fact that federal funding agencies were entitled to withhold or demand information or even withhold funds without any real obligation to consider the constraints or responsibilities that service providers face. These concerns were set against a larger context of First Nations' reporting responsibilities, particularly in the First Nations Financial Transparency Act, passed in 2013 "to enhance the financial accountability and transparency of First Nations".<sup>131</sup> The Act was developed without consultation from First Nations leadership, was from the beginning defined as flawed and heavy-handed and, in protest, several First Nations refused to comply.<sup>132</sup> Of particular concern was the possibility that the federal government would withhold part or all funds transferred to the band, and that funding agreements could be terminated if a band failed to comply, constituting an abuse of power by the federal government.<sup>133</sup> Moreover, the Financial Transparency Act dramatically increased overhead costs for Band governments.

Thus, First Nations are held to a level of scrutiny, and face potential consequences for failing to use funds in strict conformity with guidelines, that is unknown to other governments and service providers. They operate against a backdrop in which the federal government commonly uses charges of fiscal mismanagement and the threat of cutting funds as a tool for managing relations with First Nations governments. Accounting and reporting requirements limited local service providers and decision makers from real-locating funds, taking a holistic approach to addressing the community's needs. Crossing the many lines established in policy guidelines could result in them being subjected to an audit, and potentially having the Band's funds withheld or withdrawn completely. The irony here is that, while the federal government insists that it funds, but does not provide services, there is very little discretion left to First Nations to decide how those (scarce) funds need to be spent.

## 4.6 Conclusions

Pinaymootang First Nation's local service providers were,

at once, community members and mediators between band members and the federal (and to some extent provincial) governments. Like service providers in First Nations communities across Canada, they filled the role of leaders and mediators even as they themselves were not consulted about the community needs or asked about how to best address those needs.<sup>134</sup> Even when invited to inter-governmental negotiation tables, they felt their presence was symbolic rather than substantive, and not truly welcomed. Respondents at the community level felt powerless to influence decisions impacting Pinaymootang members, and subjected to an ever-changing set of rules and requirements in an environment marked by a remarkable lack of transparency.

In this context, service providers based in Fairford described their relationship with the federal government as one defined by an unfair burden, constant uncertainty, and risk. Burden stemmed from the multiple roles service providers filled in the community, notably as service providers and as the main employers of Pinaymootang families. Service providers shouldered a heavy administrative burden, including the need to apply for funds through grant-based models which entailed increased workloads associated with applications and reporting requirements.

Funding uncertainty made it impossible for service providers to plan ahead, including making it difficult to attract or retain qualified personnel. In the case of the school, the chronic lack of funding meant that services for high-needs students were often put on hold, notably for allied health services and accessibility equipment. This uncertainty also negatively impacted relationships between community members and service providers, the latter who were tasked to deliver the message when a service or program was discontinued.

Providing services in Fairford was therefore a risky task. On the one hand, service providers had to work hard to access families and gain their trust, but that trust could shatter if funding stopped and services were discontinued. Respondents were also concerned that (by providing a basic service such as respite care) they were creating a need, and families would be worse off once the service was dis-

continued than at the beginning of the program.

The local service providers we spoke with cared deeply about the wellbeing of their community and were dedicated to their work despite the difficult conditions associated with burden, uncertainty and risk. They have struggled, and continue to struggle, to make sure band members have access to the services they are entitled to by law. Respondents sought to address the needs of community members sometimes at great personal cost. We witnessed high levels of stress and exhaustion among respondents working in service provision, which, in the literature, are linked to a deterioration of physical and / or mental health.<sup>135</sup>

In this report, we documented the experiences of children with special healthcare needs living in Pinaymootang in 2016, along with the experiences of their families and their service providers. We focused on the experiences of children with special healthcare needs (children who require ongoing, complex interventions from different service agencies and professionals<sup>136</sup>) not because they were the only community members underserved, but because their needs were deemed urgent by their community and they were a discrete group of under-served community members. These children have well-defined needs that span a variety of services. They face multiple discriminations. And their lack of access to services compromises their ability to thrive or even just to survive. Understanding and addressing their needs is one step towards meeting the human, constitutional and treaty rights of all other First Nations children. The children's needs also highlight the needs of First Nations adults: for the families and service providers in our study, the lack of services available to support children with special needs through the transition to adulthood and beyond was a pressing concern.

We examined the experiences of children with special healthcare needs with respect to medical services (primary and specialized), allied health services (e.g., occupational therapy, physiotherapy), and additional care services (assistive devices, prescription medication, medical equipment, and medical relocation). We found children living in Pinaymootang encountered disparities in all three service categories, and, as a result, they experienced denials, delays,

and disruptions of services ordinarily available to children in similar circumstances in nearby off reserve communities. These disparities were less pronounced in regards to primary and specialized medical services, reflecting, on the one hand, a general scarcity of qualified medical workforce in the Interlake region (which, even so, was more acute for First Nations children); and, on the other hand, the centralization of specialized medical care in Winnipeg. Service disparities were most acute with allied health services, especially with early intervention services (0–5 years) being unavailable on reserve. Allied health services for children over the age of five were provided through the school, although the range and frequency of these services were markedly inferior to those provided by provincially-funded schools in nearby off reserve communities. While geography was the main factor explaining disparities in medical services, the discrimination that Pinaymootang First Nation children with special healthcare needs encountered when trying to access allied health services were distinctly a consequence of funding disparities between services provided by the federal and provincial government.

Service disparities also extended to the caregivers of children with special healthcare needs. In stark contrast with the services provided for caregivers of children with special healthcare needs elsewhere in the province, those living in Pinaymootang received no respite care, were not eligible for Manitoba's Primary Caregiver tax credit, and had extremely limited access to training and counselling services. Indeed, at the beginning of this project caregivers received no support whatsoever to help them care for their children. That changed with the launch of the Ninijjaanis Nide program in early 2016. This program was designed and implemented by Pinaymootang Health Centre with temporary federal funding to address the needs of children with special healthcare needs living on reserve and their families.

The lack of services in Pinaymootang meant that the families of children with special needs were faced with an impossible decision: forego receiving the services their

children needed and stay in the community; leave the community to receive services, which meant losing their community-based support systems; or transfer custody of their child to a mandated agency, in the hopes that this way they would be able to access the services they needed. As we showed, none of these options were desirable. Families faced these undesirable choices despite the best efforts of primary service providers in the community. It is important to note that Pinaymootang First Nation's leadership has been proactive in pursuing diverse means of maximizing the services they can provide to community members and have been recognized for their outstanding work.

Our findings indicate that the service disparities experienced by Pinaymootang children with special healthcare needs and their caregivers can be attributed to three primary factors. The first factor is administration, mainly the uneven distribution of responsibilities between the federal and the provincial government, including jurisdictional ambiguities, and overly bureaucratic guidelines and / or procedures for accessing services. The second factor is funding gaps, or the difference in resources allocated by the provincial and federal governments to provide services for children with special healthcare needs on and off reserve. Finally geography (or distance from a service hub) played a role in access disparities. Although the limitations of our data prevent us from drawing definite conclusions about the comparative impact of each one of these factors, our results indicate the need to consider each factor seriously.

These main factors made it difficult, if not impossible, to provide the services children with special healthcare needs and their families needed on reserve. Our findings indicate that the offloading of responsibilities from the federal government onto community service providers resulted in an unfair burden, increased risk, and high levels of uncertainty. Community managers were unable to hire, retain, and train personnel with funding that could be discontinued on short notice and, in any case, did not enable them to offer competitive salaries compared to provincial employers.



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# Chapter 5

Reflections and Call for Action

## 5.1 A legacy of discrimination

The discrimination Pinaymootang children with special healthcare needs experience is not unique: children face the same barriers to services in other First Nations' communities across the country. The anchoring framework for this discrimination is a body of legal documents governing the relationship between the Canadian government and First Nations. These documents (which include, but are not limited to, the Constitution Act of 1867 and the Indian Act) establish that medical, social, and educational services for First Nations children living on reserve are the purview of the federal government, even when programs are administered by First Nations governments. For the vast majority of non-First Nations Canadians, these services are provided and administered by provincial and territorial governments.

Over time, this dual system for the provision of public services has resulted in dramatic service disparities that affect First Nations children with special healthcare needs living on reserve in particularly harmful ways. These disparities are the result of a system of institutionalized racism against Indigenous peoples in Canada that is embodied in the uneven distribution of funding on and off reserve and the administration of policies and programs (which includes, but is not limited to, jurisdictional ambiguities and disputes, problems with fund transfers, reliance on grant-based funding, etc.). Rural communities like Fairford face barriers to services due to their distance from urban centres.

## 5.2 Now is the time to end discrimination

We started working on this report in late 2015, just a few months before the Canadian Human Rights Tribunal ruled that the current system for the provision of services on reserve violates First Nations children's rights under the Canadian Human Rights Act, and thus is an act of racial discrimination. As one of several immediate remedies, the CHRT ordered the federal government to fully implement Jordan's Principle, a child-first principle intended to ensure that First Nations children do not experience denials, delays or disruptions of services ordinarily available to other children (*Caring Society vs Canada*, 2016).<sup>137</sup>

In Manitoba, the Assembly of Manitoba Chiefs and Nanaandawewigamig: First Nations Health and Social Secretariat of Manitoba have repeatedly called for the full and meaningful implementation of Jordan's Principle.<sup>138</sup> At the national scale, the Truth and Reconciliation Commission of Canada issued a series of recommendations to improve relations between Indigenous and non-Indigenous peoples in Canada; full and meaningful implementation of Jordan's Principle is recommendation #3.<sup>139</sup>

There is mounting pressure for Jordan's Principle to be fully implemented, but also evidence that the federal government continues to skirt its responsibility towards First Nations children. Notably, while the CHRT unequivocally ruled that Jordan's Principle applies to all First Nations children, the federal government has repeatedly attempted to interpret the principle as being applicable only to Status First Nations children living on reserve and who have either a long-term disability or a short-term critical condition. While the federal government recently shows

signs of moving towards broader interpretation, as of March 2017 it has not complied with the CHRT's decision. The complainants in the CHRT case (the First Nations Child and Family Caring Society of Canada and the Assembly of First Nations) have filed two motions of non-compliance since the initial ruling in January 2016.<sup>140</sup> At issue is the question of whether or not the federal government has complied with the terms of the CHRT rulings and, in particular, if they have taken the necessary steps to immediately and fully implement Jordan's Principle throughout Canada.

At the same time, INAC and Health Canada have both recently pledged millions of dollars to remedy existing inequalities. In October 2016, Health Canada announced the allocation of up to \$382 million over three years for service coordination for children with disabilities,<sup>141</sup> and, although this allocation falls far short of realizing Jordan's Principle, it does represent an important step towards better meeting the needs of children with special healthcare needs. Throughout 2016, service providers in Pinaymootang have seen their operating funds increased significantly, allowing them to put in place strategies to better address the needs of children with special healthcare needs and their families. Pinaymootang School is part of the first group of band-operated schools to become part of Canada's first Indigenous School Board, and as a result its funding has been doubled, making it almost equal to funding for provincial schools in Manitoba. Pinaymootang Health Centre has also received increased funding to keep implementing the Niniijaanis Nide program over the next two years. This program is specifically designed to serve children with special healthcare needs.

Although the allocation of these additional funds is a step in the right direction, they do not address the administrative roots of the discrimination against First Nations children in the Canadian system for service provision. It is telling, for example, that as of February 2017 the federal government has only spent 11 out of the 127.3 million dollars it allocated to implement Jordan's Principle throughout Canada in the current fiscal year—arguably because they could not find enough Jordan's Principle cases to spend that money on, even though these cases

are known to people who work in First Nations communities.<sup>142</sup> New funds are grant-based, temporary, and allocated unilaterally by the federal government. Thus, the allocation of new funds reproduces the administrative problems that contribute the service disparities experienced by First Nations children living in Pinaymootang. The service disparities are a form of institutionalized racial discrimination that violates these children's human, constitutional, and treaty rights. This report gave evidence of how that mentality informs and derails current efforts by community members, parents and service providers.

### 5.3 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 FN-HSSM<sup>143</sup> 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 program 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 on 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.

## References

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139. Truth and Reconciliation Commission of Canada, 2015
140. Canadian Human Rights Tribunal, 2016c, 2016d
141. Indian and Northern Affairs Canada, 2016
142. Tasker, 2017a, 2017b
143. Assembly of Manitoba Chiefs & First Nations Health and Social Secretariat of Manitoba, 2016



# Appendices

## APPENDIX A: METHODOLOGICAL APPENDIX

### Purpose of the study

Two main research questions were developed from the initial proposal:

1. What are the obstacles that Indigenous children living in First Nation communities face in accessing services, equipment, and treatment ordinarily available to non-Indigenous children?
2. What are the experiences of on reserve First Nations families attempting to access equitable services for their children?

### Approach

This report began as a community-based research project initiated by Pinaymootang service providers. It is the result of the collaboration between Pinaymootang First Nation, a team of McGill-based researchers, and other regional and provincial stakeholders represented in the project's Advisory Committee. This collaboration began in the summer of 2015. The Jordan's Principle Working Group (which includes representatives from the Assembly of First Nations, the Canadian Paediatric Society, UNICEF Canada, the Canadian Association of Paediatric Health Centres, and a research team whose members were primarily based at McGill University) released a report earlier that year summarizing governmental responses and policy contexts for Jordan's Principle in Canada (Jordan's Principle Working Group, 2015). Pinaymootang leadership had already identified the need to document the struggles that families of children with special healthcare needs and the community as a whole were experiencing to access medical services, allied health services, and additional care services ordinarily available to other Canadian children.

### Governance framework

The terms of reference for this research project are summarized in a Research Agreement signed in January 2016 by Chief Barry Anderson, Gwen Traverse (Executive Health Director, Pinaymootang First Nation), Vandna Sinha and Luna Vives (members of the McGill-based research team). A summary of this research agreement can be found in Appendix F.

Key to this agreement was the establishment of an Advisory Committee. This governing body has been instrumental in defining the goals and procedures of the research project, facilitating access to information and participants, assisting in the interpretation of data, and providing feedback on earlier drafts of the report. The Advisory Committee has also been responsible for making decisions about how findings should be published. Decisions have been made by consensus during Advisory Committee meetings, conducted both in person and remotely via teleconference.

# Data and Sampling

In this report we have combined secondary and primary data.

## Secondary data

To create a socio-economic profile of Pinaymootang First Nation we have used statistical data provided by Statistics Canada, INAC, and the Band. The historical background for this discussion has been assembled using a combination of official historical sources and academic papers. To understand the policy context, the structure of service provision and the funding framework regulating the access of First Nations children with special healthcare needs to the medical

Section of the report	Secondary data	Primary data
<p><b>Chapter 1</b> Pinaymootang First Nation – Socio-economic profile and historical context</p>	<p>Statistics Canada, INAC, published material (academic articles and media articles).</p>	<p>Interviews with members of Pinaymootang’s Band Council and service providers.</p>
<p><b>Chapter 2</b> National and provincial policy context for the provision of services, equipment, and treatment in First Nation communities in Manitoba and Canada</p>	<p>INAC and Health Canada policy documents, information about legal cases obtained through access to information requests, Assembly of Manitoba Chiefs reports, published and unpublished material (academic articles, analysis documents).</p>	<p>Interviews with local, regional, and provincial service providers.</p>
<p><b>Chapter 3</b> Community and family experiences when trying to access services, equipment, and services for children with special healthcare needs</p>	<p>Information about legal cases obtained through access to information requests, published and unpublished material (academic articles, media articles, analysis documents).</p>	<p>Interviews with families of children with special needs in Pinaymootang and Winnipeg, Manitoba.</p>
<p><b>Chapter 4</b> Service provider experiences of burden, uncertainty, and risk in delivering services to children with special healthcare needs and their families</p>	<p>Published material (academic articles and media articles).</p>	<p>Interviews with members of Pinaymootang’s Band Council and service providers, interviews with local, regional, and provincial service providers.</p>
<p><b>Chapter 5</b> Discussion of overall findings, and recommendations.</p>	<p>Published material (academic articles and media articles).</p>	<p>Interviews with families of children with special needs in Pinaymootang and Winnipeg, Manitoba, interviews with members of Pinaymootang’s Band Council and service providers, interviews with local, regional, and provincial service providers.</p>

services allied, health services, and additional care services that they need, we have drawn from policy documents and academic publications. Documents regarding ongoing legal cases obtained through access to information requests, academic articles, and media articles have been used to provide a background for the discussion of the efforts that Pinaymootang families and the community as a whole have made to access services, equipment, and treatment for children with special needs that are ordinarily available to other Canadian children. The analysis of these documents was done manually, and the information was used in this report following the judgement of the Advisory Committee.

## **Primary data**

Primary data used in this report originates from a series of semi-structured in-depth interviews. We used a purposive sampling method and arrived at a sample including:

- (9) key informants
- (12) family members

To gather information on medical services, allied health services, and additional care services available in the community for children with special healthcare needs we conducted structured qualitative interviews with key informants who were members of Pinaymootang's Band Council, representatives of local and regional service providing organizations, and provincial First Nations organizations. The interviews were conducted at the band office and the health centre. They were partially transcribed and coded manually. Interview guides for the interviews with key respondents are provided in APPENDICES B and C.

Caregivers and family members generously shared their experiences caring for their children and trying to access medical services, allied health services, and additional care services that are usually accessible to other Canadian children and families such as diagnostic services, respite care, specialized care, speech therapy, physiotherapy, wheelchairs, specialized teachers, etc. These semi-structured qualitative interviews were conducted at participants' homes or at a location chosen by participants. They were transcribed in full and coded manually. An interview guide for the interviews with family members is provided in APPENDIX D.

## **APPENDIX B: Interview guide for expert interviews (service providers)**

Thanks very much for agreeing to speak with us.

As you know from your participation as a member of the project's Advisory Committee, we want to talk to you about the situation of children with special medical needs in Pinaymootang. The project grew out of concerns and questions around the implementation of Jordan's Principle: a child first principle designed to ensure First Nations children living on reserve do not experience delay/denial/disruption of services ordinarily available to other children.

We are here to document the experiences of children and family in Pinaymootang in regards to Jordan's Principle.

There is no systematic documentation about disparities in health and social services for First Nations children living on reserve and all other Canadian children. We don't have a clear understanding of the structural factors which might contribute to disparities or the policies/programs which might help address those disparities. The experiences of children with complex medical needs, their families and their communities as they try to access treatment, services and equipment have also not been systematically documented.

In this interview we would like you to draw from your knowledge as a \_\_\_\_\_ to better understand the policy framework as it shapes these structural factors and family's experiences.

We ask you to please avoid identifying any children or families and use hypothetical examples instead. If any identifying information is accidentally shared, it will be removed from the transcriptions and will not be used in the analysis.

We will be asking you for some background information that will not be used in the report but will give us valuable information to understand children and families' experiences.

I will be taking notes during the interview and, if it's ok with you, will record this conversation as well. Once the interview is transcribed we will send you the text file. We will ask you to identify any sections that you don't want us to use in the report.

This interview should take about 1.5 hours. It is ok if you want to withdraw at any time.

We ask you to read and sign the consent form. There are two copies, please keep one for your records.

### **Examples of topics / questions that could be used during the interview:**

- Ask about interviewee's occupation, time in current position.
- Identify the kinds of situations where the interviewee comes into contact with the target population.

#### **Services:**

What are the health / social / education services that the institution / department you work for (school, health centre, regional office) makes available for children with the following functional limitations in Pinaymootang?

- A child with gross motor impairment – e.g., needs a wheel chair or a walker to move around the community.
  - ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).



- ▶ How has the amount available for these services changed over time?
  - ▶ How has the range of available services changed over time?
  - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
  - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non- First Nations (FN) communities?
  - ▶ How do you know this information about services / funding in other communities?
  - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
  - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
- A child who need assistance with activities of daily living – e.g., needs help getting dressed or feeding, uses diapers beyond the age of 4.
    - ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).
    - ▶ How has the amount available for these services changed over time?
    - ▶ How has the range of available services changed over time?
    - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
    - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non-FN communities?
    - ▶ How do you know this information about services / funding in other communities?
    - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
    - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
- A child that has difficulty expressing him/herself so that others understand them or has difficulty understanding others.
    - ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).
    - ▶ How has the amount available for these services changed over time?
    - ▶ How has the range of available services changed over time?
    - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
    - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non-FN communities?

- ▶ How do you know this information about services / funding in other communities?
  - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
  - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
- A child with emotional-behavioural dysregulation – e.g., has difficulty calming down when agitated, is aggressive towards others, is often anxious and worried.
    - ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).
    - ▶ How has the amount available for these services changed over time?
    - ▶ How has the range of available services changed over time?
    - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
    - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non-FN communities?
    - ▶ How do you know this information about services / funding in other communities?
    - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
    - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
  - A child that has cognitive impairments – e.g., has trouble remembering things.
    - ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).
    - ▶ How has the amount available for these services changed over time?
    - ▶ How has the range of available services changed over time?
    - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
    - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non-FN communities?
    - ▶ How do you know this information about services / funding in other communities?
    - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
    - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
  - A child who is slow at making friends, is often alone, or refuses to engage in outdoor activities.

- ▶ How are services funded? (Ministry, Agency / Department, pocket of funding – please be as specific as possible).
  - ▶ How has the amount available for these services changed over time?
  - ▶ How has the range of available services changed over time?
  - ▶ Please describe the process that the family of a child with this kind of impairment would go through in order to access available services.
  - ▶ Do you know anything about how services/funding for these services in Pinaymootang compares to services / funding in neighboring, non-FN communities?
  - ▶ How do you know this information about services / funding in other communities?
  - ▶ Are there particular services / service areas in which there are gaps / disparities in Pinaymootang services, in comparison with services in neighboring communities?
  - ▶ Have there been any efforts to address gaps/disparities in these services? Can you tell me about those efforts and the governmental response?
- As you know, our focus for this project is on Jordan's Principle, a child-first principle which states that First Nations children should receive the health and social services that would be ordinarily available to other Canadian children in similar circumstances, and that jurisdictional disputes should be resolved afterwards.
    - ▶ How many cases have you personally encountered that fall under this category since you stepped into your current position?
    - ▶ How many of these cases have actually been reported as such? If any:
      - Could you describe the process of negotiation between your organization / institution / community and the provincial or federal government in these cases?

## **Wrap up**

- Are there any factors which affect children's access to services, treatment or equipment that we didn't discuss?
- Anything else you'd like to add/ask?
- We'd like to send you a copy of our notes from this interview – if you're able to take a quick look at them and verify that they make sense to you, that would be great. As you read through the document, please identify any sections that you do not want us to use in the report.

## **APPENDIX C: Interview guide for expert interviews (policymakers, policy analysts, leadership, and community organizations)**

Thanks very much for agreeing to speak with us.

As you know from your participation as a member of the project's Advisory Committee, we want to talk to you about the situation of children with complex medical needs in Pinaymootang. The project grew out of concerns and questions around the implementation of Jordan's Principle: a child first principle designed to ensure First Nations children living on reserve do not experience delay/denial/disruption of services ordinarily available to other children.

We are here to document the experiences of children and family in Pinaymootang in regards to Jordan's Principle.

There is no systematic documentation about disparities in health and social services for First Nations children living on reserve and all other Canadian children. We don't have a clear understanding of the structural factors which might contribute to disparities or the policies/programs which might help address those disparities. The experiences of children with complex medical needs, their families and their communities as they try to access treatment, services and equipment have also not been systematically documented.

In this interview we would like you to draw from your experience as a \_\_\_\_\_ to fill these gaps. We will be asking you to identify and discuss structural factors that, in your opinion, facilitate or get in the way of these children and their families as they try to access services. We will also ask you to discuss the ways in which these children and families' struggles have impacted you at a professional level.

We ask you to please avoid identifying any children or families and use hypothetical examples instead. If any identifying information is accidentally shared, it will be removed from the transcriptions and will not be used in the analysis.

We will be asking you for some background information that will not be used in the report but will give us valuable information to understand children and families' experiences.

I will be taking notes during the interview and, if it's ok with you, will record this conversation as well. Once the interview is transcribed we will send you the text file. We will ask you to identify any sections that you don't want us to use in the report.

This interview should take about 1.5 hours. It is ok if you want to withdraw at any time.

We ask you to read and sign the consent form. There are two copies, please keep one for your records.

### **Examples of topics / questions that could be used during the interview:**

- Ask about interviewee's occupation, time in current position, previous positions where s/he may have gained understanding of issues regarding access to services for FN children living on reserve.
- Identify areas of policy that the interviewee is familiar with and how they relate to FN children's access to services.

### **Policy governing FN children's access to services in Manitoba / Pinaymootang:**

- What is the overarching policy framework governing FN children's access to health and social services in Manitoba?
  - ▶ Are there any other relevant areas of policy, regulations, legislation, etc. that we should be paying attention to in

order to better understand the structural conditions that facilitate / limit FN children's access to services in the province / Pinaymootang?

- ▶ How have these changed over time?
- ▶ According to your professional experience, would you say that there has been a tendency towards / away from facilitating FN children's access to services, or have things in Manitoba remained fairly stable since you first started working on these issues?
  - More / less funding, more / less access to services provided by the province (e.g. ad hoc agreements giving children access to services provided by the province), more / less specific programs to hire personnel for local health centres ...
- I want to ask you some questions about services for children
  - ▶ If a non-Aboriginal child with x condition living off reserve required y services/support/equipment, how would his/her family access these needed services/support/equipment?
    - What provincial programs exist to meet these needs?
    - What is provided through the program?
    - What are the eligibility requirements for these programs?
  - ▶ Now I want to ask you questions about services for the caregivers of a child in the situation we just discussed: if the family of a non-Aboriginal child with x condition living off reserve required z services/support in relation to caring for their child, how would the family access these needed services/support?
    - What provincial programs exist to meet these needs?
    - What is provided through the program?
    - What are the eligibility requirements for these programs?
- In your professional experience, how do services / treatment / equipment available for FN children living on reserve compare to those available to other children in the province?
  - ▶ In terms of funding available, speed of access, distance from services, quality of services, adequacy of services, and any other parameter that seems relevant to the interviewee.

## **Wrap up**

- Are there any factors which affect children's access to services, treatment or equipment that we didn't discuss?
- Anything else you'd like to add/ask?
- We'd like to send you a copy of our notes from this interview – if you're able to take a quick look at them and verify that they make sense to you, that would be great. As you read through the document, please identify any sections that you do not want us to use in the report.

## **APPENDIX D: Interview guide for interviews with family members / caregivers**

Thanks very much for agreeing to speak with us.

As you may remember from the sharing circle back in November, we are here at the request of the community to document the difficulties that children with complex medical needs in Pinaymootang and their families have to access the services that they need (services like wheelchair accessible buses, speech therapy, medication, etc.).

About a month ago we interviewed service providers and leadership here in Pinaymootang to understand the general framework for the provision of those services – who pays for what, what is supposedly available in the community, and so on.

In this second round of interviews, we are trying to understand the experiences of children with complex medical needs, their families and their communities as they try to access treatment.

In this interview we will be asking you about your child’s diagnosis to have a better understanding of the services that s/he may need. We will also ask you to be as detailed as possible when discussing your efforts to access the treatment, services, and equipment that your child, your family, and yourself need.

Please remember that only Vandna, Luna, and the person transcribing the interview will have access to this conversation. Before we use anything that you share here today with anyone else, we will send you a copy of the transcription and ask you to identify parts of the conversation you do not want us to use in the final report.

For this project we are working with an Advisory Committee here in the community. The Advisory Committee will only have access to summaries where we analyze the experiences of all families. Members of the committee will not have access to the audio files or to the transcription of individual interviews.

The goal of this project is to produce a final report where we summarize the challenges that children in Pinaymootang and their families face when trying to access treatment, services, and equipment. We will come back to the community in the Fall to present the final draft to you. At that point, you will be able to make suggestions that we will do our best to integrate into the report.

I will be taking notes during the interview and, if it’s ok with you, will record this conversation as well. Once the interview is transcribed we will send you the text file.

This interview should take about 1.5 hours. It is ok if you want to withdraw at any time.

We ask you to read and sign the consent form. There are two copies, please keep one for your records.

### **Introduction**

- Could you please introduce yourself?
- Could you please talk a bit about your child? (age, history of diagnosis).
- What services or resources does your child need to address his needs?
- Could you describe a regular day in your family’s life, from the time when you wake up to the time you go to bed? Please focus on your roles and responsibilities as the child’s main caregiver, and name anyone else who is involved in providing for his/her needs.

- As the main caregiver of a child with special needs, which services, training, or resources would you need to be able to care for this child in an appropriate way?

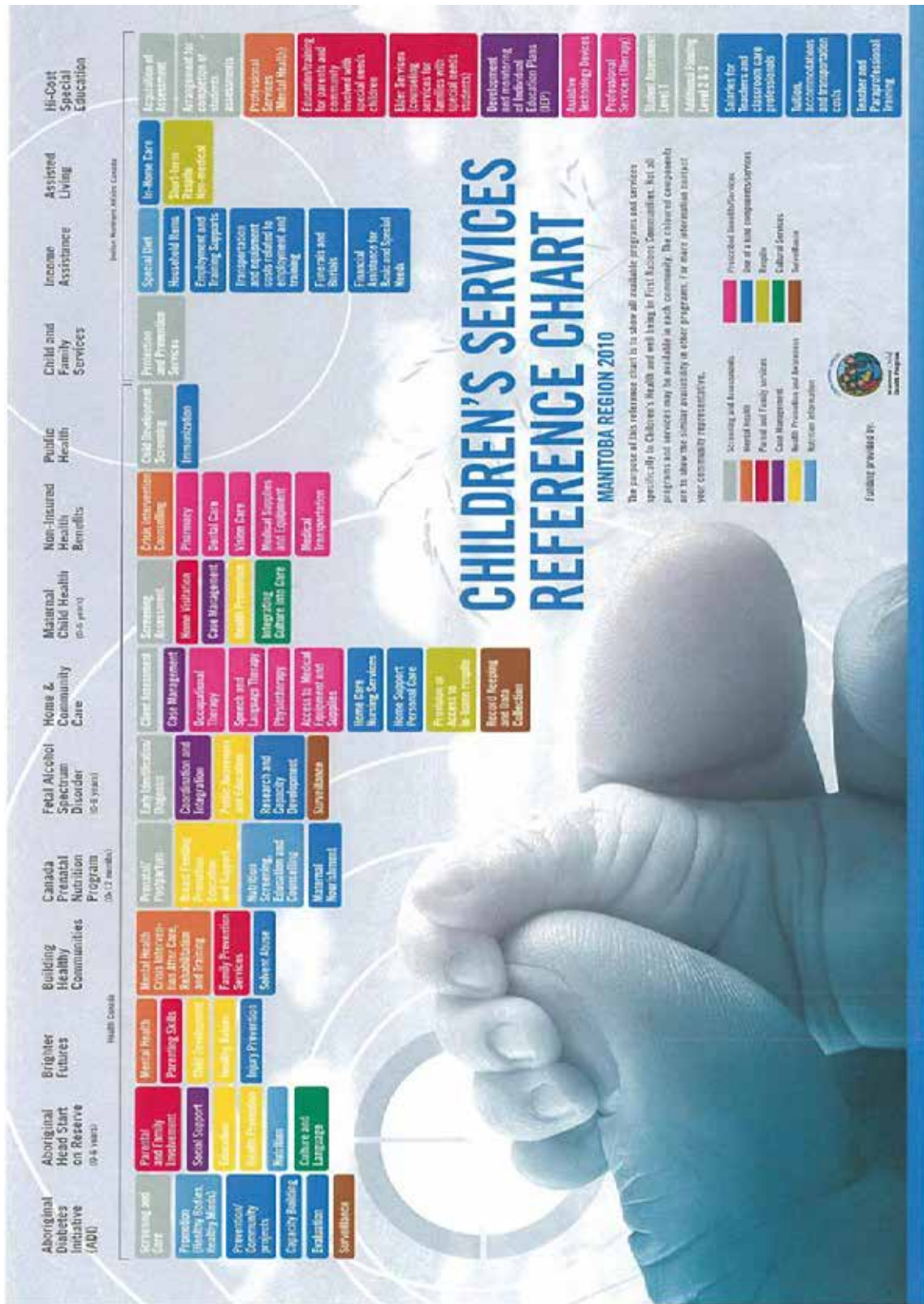
## **Experiences trying to access treatment, services and equipment**

- Have you tried to access these services, training, or resources? Please describe your experience in as much detail as possible.
  - ▶ Have you tried to access medical specialists to diagnose or treat your child? When? Where? Which agency / department did you approach? Please describe your experience.
  - ▶ Have you tried to access specific services to support your child or your family? Which services? When? Where? Which agency / department did you approach? Please describe your experience.
  - ▶ Have you tried to access equipment that you or your child need (e.g. a wheelchair, an iPad to facilitate communication with your child)? When? Where? Which agency / department did you approach? Please describe your experience.
    - Which services have you (not) been able to access for the child?
    - Can you describe the ways that government representatives and service providers have engaged with you during your attempts to access services? Have they been prompt? Responsive? Respectful?
    - Have you encountered other families in a similar situation to yours, in Pinaymootang or elsewhere in Manitoba?
    - Do you have a sense of what would be available for you and your child if you were not living on reserve?
    - Have you appealed to a government/department to consider your child's situation a Jordan's Principle case?
    - Do you feel that you have other ways to ensure that the child's needs are met?

## **Wrap-up**

- How do you think things could be done differently to make sure that your child, your family, and other First Nations children and families in a similar situation can access the services that they need?
- Is there anything important about your experience trying to access services for you and your child that we have not asked about?
- Anything else you'd like to add/ask?
- We'd like to send you a copy of our notes from this interview – if you're able to take a quick look at them and verify that they make sense to you, that would be great. As you read through the document, please identify any sections that you do not want us to use in the report.

**APPENDIX E: CHILDREN'S SERVICE REFERENCE CHART, MANITOBA REGION (FNIHB, 2010)**  
**Author: Mary Brown. FNHIB, Winnipeg**





## **APPENDIX F: TERMS OF REFERENCE FOR THE COLLABORATION BETWEEN PINAYMOOTANG FIRST NATION AND THE MCGILL-BASED RESEARCH TEAM**

This report is the result on the collaborative efforts of Pinaymootang First Nation and the McGill-based research team. The contribution of the First Nations Health and Social Secretariat of Manitoba and Anishinaabe Child and Family Services has also been crucial for its completion.

The terms of this collaboration were outlined in a Research Agreement signed between Chief Barry Anderson (Pinaymootang First Nation), Gwen Traverse (Executive Health Director, Pinaymootang Health Centre), Vandna Sinha (Professor, School of Social Work, McGill University) and Luna Vives (Postdoctoral Fellow, Centre for Research on Children and Families, McGill University) on January 27, 2016. What follows is a summary of the main principles outlined in that Research Agreement.

### **1. Governance of the project:**

In order to allow for ongoing communication and cooperation with the community throughout the different stages of the project, we agreed to form an Advisory Committee. The members of the committee (nominated collaboratively by the research team and representatives of the Pinaymootang First Nation) represent the perspective, expertise and interests of:

- Pinaymootang First Nation Council.
- Pinaymootang Health Centre.
- Pinaymootang School.
- Nanaandawewigamig First Nations Health and Social Secretariat of Manitoba (FNHSSM).
- Anishinaabe Child and Family Services.
- The McGill-based research team.

Between January 2016 and January 2017 the Advisory Committee met monthly to:

- Ensure that the research project responds to the community's needs.
- Facilitate data collection.
- Assist in the interpretation and contextualization of data.
- Produce and disseminate the final report.
- Review and approve any subsequent analysis or publication.

The Advisory Committee did not have access to individual interviews, only to summaries of data and preliminary analysis.

### **2. Compliance with OCAP principles:**

The Advisory Committee agreed to comply with OCAP principles to the maximum extent possible, with limitations imposed by the particularities of this research project (specifically, the fact that a non-Aboriginal research team will lead the project, and the impact that the research could have on individual committee members and on the provision of services in the community).

During meetings with Chief and Council and service providers, we agreed that decisions about the project would be made by the Advisory Committee (see above). Decisions were made by consensus, with any individual Advisory Committee

member having the ability to block a decision if they felt it would violate the terms set out in this research agreement. We also agreed on the following terms to manage ownership, possession, access, and control of the research data:

- Ownership of the data:
  - ▶ The information collected is co-owned by the individual Pinaymootang First Nation families participating in this study and by the research team, based at McGill University.
  - ▶ Pinaymootang First Nation owns the final report.
- Control over the research project:
  - ▶ Control over the project was exercised by an Advisory Committee consisting of community and research team members.
  - ▶ The composition, roles, and responsibilities of the Advisory Committee were outlined in the Research Agreement signed on January 27, 2016.
- Possession of the data:
  - ▶ Families received an audio recording of the interview, along with a transcription and a summary of their case.
    - Caregivers were invited to indicate any part of the interview that they do not wish to be used in the final report.
    - It will be up to the families to decide if and how they wish to share the information contained in these files and documents outside of the agreement made with the research team (e.g., when advocating for their own children).
  - ▶ The research team retains possession of the data for use in accordance with the Research Agreement for this project. Researchers will store all digital files and printed documents in a secure location at the Centre for Research on Children and Families, McGill University. Researchers will not use material from the interviews for anything other than the final report, unless given explicit permission from the project's Advisory Committee. All data collected for this research project (digital as well as print-out copies) will be destroyed 7 years after the release of the research report.
- Access:
  - ▶ Caregivers had direct access to all interview material pertaining their family at all times during the research process.
  - ▶ Members of the Advisory Committee had access to summary and synthesis reports prepared during the research process.
  - ▶ Members of the research team had direct access to all research material at all times during the research process.
  - ▶ The research team visited the community to present the preliminary results prior to the release of the final report, on November 2, 2016. Community feedback was incorporated into the final report to the extent possible.
  - ▶ The final report will be posted on websites agreed upon by the Advisory Committee.
  - ▶ The research team will print copies of report for participants and Advisory Committee members. The research team committed to seeking more funds to enable broader printing.
  - ▶ The research team will publish a summary of the research results in an open-access journal article, to be agreed upon by the Advisory Committee.
- Confidentiality:
  - ▶ Public officials, Band Council members, and service providers interviewed for this study will not be identified in the final report by name, but by their job title only (e.g., Health Technician, Band member, policy analyst).

- ▶ After discussing the risks and benefits of different privacy and confidentiality options available for this project, members of the Pinaymootang Band Council expressed their wish to have their community identified in the final report and any other publications or official communications that result from this project. This is crucial for their advocacy efforts.
- ▶ Caregivers chose to use pseudonyms in the final report to protect their identities and the identities of their children and other relatives. We clearly explained to caregivers that, given the small size of the community, their identity could not be fully protected despite the use of pseudonyms.

### **3. Informed Consent:**

The signing of the agreement by Pinaymootang First Nation's Chief and Council indicated collective consent to undertake this project. Individual participants were asked to provide their free and informed consent prior to the beginning of the interview. The consent form used was reviewed and approved by representatives of Pinaymootang First Nation. Participants were asked to sign this form before the beginning of the interview.

### **4. The research team agreed to abide by the following ethical principles, shared and followed by Pinaymootang First Nation:**

- To always refer to this research agreement between Pinaymootang First Nation and the McGill-based research team, and to seek advice from the Advisory Committee when additional decisions need to be made.
- To treat participants and the information they share with the research team with the outmost respect.
- To take all the necessary measures to avoid harm to participants, including negative consequences resulting from their participation in this research project.
- To discuss intellectual property frankly and openly with the Advisory Committee.
- To be conscious of the multiple roles that all members of the Advisory Committee (including the members of the research team) had to negotiate during this project, and minimize any conflict of interest should that may arise.
- To follow the informed consent rules outlined in this agreement at all times.

### **5. Communications:**

Decisions regarding the dissemination of the results were made collaboratively by the committee.

### **6. Funding:**

The amount of \$20,000 was initially allocated from within a SSHRC partnership grant (Trocmé et al, 2012-2018; Centre for Research and Families, McGill University). Funding covered the costs of research team members to engage with the community and stakeholders, conduct interviews, transcribe, and analyze interview data. It also covered travel to Pinaymootang, small honoraria for families participating in the study, and the costs of producing a final report summarizing the research findings (design, layout, and printing). The principal investigator's time was an in-kind contribution from the Centre for Research on Children and Families, McGill University. Members of the Advisory Committee were asked to contribute their time and expertise to this project. Caregivers are also asked to contribute their time and personal experience.

### **7. Commitments by each party:**

Representatives of Pinaymootang First Nation agreed to:

- Abide by the terms of this agreement at all times.
- Inform the Advisory Committee of any conflicts of interests that may arise during the project, so that adequate measures could be taken to minimize their impact.
- Respect the privacy of caregivers by keeping information discussed during Advisory Committee meetings confidential.
- Attend as many Advisory Committee meetings as possible, taking into account other professional and personal commitments.
- Provide feedback on synthesis reports, summaries, and report drafts in a timely fashion.

Members of the research team agreed to:

- Abide by the terms of this agreement at all times.
- Seek advice from the Advisory Committee throughout the duration of the project.
- Respect and abide by the decisions made by the Advisory Committee.
- Protect participants' identity and privacy as much as possible during the preparation of summaries, synthesis reports, report drafts, and the final report.
- Respect the privacy of caregivers by keeping information discussed during Advisory Committee meetings confidential.
- Do their best to integrate feedback from the participants and the Advisory Committee into the final report.
- Do their best to respect the timeline and work plan proposed to the community.



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