

Josée G. Lavoie
Joseph Kaufert
Annette J. Browne
Sharon Mah
John D. O'Neil
Stephanie Sinclair
Kathleen BlueSky

Negotiating barriers, navigating the maze: First Nation peoples' experience of medical relocation

Abstract: This study documents the policy framework that shapes First Nations' experience of relocating to access medical care. We analyzed policy documents and government websites, interviewed individuals who have experienced relocation, family members, healthcare providers, health administrators, and conducted two focus groups with government representatives. Federal and provincial program managers interpret policies, make decisions on eligibility, to extend or deny coverage. Decisions are shaped by shrinking budgets, fragmented program coverage, and jurisdictional confusion. Provider advocacy can help, but also perpetuate perceptions of arbitrariness and distrust. National policy renewal is required to redress this issue.

Sommaire : La présente étude documente le cadre stratégique qui façonne l'expérience de déplacement des Premières Nations pour avoir accès aux soins médicaux. Nous avons analysé des documents de politiques et des sites Web gouvernementaux, interviewé des personnes qui ont dû déménager, des membres de ces familles, des prestataires de soins de santé, des administrateurs de services de santé, et avons mené deux groupes de concertation avec des représentants gouvernementaux. Les gestionnaires de programmes fédéraux et provinciaux interprètent les politiques, prennent des décisions relatives à l'admissibilité, pour accorder ou rejeter la couverture. Les décisions sont dictées par des compressions budgétaires, une fragmentation des champs d'application de programmes, et une confusion d'ordre juridique. Les activités d'intervention menées par les prestataires peuvent aider, mais elles peuvent également perpétuer des perceptions de procédure arbitrale et de défiance. Un renouveau de la politique nationale est nécessaire pour redresser cette situation.

Josée G. Lavoie is Associate Professor, Community Health Services, and Director of Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR), University of Manitoba. Joseph Kaufert is Professor, Community Health Services, University of Manitoba. Annette J. Browne is Professor, School of Nursing, University of British Columbia. Sharon Mah is Research Associate, MFN-CAHR. John D. O'Neil is Dean, Faculty of Health Services, Simon Fraser University. Stephanie Sinclair is Policy Analyst/Researcher, Intergovernmental Committee on Manitoba First Nation Health (ICMFNH). Kathleen BlueSky is Coordinator, ICMFNH. Funding for this study was provided by the Canadian Institutes of Health Research. This study was conducted in partnership with the Assembly of Manitoba Chiefs' Health & Social Development Secretariat. The authors want to acknowledge the invaluable contribution of the Chiefs' Taskforce on Health, the AMC Manitoba First Nations Health Technicians Network and the Manitoba First Nations Social Development Advisors Technical Group. We would also like to acknowledge the invaluable contribution made by those who reviewed an earlier draft of this manuscript.

Introduction

Like many Canadians living outside urban centres, First Nation peoples must regularly leave their rural community or reserve to access general practitioners, specialists, for hospitalizations, or other services. In some cases, absence from the community may span a few hours to a few days. The term “medical relocation” refers to situations where First Nation peoples relocate to an urban centre for an extended period of time to access care. In some cases, the relocation is permanent (end-of-life care, dialysis, personal preference); in other cases, it is a single event that is time-limited and results in a return home (acute, time-limited illnesses; time-limited cancer treatment; high-risk pregnancy). In many cases, however, medical “relocation” is a misnomer because the need to balance personal, family and community commitments with the need for specialized health services results in *multilocality*, where individuals move back and forth between an urban centre (to access care in the diagnosis phase and during acute episodes) to a regional centre (for episodes of lower acuity), to the home community (to attend to personal, family, community and cultural obligations). This “circuit,” rather than being time limited, becomes a permanent feature of peoples’ lives.

Medical relocation is not a new phenomenon. For example, more than twenty years ago, Mollins documented First Nations transplant recipients’ complex treatment-related relocations, which involved multiple moves between home communities, rural points of care and urban treatment centres (Mollins 1991). What is new is that this complex journey is increasingly the norm. What is also new is that shifts in health and social policies, more stringent concepts of accountability (Hughes Tuohy 2003), and budgetary constraints, have “sharpened the edges” of policies previously more flexible, resulting in a decreased ability for the bureaucracy to be responsive to shifting needs (Lipsky 2010).

We argue that the multi-jurisdictional policy framework is characterized by gaps and ambiguity impacting decisions of federal and provincial program managers who interpret and implement medical relocation for First Nation peoples

This article is part of a larger study that aimed to a) map the policy framework that currently shapes the experience of medical relocation/multilocality; and b) document the experience of First Nation peoples as they negotiate jurisdictional boundaries and navigate the healthcare system. We argue that the multi-jurisdictional policy framework is characterized by gaps and ambiguity impacting decisions of federal and provincial program

managers who interpret and implement medical relocation for First Nation peoples. This paper focuses on Manitoba, home to the highest proportion of First Nations in the provinces (15%); jurisdictional confusion is regularly discussed at federal-provincial policy tables.

This paper is organized in five sections. The first section provides some theoretical background to guide this study. The second section describes the methods used to gather and analyze the evidence for this paper. The third and fourth sections summarize the research findings and the policies that come into play when First Nation peoples relocate for medical reasons. Our analysis focuses on areas of policy ambiguity; ensuing implications for access to services, transfer payments and psychosocial impacts for patients, families, First Nation communities and providers are highlighted. This is followed by a discussion of First Nation peoples' experience of medical relocation, based on in-depth interviews with First Nation patients who experienced relocation, family member caregivers or guardians, and healthcare providers. The last section discusses key themes, implications for policy and healthcare delivery, and conclusions.

Theoretical framework

Policy has been conceptualized as written rules and as a set of decisions made by "street-level bureaucrats"¹ (Lipsky 2010) in their everyday practice. Lipsky has demonstrated that street-level bureaucrats implicitly mediate the relationship between the state and citizens by arbitrating between public interest and the interest of individuals seeking access to public goods. Lipsky calls this mediation "agency policy," and argues that street-level bureaucrats actively engage in policy-making when negotiating the space between official policies (state-agent role) and individual circumstances (implementation-control-discretion, Lipsky 2010). Maynard-Moody and Musheno (2012) argue that the prevalent narrative of state-agent and policy implementation-control-discretion show that the decisional judgments of both administrators and frontline workers (street-level bureaucrats in this context) frequently operate outside the bounds of rule-based discretion as they engage in creating and conserving the structure of the state (Maynard-Moody and Musheno 2012: S18, S20). When a decision results in a bad outcome, the street-level worker can be seen as acting without authority (Maynard-Moody and Musheno 2012: S19).

On the other hand, scholars have suggested that greater access-to-information has led to unprecedented visibility of bureaucratic decision-making to the public: anonymity can no longer be guaranteed (Mintzberg and Bourgault 2000; Savoie 2003). Mintzberg and Bourgault (2000) argue that modern public management requires a balance between political (negative public reactions to decisions), operational (policy and budget

constraints) and stakeholder (users and beneficiaries of programs) interests (2000: 49). Senior, middle and street-level bureaucrats must balance and manage these interests, mindful that each level of the bureaucracy will weigh the importance of these interests differently.

In the context of First Nations, we argue that *creating and conserving the structure of the state* (Maynard-Moody and Musheno 2012: S20) requires street-level bureaucrats – those deciding on eligibility for support from programs they manage – to base their decisions on a drafty “maze” of federal and provincial funded programs, and strike a balance between:

1. implementation of rules (based on perceived and real user needs as understood by the manager);
2. possible politicization of decisions (when eligibility is denied or needs remain unmet); and
3. management of increasingly slender budgets.

Striking a balance is complex because the jurisdictional divide requires that decisions consider program eligibility and jurisdictional responsibility amidst jurisdictional uncertainty, continuously shifting rules, and contradictions (Lavoie, Forget, and Browne 2010).

The fuzziness of jurisdictional boundaries create opportunities for street-level bureaucrats to act as advocates when trying to ensure that users have access to programs and resources, or gatekeepers when enforcing access rules especially in the context of budget constraints (Evans 1991). Options perceived as (potentially) precedent setting and thereby higher risk for the street-level bureaucrat and its employer, may be overlooked in favour of denying coverage. The perceived risk is largely subjective. As a result, the boundary between structural constraints and individual influences over decisions is blurred. This context creates a paradox, where explicit rules result in inflexibilities and jurisdictional gaps, and where case-by-case decision-making results in perceived arbitrariness perpetuating distrust in program managers. We argue that the enhanced public scrutiny into First Nations’ health and social welfare (by Amnesty International Canada, the United Nations Special Rapporteur on the Rights of Indigenous Peoples, First Nations themselves, scholars, non-government organizations, etc.) heightens a sense of risk and further limits flexibility and responsiveness.

This study fills a significant gap in the literature. Although the role of street-level bureaucrats in policy-making has received some attention (Carroll, Siegel, and Institute of Public Administration of Canada 1999; Mintzberg and Bourgault 2000; Wellstead and Stedman 2010; Wellstead, Stedman, and Linquist 2009), we were unable to locate a study of street-

level bureaucracy operating in the context of First Nation's healthcare delivery or policy.

Methods

The dataset we draw on for this article focuses on a detailed review of federal and provincial policies that support and constrain First Nations' experience of medical relocation. The study was informed by a partnership between the Assembly of Manitoba Chiefs (AMC) and university-based researchers from the University of Manitoba, the University of Northern British Columbia, the University of British Columbia, and Simon Fraser University. The policy review was commissioned by the Intergovernmental Committee on Manitoba First Nations Health (ICMFNH, which include federal and provincial decision-makers).² The larger study, which explored First Nations' experiences of medical relocation, was funded by the Canadian Institutes for Health Research. Ethical approval was obtained from the University of Manitoba, the University of Northern British Columbia and the University of British Columbia's Ethics Boards.

For the policy review, we analyzed coverage rules of all relevant programs as described on governmental websites and in key policy documents (Assembly of First Nations 2005; Health Canada [FNIHB] 2003, 2005; Manitoba Family Services and Housing 2005; Manitoba Health 1997, 2005a, 2005b, 2005c, 2005d; Manitoba Ministry of Health and Social Affairs 2007). We engaged in several discussions with ICMFNH representatives, at times as a group, at times individually, to clarify program rules. Two focus groups were held in 2007 and 2008 with First Nations Health and Social Development Directors (10 and 19 participants, respectively) to explore how rules were applied. Preliminary findings were discussed at length with the ICMFNH federal and provincial representatives for validation. We did not interview individual federal and provincial program managers because we recognized the heightened sensitivity around issues of eligibility, coverage and precedent setting, and might not be able to ensure confidentiality given the small number of individuals involved.

To provide context, we carried out 91 interviews (99 individuals) with people who had experienced relocation, with family members of relocatees if the individual had died or was unable to be interviewed (cognitive impairment, critical health issue), and with nine First Nations' community-based and fifteen provincial healthcare providers (see Table 1). Most interviews were with a single individual. Eight patients preferred being interviewed with a family member for support, who also contributed their own perspective. Sampling was purposive and theoretical (Denzin and Lincoln 2011) to capture a wide variation of experiences. In First Nation communities, healthcare providers and/or health

Table 1. *Breakdown of Interviewees*

<i>Type</i>	<i>N of participants in urban settings</i>	<i>N of participants in on-reserve settings</i>
Family members or guardians	4	32
Patients	15	19
Healthcare Providers	15	9
Healthcare administrator and decision-makers	29	5
Total	63	65

administrators identified possible patients and family members for interviews. These individuals were then contacted by the provider or administrator, informed of the study, and asked whether they wanted to be interviewed. Eligible patients were those aged 19 years and over, without cognitive impairment, and who had experience of relocation themselves or with a family member. Patients or family members who consented to participate were interviewed at the First Nation health clinic (if on-reserve) or at an agreed upon location (in urban settings). Providers were identified through reputational sampling. Key informants from the provider sample were interviewed in their work place. After written informed consent forms were signed, participants were interviewed by a research team member. Open-ended questions explored participants' experiences with relocation. All participants were interviewed once.

All interviews were digitally recorded, transcribed verbatim and cleaned of personal identifiers. Transcripts were first compared with the audio recordings for technical accuracy. Using interpretive thematic analysis for qualitatively derived data (Thorne 2008), the team reviewed the transcripts to identify concepts and processes, and linkages to theoretical perspectives as well as any recurring and contradictory patterns in the data. NVivo 10 was used to code and organize the interview data. This facilitated the coding of data into broad codes, and the identification and refinement of sub-codes. Eventually, analyses shifted to more abstract and conceptual representations of the processes and themes reflected in the data.

Current policy framework

First Nation peoples moving from their reserve community to an urban centre to access healthcare face a number of challenges. Some – such as access to housing, family dislocation, and economic stress – are not unique to First Nation peoples. When the onset or progression of a chronic or acute illness requires relocation to an urban or regional centre

to receive appropriate treatment, most individuals will experience considerable anxiety as they try to sort out logistics (where to live), family issues (who stays, who leaves, depending on the expected length of the relocation) and financial issues (loss of income or employment, costs associated with the relocation).

Unique to First Nations peoples is the historical and continued experiences of dismissal, racialization, stigma, and often diminishment of their health concerns (Anderson et al. 2003; Browne et al. 2011, 2012; Tang and Browne 2008). These experiences shape First Nation peoples' understandings of program managers' motivations and actions. Conversely, the political position that First Nation peoples occupy in the Canadian political landscape, and how they are reflected in the media and in everyday social discourses can also influence program managers' understanding of First Nation individual's needs and entitlements.

Also unique is the federal-provincial jurisdictional divide and its impact on lived experiences. The 1867 British North America Act defined health as a matter of provincial jurisdiction, whereas "Indian affairs" was defined as a matter of federal jurisdiction. This jurisdictional division has created ambiguities in terms of services delivery for First Nations. The federal government now assumes responsibility for funding public health and limited primary care services on-reserve. The federal government's position is that health promotion, prevention and (some) primary care provided by nurses have historically been provided on humanitarian ground, outside of constitutional or legislated obligations (Lavoie et al. 2013). Provincial governments shoulder the responsibility for the provision of health services, to individuals living on or off-reserve. This includes services required under the Canada Health Act (access to physicians, specialists and hospitals). Services not prescribed by the Canada Health Act, but provided by the provinces as a matter of policy, may or may not be extended to First Nation peoples, based on official or more localized interpretations of policies (Lavoie et al. 2013). The division of responsibility appears relatively neat, but federal-provincial jurisdictional ambiguities have been repeatedly reported for nearly five decades (Booz Allen Hamilton Canada Ltd. 1969; Lavoie, Forget and Browne 2010; Lett 2008) and create barriers to accessing care.

In addition, federal program managers operate in a heightened level of visibility, as self-government opportunities have emerged. The 1985 Constitutional reform resulted in opportunities for First Nations to take on management and delivery of community-based health and social programs. As of 2008, the First Nations and Inuit Health Branch of Health Canada (FNIHB)³ reports that 89 percent of eligible communities have some level of self-government over health services (Health Canada [FNIHB] 2008). Funding agreements include community-based primary

care (where these exist) and prevention services. The federal Non-Insured Health Benefit program is explicitly excluded, a key program where this paper is concerned, because it provides funding for medical transportation, oral health, prescription drugs and eye care. A handful of communities have opted to manage this program on behalf of FNIHB, through yearly contribution agreements. In other communities, the program is managed by a federally hired Transportation Clerk who works in local communities. In the context of medical relocation, these Transportation Clerks (whether First Nation or FNIHB-employed) are tasked with reconciling federal program rules defined nationally and managed by regional managers, with patient needs as defined by healthcare providers, families and the patient (Lavoie et al. 2005). The fit between the patient's and the family's care need and rules regulating the individual's access to services and financial support is often poor. First Nation engagement in health services planning and delivery has increased the visibility of federal decision-making and increased the possibility for "push backs," contesting decisions understood as unjust and arbitrary. Such push backs can be public, and result in national and international embarrassment (Lett 2008).

Diverse federal, provincial, regional health authorities, hospital, and First Nation policies may apply at different times in a medical relocation. However, most healthcare providers, First Nations, and family members we interviewed commented on the challenges associated with continued accessing Income Assistance (IA). This requires shifting coverage received from their First Nation (and funded through the Aboriginal Affairs and Northern Development Canada, AANDC⁴) to coverage from the Manitoba Department of Jobs and Economy (MJE).⁵ Participants also commented extensively on shifts associated with access to financial support from FNIHB for medical transportation. Both are reviewed in more detail below.

FNIHB's medical transportation policy

Table 2 reflects coverage from different policies from the time a treatment requires a First Nation individual to travel regularly to receive care. At the time of writing, FNIHB's medical transportation policy allows an individual to travel back and forth for up to *four months* before they are asked to relocate (Health Canada [FNIHB] 2005), with this qualification: "During this time, an assessment will be conducted involving the treating physician, other relevant health professional(s) and the client to determine the provision of further benefits, taking into consideration the client's medical condition" (Health Canada [FNIHB] 2005). Individuals are asked to relocate when it is known that, (a) they

Table 2. *Impact of the Change to the Definition of Ordinarily Resident On-reserve (if/when Implemented)*

	<i>Before the change in Income Assistance (IA) policy</i>	<i>Since the (not yet implemented) change in IA policy*</i>
	<i>Those eligible for IA</i>	<i>Those eligible for IA</i>
	<i>Those not eligible for IA</i>	<i>Those not eligible for IA</i>
FNIHFB	<ul style="list-style-type: none"> • Assistance with medical transportation, housing and meals provided when commuting to care. • After a max of 4 months, individuals are expected to relocate. • After relocation, assistance with medical transportation, meals and housing is provided for 3 months. 	
AANDC	<ul style="list-style-type: none"> • IA provided for 3 months after relocation. • No provision 	<ul style="list-style-type: none"> • IA provided after relocation (no time limitation). • No provision
MJE	<ul style="list-style-type: none"> • Eligibility for IA begins after 12 months once relocation. • No provision 	<ul style="list-style-type: none"> • N/A, Coverage provided by AANDC • No provision

* (Indian and Northern Affairs Canada 2007; Aboriginal Affairs and Northern Development Canada 2012)

cannot return home due to their condition, or (b) access to services is not possible in their community, or (c) the travel is unduly onerous. Once relocated, FNIHB also covers “the cost of meals, accommodation and in-city transportation to access the medical care/treatment, when they are not covered by provincial/territorial health or social programs, other publicly funded programs or private insurance plans, may be covered for up to a **three month** transition period only” (Health Canada [FNIHB] 2005). According to FNIHB, the policy is applied with some flexibility, to reflect circumstances (Lavoie et al. 2009). For example, extensions to the initial pre-relocation four-month limit may be provided when there is a realistic possibility that the client will be returning home in the near future. Individuals receiving cancer or other therapies for a fixed duration that may extend beyond four months may also be provided with an extension.

For those living in communities where road access is dependable and who have ongoing travel needs, the four-month coverage is intended to provide time to make other arrangements or to relocate. Relocation may come sooner as a result of treatment requirements, frequency of trips required, remoteness, cost-effectiveness, personal choice and other factors. Some communities have developed effective transportation systems, and can support ongoing travel to care (Lavoie et al. 2009). However, healthcare providers reported that the flexibility in applying this policy to suit individual circumstances has shrunk in response to an increased focus on accountability. Tighter budgets and increased scrutiny create an impetus for more conservative decision-making. One provider commented on the diminished flexibility in policy limiting the capacity of FNIHB staff to argue for extension of support for living expenses:

[C]ertainly at one time, they used to be much more generous in their coverage. And we’ve had people stay for months. As long as – you could make the argument, “Well, it’s sort of temporary.” But they’ve got a much – they’re actually following their rules now. They had rules all the time saying that they would only cover up to 3 months (Healthcare Provider 40).

Issues also arise when the process of relocation does not follow the norm “imagined” by policy-makers. A provider emphasized the problems of patients qualifying for continuing benefits and assistance to meet the immediate costs of relocation and living expenses when they had not established the urban residence required for provincial benefits:

[P]eople come here for medical attention, whether they were Medivac-ed out or Lifelined out for emergency purposes and they come with the clothes on their back....the Non-Insured Health Benefit/Medical Transportation Program [will not] cover that cost for this person to go back and get their stuff. And they’re expected to relocate while they’re in the hospital, maybe living in a boarding home in the interim. And the cost of airfare, you know, to bring your stuff out. Like, who’s gonna provide that support for that relocation? That’s a huge, huge [issue] (Healthcare Provider 22).

The rules of eligibility are generally broadly spelled out in documents. Implicit in the quote above is a policy interpretation that strikes a balance between the implementation of rules, the risk of politicization of decisions, and fear of setting jurisdictional precedents. First Nation communities managing the medical transportation budget are expected to enforce guidelines that are broadly defined in documents, but more strictly defined by the process of approval, lest they find themselves responsible for the cost. A First Nation participant with experience in health program administration described this process:

[B]ecause we're administering this program on behalf of FNIHB, and because we're having to make our own people jump through their hoops, our people blame us... There is no choice [to abide by FNIHB's eligibility decisions]. You try to negotiate [with FNIHB] and say, "You know, that's not gonna work for us..." [A]gain, then it turns into [FNIHB's] interpretation of public policy (First Nation Healthcare Administrator 102).

Medical transportation clerks working on-reserve manage a program where eligibility is decided by the FNIHB regional office. Tensions can emerge when eligibility is denied for reasons not explicitly stated in policies (for example, denial for attending a recurring medical specialist appointment after the completion of chemotherapy, or for escort support when explicitly requested by a family physician).

Political risk can be heightened by inflexibility, and must be carefully managed. Some participants suggested that FNIHB purposefully uses dif-fused or ever changing lines of accountability to manage the risks associated with negative decisions:

[W]e know [their] management practices... "Well, you're a clerk. Give me your supervisor..." You phone the supervisor. "Oh, well, we've just reorganized and restructured." And they're doing this constantly. "Oh, you shouldn't be talking to me. We have Unit Supervisors now" (Healthcare Provider 102).

This quote reflects the frustration experienced by healthcare providers in being able to find the right person to talk to for coverage approval for a First Nation patient because of constant restructuring and changing eligibility criteria.

AANDC/MJE and the income assistance policy gap

Table 2 shows that, at the time of the policy review (2007) for individuals eligible for Income Assistance (IA), coverage from AANDC continues for three months after relocation. Coverage from MJE is picked up after 12 months if a residence has been established off-reserve. No official policy provides IA coverage between month 3 and 12. MJE coverage may still

be denied after 12 months if an individual retains a residence on-reserve. MJE coverage can start on month 4, but they require identification which is often where the gap occurs in the transition. While it appears that coverage is in effect possible between month 3 and 12, the transition is generally difficult and confusing.

I've been working with her for 4 months, ... she's on [provincial] Income Assistance – Disability. Disability won't cover [her] since she's Treaty. And then, when I phone her band, she's – they tell me, "She's off-reserve so we can't help her out." So [she's] caught (Healthcare Provider 17).

In this case, a First Nation woman living with a disability is being denied coverage, despite being on provincial Income Assistance, because of perceived ineligibility by a provincial employee because she is "status." While patient advocates can often address such misunderstanding, these cases require time to resolve, and result in delayed coverage.

It's a challenge actually getting [First Nation patients having just relocated] to apply and to fill in their applications because it's dealing with all kinds of their internal policies, ... all kinds of criteria to fill out their applications for housing and Employment and Income Assistance. So they need all these documents – back-up documentation to help support their applications. A lot of [First Nation peoples] don't even have that. A lot don't have identification (Healthcare Provider 19).

Many providers explained that First Nation individuals relocating to urban centres often lack identification, rental references and credit rating, creating barriers for them to access support services and public housing.

Table 2 also shows the impact of the 2007 changes to the AANDC's IA Program – National Manual (Indian and Northern Affairs Canada 2007). According to Section 2.3.3, First Nation peoples who are *ordinarily resident on a reserve* are eligible for IA. Based on the 2007 changes to this definition, individuals relocating off-reserve for the purpose of obtaining care or accessing social services not available on-reserve continue to be considered *ordinarily residents*. The change is also reflected in the most recent update to this manual (Aboriginal Affairs and Northern Development Canada 2012: Section 2.1.5).

At the time of writing, this change had yet to be broadly operationalized. An exception is for those transferring to a personal care home, where coverage off-reserve is now possible. If broadly implemented, coverage in IA would no longer lapse between months three and twelve, and no longer be conditional on individuals giving up their reserve address. This could be a major improvement, but implementation is complex for several reasons. First, there are financial implications for AANDC's regional offices and for First Nation communities. To date, these responsibilities have not been communicated to First Nations and

budgets have not been adjusted. Second, AANDC and First Nation's administration have no mechanism to deliver IA programs off-reserve. Further, the delivery of IA in areas with employment opportunities would create an obligation to deliver active measures for those deemed employable (training, job search monitoring, etc). According to official documentation, the policy change has happened, resulting in a shift in responsibility, where First Nation communities are, on paper, responsible for providing IA off-reserve. A First Nation Healthcare Administrator described his concern:

[I]t was just something that fell on [First Nation administrators'] table...We're never told any of the provincial changes or the federal changes... All of a sudden, it just shows up... Well, they put it under the carpet. And suddenly you're responsible. And it's in the newspaper (First Nation Healthcare Administrator 101).

This paper shift, which has not been well communicated or matched with resources, stands as a potential liability.

Policy framework: key points

The two exemplars discussed above demonstrate the weakness in the medical location policy framework. Program definitions carry ambiguities that can only be sorted out on a case-by-case basis. The process is onerous, and gaps remain. Program managers are left to assess the fit between needs and policy guidelines, making decisions and risking criticism if something goes wrong or if a case gets public attention. This was discussed extensively by government representatives; in their view, increased rigidity in policy coverage has increased gaps. Several policy makers were aware that shifts in jurisdiction – that is, when coverage for certain expenditures shifts from the province to the federal government or vice versa – are not always smooth. It appears that in at least some cases, agencies do not communicate or coordinate shifts in jurisdiction and coverage to ensure seamlessness. Clients may be advised that they no longer qualify for their coverage by one agency, and told to contact another government to ensure continued coverage. They could not comment on the extent of the problem, and the impact this has on First Nation individuals. All agencies and the providers we interviewed raised this as an issue. The inflexibility built into the more stringent accountability framework appears to be a barrier to resolving the issue of payment for services. One healthcare provider emphasized the fears of setting a precedent and new expectations with regard to eligibility to programs and services as the reasons why managers adopt a case-per-case approach when interpreting policies:

Every situation is dealt with separately. And my opinion is that it's done that way to keep everything off-kilter. So people don't recognize that there are ways to do things. "Oh, we don't do that. We don't – we're not setting a precedent." They say that that would be setting a precedent and, "We don't do that. We just take it case-by-case" (Healthcare Provider 25).

The inflexibility built into the more stringent accountability framework appears to be a barrier to resolving the issue of payment for services

As discussed below, this results in an environment where perceived arbitrariness, confusion, red tape, frustration, distrust and unmet needs are salient.

Negotiating jurisdictional barriers and navigating the healthcare system

The two policy exemplars from our dataset are representative of the large jurisdictional context that is intended to support First Nations relocating for medical reasons. A salient theme in most interviews of patients, family members and health providers was the amount of red tape to sift through for needs to be met. One patient emphasized the experience of navigating the urban treatment system and negotiating entitlements:

It's hard to get anything out of – to get help – that much – from these people. And then, they give you a total run-around a lotta times. My appointments: they would send those papers in last minute. [W]hen we'd leave here, they have to – like, when we get to the City, we have to – they give us a number to phone to tell us where to go and stay. And they don't make those arrangements ahead of time (Patient 54).

Another described bureaucratic imposition of what we assume are budget-related delays:

I had the doctor's note and I had the prescriptions [for orthopaedic shoes]. And then, they were all approved and, all of a sudden, "Oh, you gotta wait till April 1st." "Why April 1st?" And this was way back, I think, in September or whatever or maybe longer than that (Patient 016).

In a complex referral system, many patients wait for months or years to be scheduled for an appointment with an urban specialist. Not surprisingly, the role of street-level bureaucrats in approving or denying transportation expenses was a source of frustration and conflict, as described by this patient:

So I just waited... I waited a whole year. And when the appointment did come – and then, [FNIHB medical transportation] just about turned me down here. And I said, “No.” I said, “I need to go to that appointment. I waited one year for that appointment.” And I said, “I need to go...” So, like, when you have appointments down here, it seems like you gotta tell them a month ahead. And when you do, it seems like you’re fighting with them for money to go to your appointment (Patient 50).

Another patient described having to justify the necessity of his continuing monitoring and care through regular visits with their consulting specialist:

And I was asked, “Did you – do you have a referral letter?” I said, “Why do I need a referral letter when I’ve been seeing the same doctor all these years? It’s just that I have to go either if – once a year, every 6 months, whenever he wants me back (Patient 54).

The above quotes reflect patients’ experience in attempting to access resources required to access care, in this case mainly the support from FNIHB for medical transportation. Although complete details of each case are not known, eligibility does not appear to be an issue. Rather, the decision-making of program officers often appear to reflect other priorities such as cost containment. This cost containment results in a substantial time investment from healthcare providers and administrators in brokering access, as discussed in the following quotes:

They always have the red tape; it’s what it is. We have to contact this person, then this person, then this person, then this person. And sometimes the information is lost in the shuffle. Then you have to start all over again (Healthcare Provider 25).

I mean by trying to discourage, putting up roadblocks. “Okay, we’ll – you know, we can’t fight the fact that the doctor’s given the letter... But the doctor never said she needs an escort for medical reasons so no escort.” You think that 75-year-old elder in a wheelchair who’s probably never been to Winnipeg – or rarely – is gonna go? She’s not going now (Healthcare Provider 102).

Just last week, we had an incident where one of our members had a doctor’s referral. She’s pregnant and she had to be in Winnipeg – high-risk pregnancy...we have no control over the services provided through [the Health Authority] so our people have to go to Winnipeg. The doctor’s referral, according to this national policy framework that we’re obligated to follow, which we’re following, states: “On a doctor’s referral, this can happen. Provide this information.” Assume: okay, we’re following your rules. Nothing should happen. It was stalled. The – the doctor’s referral was questioned by one of the [FNIHB] transportation clerks... A clerk questioned a doctor’s note... “Why does she need an escort?” Kay, to me, this – it becomes a – and I don’t know the law enough – but to me, it’s a privacy issue. “It’s none of your business. It’s none of your business why this person – what condition they have, you know, why the doctor’s recommending this... “What gives them the right to know that this person – anything about this person’s condition?” (Healthcare Provider 102).

Although the above quotes may suggest the application of stringent rules of eligibility, the evidence we collected demonstrates that self-advocacy, or advocacy from family members or health providers, may result in rules being implemented differently:

But if you can't talk for yourself, forget it; you're – you're down there somewhere, you know, to do whatever they want. But I told them, "You can't do whatever you want with me or my husband." I said, "I will speak up" (Patient 208).

With the First Nation-specific – I try and go through the exceptions process. . . , a lotta times, there is nowhere else to go to because the level of, like I said, funding that they receive on reserve is very limited and the programs that are funded are basically education and awareness and that kinda stuff. . . And a lot of times, we have to rely on the Band or ask the Band if they can provide some of the costs that is [are] required to get this patient home. Also, at the same time, sometimes there's province-to-province referrals that is [are] not covered (Healthcare Provider 22).

Our dataset shows that providers, families and patients often turn to First Nation communities to seek assistance (for prescription drugs or medical transportation needs not covered by FNIHB, for example) when all other avenues have been explored. These requests are met with mixed success, depending on program restrictions, eligibility, and First Nation budgets and sources of revenue

In this quote, a provider seeks support from a First Nation community (the Band) so that a patient can return home. Our dataset shows that providers, families and patients often turn to First Nation communities to seek assistance (for prescription drugs or medical transportation needs not covered by FNIHB, for example) when all other avenues have been explored. These requests are met with mixed success, depending on program restrictions, eligibility, and First Nation budgets and sources of revenue.

While policies may have some rigidity in terms of eligibility, persistence and repeated attempts at advocacy appears to result in solutions being reached. The need to self-advocate is not unique to First Nations. What is unique here is that self-advocacy must take place in a context of blurred jurisdictional boundaries, where all agencies involved may understand the request as someone else's responsibility.

Discussion and conclusions

We have argued the policy framework that supports and constrains First Nation peoples' experiences of medical relocation is rife with gaps, contradictions and ambiguities, leaving program managers located in both First Nation communities and in urban-based bureaucracies to sort out how to implement policy guidelines on a case-by-case basis in the midst of

jurisdictional fuzziness. Program managers as street-level bureaucrats are left to implement incomplete and at times contradictory policy guidelines, decide on eligibility, and find solutions while worrying about setting precedents. Moreover, program managers are social actors embedded in national, regional and local discourses on First Nation entitlement, which informs their decision-making. Advocacy can help, but it reinforces the impression that decisions are individually negotiated, rather than policy-informed, and often arbitrary. This perpetuates the impression of inequity in the application of rules, and promotes the politicization of negative decisions.

Our findings show that the policy framework in place to support First Nation peoples who relocate for medical reasons is complex, multijurisdictional, and subject to interpretations by street-level bureaucrats. Decisions on eligibility will invariably require policy interpretations shaped by values, dominant practices, priorities, budgetary constraints and trust. However, ambiguities and gaps in the framework multiply the opportunities for interpretation, variations, inconsistencies and frustrations. Evidence from providers' and patients' success in advocating for coverage after initial denial variously suggests: (1) that the policies are either not as inflexible as expected, (2) that program managers have discretion, or (3) that program managers balance the implementation of rules with the risks associated with advocates who may "go public" by politicizing refusals.

At a time when all governments decry rising health-care costs and express concerns with sustainability, the inefficiencies reported in this paper are concerning

Considerable time is spent advocating by health providers, administrators, First Nation peoples who are relocating and/or their family members. This leads to frustration, loss of trust in the system, uneven application of rules, and ad hoc and often inequitable results between those who advocate and others who cannot. This is partly due to street-level bureaucrats' interpretations, personal understanding of jurisdictional obligations, risk management related to establishing precedents, and is compounded by a policy framework disjointed as a result of jurisdictional fragmentation. This unique context fuels rather than alleviates tensions, and perpetuates an adversarial and politicized environment where access to appropriate care can become compromised, despite best intents. The lack of federal and provincial coordination in the definition of programs and eligibility criteria continues to undermine First Nations' access to healthcare and support services. This gap has been discussed for over fifty years, and is likely to remain as long as healthcare is recognized as a provincial jurisdiction and

First Nation affairs remain a matter of federal jurisdiction. Attempts at changing the latter have been continually debated among First Nations leaders and appear unlikely to be resolved.

More research is required to identify which factors prevail in lower level bureaucrats' decision-making, and the implications therein. More research is also required to track the impact of these structural issues on First Nations' health outcomes, given documented health inequities. Finally, more research is required to quantify the costs of these structural inefficiencies in terms of providers' time. At a time when all governments decry rising healthcare costs and express concerns with sustainability, the inefficiencies reported in this paper are concerning.

In addition, we propose a national policy framework that includes a mechanism for federal-provincial coordination. The first step would be to create federal-provincial-First Nation coordination tables, akin to the British Columbia Tripartite Table (First Nations Health Council, Government of Canada, and Government of British Columbia 2010) or the Intergovernmental Committee of Manitoba First Nations Health (Intergovernmental Committee on Manitoba First Nations Health 2008). The second step would involve the transfer of some federal decision-making authority to these tables to improve regional coordination. Developments in British Columbia (BC) related to the newly established First Nations Health Authority suggest openness to this recommendation, and results to date appear encouraging.

[W]e propose a national policy framework that includes a mechanism for federal-provincial coordination

A key difference between the context described in this paper and the emerging context in BC is the high level of commitment and investment by the provincial government, the Health Authorities, Health Canada, the First Nation Health Authority and First Nation communities to joint planning and decision-making and to reciprocal accountability in terms of outcomes (First Nations Health Council; First Nations Health Authority 2013). There is potential for service level and system decisions to shift focus from jurisdictional boundaries to bridging jurisdictions using a collaborative model informed by Jordan's principle to better serve First Nations' needs (Lett 2008).

Notes

- 1 Lipsky described street-level bureaucrats as "teachers, police officers and other law enforcement personnel, social workers, judges, public lawyers and other court officers,

- health workers, and many other public employees who grant access to government programs and provide services within them" (2010: 3).
- 2 The Intergovernmental Committee on Manitoba First Nations Health (ICMFNH) includes representatives from the Assembly of Manitoba Chiefs, the Southern Chiefs Organization, the Manitoba Keewatinook Ininew Okimowin, Aboriginal Affairs and Northern Development Canada (formerly Indian and Northern Affairs Canada), Manitoba Aboriginal & Northern Affairs, the First Nations & Inuit Health Branch of Health Canada – Manitoba Office, Manitoba Health, the Public Health Agency of Canada, Manitoba Family Services & Labour (formerly Family Services & Housing). This policy review was funded by the Manitoba Department of Aboriginal Affairs.
 - 3 FNIHB is the federal department responsible for the funding of health services delivered on-reserve.
 - 4 The federal department now known as AANDC was previously known as Indian and Northern Affairs Canada (INAC).
 - 5 The Manitoba Department of Jobs and the Economy (MJE) is responsible for the delivery of Employment and Income Assistance to eligible Manitobans.

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