McGill | Faculty of Medicine and Health Sciences | School of Physical and Occupational Therapy

“BURYING IN ITSELF”

Challenges faced by practitioners accessing Jordan’s Principle across provinces and territories in Canada

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McGill University stands on the unceded Indigenous lands of the Kanien'keha:ka, Keepers of the Eastern Door of the Haudenosaunee Confederacy.

The Kanien'kehá:ka Nation are recognized as the custodians of the lands and waters of Tiohtiá:ke/Montréal, which has long served as a site of meeting and exchange amongst Indigenous peoples, including the Haudenosaunee and Anishinaabeg nations.

This project elicited perspectives from across Canada, a country subject to respecting treaty relationships, the inherent rights of Indigenous peoples, and with stated commitments to implement the United Nations Declaration of the Rights of Indigenous Peoples.

HOW TO CITE THIS POLICY REPORT

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EXECUTIVE SUMMARY

The Canadian Human Rights Tribunal has adjudicated that substantive equality is not met in the implementation of Jordan's Principle. Further, there is evidence that each province and territory receive differential supports and access to funding via Jordan's Principle, resulting in ongoing health disparities. This policy report is based on a study conducted between 2021-2022 that explored Indigenous Services Canada's administrative functioning at the locus where frontline clinical and administrative practitioners apply for funding through the federal bureaucracy of Jordan's Principle.

The qualitative findings describe the perspectives of 41 frontline practitioners across provinces and territories in Canada whose everyday work requires accessing Jordan's Principle funding and services. Their stories illustrate that the Canadian federal administrative processes underlying Jordan's Principle follows a colonial logic operationalized through a passive deliberate obscurity (inaccessible information, lack of support and accountability) and active punitive gatekeeping (breaches of confidentiality, pulling funding or denying requests if practitioners complain, engaging in culturally unsafe practices, and imposing processes not tailored to local realities). The consequences to practitioners include vicarious trauma and job insecurity as they engage in the moral imperative to resist and circumnavigate a system that does not effectively meet the standards of substantive equality. This report concludes with recommendations to Indigenous Services Canada for more accessible and effective applications to Jordan's Principle. These recommendations complement and echo those made by the Canadian Human Rights Tribunal, The Assembly of First Nations, and the First Nations Child and Family Caring Society.

Recommendations to Indigenous Services Canada

1. Develop national standards and processes tailored to each province and territory's unique demands
2. Support practitioners to better access information and improve contact with Indigenous Services Canada
3. Implement community-defined accountability measures to ensure First Nations children are receiving services in a timely and culturally safer manner

BACKGROUND AND SCOPE

It is a fact that "First Nations children continue to wait for government services, or receive services of a lesser quality and standard than those available to other children" (1). Implemented in 2005 by the Government of Canada, and reorganized in 2016, Jordan's Principle and the Inuit Child First Initiative* would ensure equitable healthcare for First Nations' and Inuit children (2); yet, studies outline ongoing concerns in the implementation of Jordan's Principle (1, 3). The Canadian Human Rights Tribunal (CHRT) has confirmed the inequities documented by First Nations families, and the First Nations Child and Family Caring Society (FNCS) has released multiple reports with recommendations to improve services and outcomes (4-7). These legal and evidence-based rulings and documents are developed by and with First Nations children, families and communities, foregrounding Indigenous self-determination. In 2020, the government of Canada released an audit of the implementation of Jordan's Principle. This audit focused on a high-level assessment of how the department is responding to the CHRT requirements, intersectoral improvements at the over-arching regional and institutional levels, and the response of federal employees within Indigenous Services Canada (ISC) to the increasing complexity and volume of Jordan's Principle requests.

The request for this study and policy report was put forward by the Canadian Association of Occupational Therapists' (CAOT) Occupational Therapy and Indigenous Health Network (OTIHN) and approved by the Occupational Therapy Truth and Reconciliation Commission Task Force (TRC Task Force). Members of the pediatric subgroup of the OTIHN identified that the barriers that they face as frontline practitioners accessing Jordan's Principle as requestors were not visibly documented, and that it was necessary to identify and address these challenges. In the present context, an estimated 1.2% of Canadian healthcare professionals identify as Indigenous (Aboriginal Nursing in Canada Factsheet). That is, the majority of clinical and administrative healthcare practitioners who interface with the bureaucracy of Indigenous Services Canada (ISC) and Jordan's Principle funding are not Indigenous. The perspectives of frontline practitioners can provide concrete everyday examples of the federal mechanisms and processes at the locus of applying for funding and services, in order to identify challenges and propose improvements in the accessibility and everyday administrative functioning of Jordan's Principle (see Fig 1 here).

The aim of this evidence-informed report is to describe the challenges and facilitators experienced by frontline clinical and administrative practitioners across provinces and territories in Canada who are responsible for interfacing with, and accessing funding through, Jordan's Principle.

STUDY METHODS

"Yes, and this is super important to probably every practitioner sitting in this group, and I know I can certainly speak for several of the people that I work with in the communities that I service, and they couldn't be more excited about a project like this"

This multi-method qualitative study applied an anti-colonial lens to interpretively describe the perspectives of 41 practitioners whose responsibilities include applying to Jordan's Principle.

Anti-colonial interpretive lens

Interpretive description has the "purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding…requires a representation in a form that explicitly acknowledges the analytic processes that occur in transforming raw data into findings" (8). The interpretive process in this study was explicitly shaped by the fact that barriers

in implementing Jordan's Principle need to be understood in the context of a settler-colonial structure (9), and that Indigenous-government administrative relations in Canada have inherited a historical intent to colonize (10). Thus, thematic descriptions and codes were interpreted within this colonial history (10-12).

Interviews

17 practitioners participated in interviews over the summer of 2022

Group meetings

24 practitioner members of the OTIHN who work in pediatrics participated in eight story-telling group meetings across 2021-2022 to share their perspectives and elaborate on the emergent research findings

Data Analysis

Analysis involved immersion and coding the data within each individual interview/ meeting, identifying emergent themes that respond to the aim of the study, then comparing and deepening the themes across interviews/meetings. The themes were triangulated with nine CHRT and FNCS documents and orders.

Member checking

The FNCS was informed of this study from its launch and communication was maintained through the FNCS Administrative and Executive Assistant who provided the team members with support in accessing all legal documents and reports pertaining to Jordan's Principle, as well as feedback in July 2022 on a midway version of content presented in this report.

The OT TRC Taskforce reviewed and provided feedback on a draft of this report in September 2022. The co-chairs of the OT-TRC taskforce and the CAOT's Government Relations Manager reviewed and provided final edits to this report.

Please see Appendix 1 for further details on the research methodology and ethics.

FINDINGS

The overarching finding is that the implementation of Jordan's Principle occurs through a bureaucracy of colonial intentions despite the principles for governing relations between Canada and Indigenous Peoples.

> ***"Even though on one hand you can say 'oh all you need to do is fill in this form' getting the information, like knowing the information to fill in the form, is sometimes... burying in itself."***

"Burying in itself" is a striking and central metaphor in this study. It was used to describe how the infinite amount of paperwork written in inaccessible jargon and difficult to find on the ISC website was 'burying' families who seek to apply for Jordan's Principle funding. This results in eligible children not getting equitable health and rehabilitation services, with negative outcomes.

The metaphor of burial strongly echoes the over 1,000 unmarked graves of Indigenous children at residential schools across Canada that were found in 2021 and continue to be investigated. Indigenous children are still impacted or dying as a result of the failings of the Canadian government, including in the present day through the barriers in accessing Jordan's Principle finding and services. Statistics concerning the number of children who were not provided services and how many children have died as a result of lack of substantive equality in service provision is also 'buried' and not available, as a Management Control Framework has yet

to be released since its announcement in the 2020 audit (see section 2.3). One proxy information can be found in the 2021 CHRT 12 orders where it is stated that in the 17 years since the establishment of Jordan's Principle, ISC has paid out only 2% of its promised funds to First Nations children, families, and communities not served by First Nations Child and Family Service Agencies.

The image of burial, of being placed out of sight, of being unfindable, of needing to dig over and over to find what is needed, or conversely, clamber out of impossible holes, is supported by the following quotes in a 2021 report released by the First Nations Caring Society on ISC's non-compliance with the CHRT orders:

"It is unfathomable that ISC was not able to connect the needs of a child with a spinal cord injury to the need for home modifications. It is even more disconcerting that the solution was to fund the child to stay in a hotel in the midst the COVID-19 pandemic when those with spinal cord injuries are predisposed to respiratory issues" (7).

"The requirement by ISC to "reapply" on a regular basis is inconsistent with the lived realities of children with disabilities and special needs and places an additional burden on families who are often stretched with caregiving responsibilities" (7).

"ISC does not consider the clock to start until Focal Points are satisfied with in the information provided. This practice does not reflect with the spirit of the CHRT orders, in which 48-hour (or 12-hours for urgent cases) starts when the request is submitted" (7).

The analysis presented in this policy report unpacks the depth and impact of this colonial logic and systemic barriers faced by practitioners accessing Jordan's Principle funding. Findings will be outlined in three sections:

(I) The ways in which the ISC colonial bureaucracy operates through deliberate obscurity and gatekeeping
(II) The harmful consequences of this bureaucracy on First Nations families and practitioners
(III) How practitioners resist, refuse and (counter)navigate the ISC bureaucracy.

For an overview of the facilitators and challenges in accessing Jordan's Principle funding, outlined by province and territory, please see Appendix 2.

I. HOW ISC BUREAUCRACY OPERATES TO MAINTAIN INEQUITY

The ISC bureaucracy maintains inequity through two primary means: deliberate obscurity and gatekeeping.

I.I. Deliberate obscurity

Deliberate obscurity relates to the concept of obscurantism, which is defined as the opposition to the spread of knowledge, or as a policy that withholds knowledge from the general public (13). In the case of Jordan's Principle, this obscuring of knowledge leaves those who are meant to be served by the policy in the dark about how to effectively apply for services. This is because healthcare professionals are also subject to this obscurantism, and must learn how to navigate the system themselves all the while being in the dark (14).

"I just see that we're being taken advantage of, and I feel like there's these systematic things and barriers in place that shouldn't be in place and it hurts me so much to see these families fight this battle, that just seems so unwinnable, you know."

Deliberate obscurity is a *passive absence* of clarity, support and engagement which is maintained in the following four ways, as described by the majority of practitioners:

Inaccessible information
Difficult to navigate websites and forms that use jargon set up an unreasonable expectation of health literacy. Health literacy is defined as degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (15).

> *"I was like this is Greek to me, like I literally print off the instructions and I'm like OK follow step one like every time because there's just kind of like a lot of nuances to it."*

> *"Given that historically Indigenous peoples in Canada have had serious difficulty with educational systems maintaining their literacy, the average person, for example, Indigenous person in [province] has a Grade 5 literacy level. Right, so you give them a government form and they're like…. I've seen people literally cry."*

Of note, it took a research team member several days of searching, downloading a new software, and multiple trials to access the basic forms to submit for Jordan's Principle as part of the preparatory work for this study.

Lack of support from ISC
Several practitioners described a lack of available support in order to navigate the application processes, compounding the passivity that leads to inaccessibility.

> *"She says Jordan's Principle is a waste of time, don't even try. So, community health professionals are telling families not even to try with Jordan's principle because of all the barriers and the red tape and the like non cultural safety that's happening."*

In some provinces and territories, having a Jordan's Principle navigator or coordinator was deemed a significant facilitator to successfully accessing and interfacing with ISC.

Lack of accountability
An accountable process establishes mechanisms for citizen oversight (16), which practitioners report as lacking in the ISC bureaucracy. Without the FNCS and other researchers' commitments, it seems unlikely that any checks and balances would have taken place as initiated by ISC, particularly with a Management Control Framework still pending in late 2023. There are multiple levels of unaccountability, as practitioners report that even in terms of basic service provision and quality assurance, there are minimal to no application and email follow-ups from ISC, as well as a lack of the evaluation of the impacts of current procedures and services.

> *"Jordan principle seems to run on like a lot of like processes of like you know yeah, send this e-mail with this title and like sometimes you don't hear back, so then you're kind of left like OK what do I do now, you know?"*

> *"Jordan's Principle is intended to fill gaps, but we don't see a long-term plan at all for eventual provincial accountability."*

> *"It's great to be afforded funding, but up in [Northern territory], practitioners can come without being licensed and there is no mechanism of accountability to verify the quality of the services that are being funded."*

I.II. Gatekeeping

Gatekeeping is when an individual or group in power controls access to goods, services and information (17). In addition to gatekeeping information and knowledge, in the case of Jordan's Principle, there is also gatekeeping of decision making, as to who gets to allocate or deny funding allocation.

> *"I submitted a letter of support to get a child a couple boxes of diapers. I didn't realize that I actually needed a letter of support for something like that. I've run into issues where I have kids as old as eight or nine, and they're not potty trained yet, which is obviously an issue. I honestly don't think you should need one for developmental toys or continence products or something like that"*

Gatekeeping is an *active process* of creating barriers and risks which occurs through the following strategies:

Breach of confidentiality

In submitting requests, several practitioners described a demand by ISC to provide information that can lead to breaches of treatment confidentiality for First Nations families. This is a particularly salient concern when one considers colonial history and how the documentation of First Nations peoples has been used to assimilate and control (18).

> *"it made me very uncomfortable that, you know we were compiling people names in a document and having like all of their personal information. Whether that was like their status number or their diagnosis, anything that you can imagine was kind of seeming to be in this document"*

> *"They [ISC] would be calling up families to ask about their rehab goals and if they have been met, and it is out of context to ask about that without understanding the whole picture. And, what about patient confidentiality? Who is the government person calling to ask?"*

Punitive measures

All practitioners spoke of advocating for and with First Nations families; however, several of them expressed a fear of ISC finding out that they are participating in this study as there can be real consequences deployed by ISC against those who do advocate.

> *"I don't really want anybody to be identified, but I guess it's just going to be general, right?... If you voice discontent with Jordan's Principle to ISC, they either stop funding your clients or decline all your applications. That has happened to me"*

> *"If a family doesn't answer the phone when ISC calls, or they don't give the requested info, then funding can be pulled. That's not ok – what if someone doesn't have a phone, and doesn't trust the agent? Why are they even asking confidential stuff about rehab goals and if you don't answer, then they'll stop paying."*

Culturally unsafe practices

Practitioners described several culturally unsafe practices required by ISC, such as directly phoning families to justify funding, surveilling children's rehabilitation outcomes in order to provide funding, and requiring the use of standardized assessments.

> *"What standardized way are you measuring outcomes, and how do you? What evidence-based way are you making the decision? That's definitely super harmful. And when the standardized assessments haven't even been standardized with that group, then they are not necessarily valid. You're making decisions based on results that aren't valid for the population you're working with"*

"a lot of barriers in place that are not effective and not reasonable like not culturally safe ones like suddenly they need these 22-page applications put in place for children to receive service for things that they're asking for"

Application processes are not tailored to local realities

The climate and environment of non-urban First Nations geographical locations influences their access to care. The available infrastructure delimits the availability of public transport, internet, and cell service making it difficult to apply for and complete the required documentation. Processing of an application often requires that the family makes phone calls and fill out forms requiring particular software, which can – in some cases - be impossible.

"There are a lot of homes where you have eight to 12 plus people and they don't have internet. There are times when people don't have running water or they're living in condemned homes."

"[The service delivery] tends to be more consultative just because there are a lot of barriers even getting into the communities. […] So, in an ideal world, we travel up every two weeks or so, but a lot of the time it ends up being like once-a-month travel for four days at a time"

The requirement for third party assessments is both unsafe as children are subjected to repeated evaluations that are not normed to First Nations and are also unrealistic to request in remote communities as the services do not exist or have unacceptably long waitlists.

"They want educational psychologist assessments. It's really hard to get a school psychologist up in our region. As you can imagine, they're [ISC] gatekeeping their application system and saying: 'we're only going to say that this child is approved for funding if they have completed a psych Ed assessment', which is a three year wait. Or they will ask for yet another evaluation by third-party in your discipline, and there is only one practitioner in that discipline in the region who already saw the child and put in the application for Jordan's Principle. In the past there were never those barriers. Now it's a nightmare."

These bureaucratic barriers in the requesting process of Jordan's Principle represent a climate of colonial continuity, where ideologies and practices of a colonial state continue to operate as legacies of power hierarchies, despite purported policies to the contrary (10). That is, disciplines that have historically aligned with colonial agendas and state power are given priority in decision-making (19), and the requirement for presupposed neutral or objective westernized third-party evaluations are either simply not feasible or invalidate the work of community-based practitioners who have built trusting relationships and contextual understandings (20). With practices that maintain colonial control and harm still present, there is a valid distrust of ISC by both practitioners and First Nations communities.

II. CONSEQUENCES: ONGOING IMPACTS OF SYSTEMIC HARM

The impacts of colonization on Indigenous populations unfortunately remain active in present generations in Canada. Understanding the perspectives of practitioners who are accessing Jordan's Principle has to be contextualized in the broader realities of the consequences of residential schools and ongoing systemic injustices such as unequal distribution of services to Indigenous children (9), as well as racism both at the systemic and individual levels (21). The transgenerational trauma and mistrust towards the Canadian government and federal services it provides extends to and includes the federal management of Jordan's Principle.

II.I. Health outcomes

Systemic issues directly impact patients' health, with a continuation of multigenerational trauma that First Nations children experience due to the sub-par services they receive, in comparison to non-Indigenous children** (22, 23). Unacceptably long wait times for funding approvals under the Jordan's Principle policy due to gatekeeping is a common barrier that hinders service delivery to children in a timely manner in four of the eight provinces represented in this study (Appendix 2). Delays in approval result in First Nations children facing further health and developmental challenges, leading to social and functional consequences in a range of activities from self-care to schooling (24)reasons, and consequences.

> *"So yeah, sometimes it's like a lot of waiting and with kids it's like they're developing as time goes on, right? So, if you finally see them two years later, they're totally different than if you would have been able to see them two years ago"*

> *"Because I've run into issues where I have kids that are as old as eight or nine, and they're not potty trained yet, which is obviously an issue there … with long term impacts on pelvis health and impacts for continence"*

The unsafe colonial practices described above continue to be imposed on First Nations families. Western practices such as standardized assessments disregard the potential harm that can be inflicted on Indigenous Peoples and can fuel the cycle of intergenerational trauma. These practices are not aligned with Indigenous cultural values and beliefs, or with reconciliation (25).

> *"It's so traumatic for families…The family has to go through that whole system again that whole traumatic system of like trying to find a touchpoint, trying to get letters of support from doctors, healthcare professionals, see if they have an assessment that's time valid enough. You know they're asking now for those assessments, every year like it's crazy it's so culturally unsafe - it's so unsafe"*

II.II. Harms to practitioners

The administrative structure and inconsistent funding processes established by Indigenous Services Canada cause downstream problems in service delivery that are shouldered by practitioners. Practitioners are at risk for burnout and vicarious trauma due to the challenges they face when working with the bureaucracy of Jordan's Principle.

> *"Therapists are leaving, therapists are getting burnt out, therapists are getting frustrated at the system... the erosion of the front line is a strategy to maintain a colonial control because with high turnover we're constantly starting over without institutional memory"*

Burnout syndrome results from prolonged exposure to job stressors (26). In the context of the current federal administration around Jordan's Principle, stressors that practitioners experience include:

1. Practitioner job insecurity
2. Advocating for substantive equality and resources to meet patient needs
3. Managing the excessive administrative load caused by gatekeeping
4. Witnessing the traumatic impacts of systemic harms on Indigenous families
5. Maintaining relationships with Indigenous families and communities in a colonial context reproduced by ISC-mandated processes.
6. Anticipation of high staff turnover leading to the fear of losing hard-earned know-how from more experienced

** Please note that the health and social impacts of inequality in the (in)accessibility of Jordan's Principle on Indigenous children are not the focus of this project. Details about the specific and extensive impacts on families and children can be found rigorously documented by Indigenous communities and researchers.

practitioners

Having to continuously deal with challenges and to manage heavy caseloads without adequate financial and emotional support may overwhelm practitioners, cause psychological trauma, and affect their physical and mental health (27). Specific examples of the challenges that practitioners face are described as follows.

- ISC fails to provide practitioners with the necessary and timely funds to meet their responsibilities.

  "Every year there would be probably four to five months at least that we didn't know if we had jobs anymore. We would just go to work and hope because Jordan's Principle hadn't responded to anything…I don't get paid for this money. I don't get paid for these kilometers, mileage and travel"

- Labor shortage in non-urban geographical locations is a common problem. Practitioners have to face the stress of managing heavy workloads and meet ISC requirements without sufficient and required human resources.

  "it's really hard to get a psychologist, a school psychologist up in our region. Sometimes the wait list is over three years…that's another issue, getting people to fill the roles up north. You have pretty high turnover rates and a lot of people not working, unfortunately"

- The long-term witnessing and experience of healthcare adversities causes emotional and psychological trauma to practitioners. They are actively dealing with the injustices and barriers inflicted on children without being able to improve quality and accessibility.

  "I am so frustrated. I never want to deal with Jordan's Principle anymore. I get a referral on my desk and my heart drops and I'm like how are we going to navigate for this poor family?"

  "Like I don't want to do it because the stress on me, the stress on the family, the anxiety, the time commitment and for like not even getting paid and you just see these families going through trauma and trauma and trauma."

- Emotional struggles, the fear of losing relationships with First Nations communities, and concerns with causing harm.

  "It was hard to start some projects with families and develop relationships. Knowing that if I'm not here next week, knowing the impact that would have. Just because of the history with the community, you don't want to be that face of harm in the way the service is set up in the end and you're not there, so that made it really hard"

- Practitioners must deal with potential acts of punishment when voicing discontent.

  "It's like a fear based like punishment system almost and it sounds really dramatic to say that, but it's not uncommon for them [ISC] to put in college complaints against therapists that express discontent"

  "Voice your discontent with Jordan's Principle and they either stop funding your clients or decline all your application…It's like you put your head on the chopping block. It's terrifying"

- Practitioners anticipate ongoing and high turnover of staff in their regions. They understand that newly hired healthcare professionals often lack knowledge and experience working with ISC, which entails a responsibility for keeping and transmitting knowledge of the system between practitioners

in a mentoring process.

"So, um, that corporate knowledge, that, that, that corporate memory can be limited, especially even in community, like look at my staff. I mean, I've been here five years, but if I left, then a lot of corporate knowledge would be lost."

"I've been really trying to put everything on a shared drive and put everything, just make sure anything, any document, any knowledge that I have - not confidential stuff, just systemic stuff- is all very well documented and very well laid out. Not only for the access of staff right now, but if I ever did leave, like in a transitionary capacity"

III. WHAT DO PRACTITIONERS DO?

In the face of a colonial bureaucracy, inequitable gatekeeping in several provinces, and harmful consequences, practitioners resist, navigate and contend with implementing Jordan's Principle through several strategies.

III.I. Refusals and resistance

Practitioners voice their disagreement by refusing the delivery of westernized approaches that are ineffective or unsafe. Colonialism is defined as the process by which the beliefs, values and practices of the colonizing group are imposed on First Nations (28). The standardized assessments and excessive information required by ISC disrespect and harm First Nations families. To oppose these, practitioners have been actively refusing, resisting and expressing discontent towards colonial principles and practices. In particular, practitioners identify and resist the practices that support deliberate obscurity

"And they have changed the forms, but I always go back to the old form because I find it's the most straightforward one from for myself"

"The federal government, it's just a colonial thing right? It's a colonial model. I think we're gonna see dilution. We're gonna see it become more community controlled, but that's why I always tell my staff, you can push back. You can say no. Jordan's Principle was described as we're building the plane while flying it. So, if we're building it while we're doing it, then this is the time for us to be like, yeah, we're not doing that. Or this doesn't work for us, or we're gonna do this instead."

Practitioners also counter navigate, circumvent and challenge gatekeeping in their own ways.

"I think for the most part I would say the majority 99% come through me as the coordinator and it skips all that extra steps for them, you know."

"You need to know how to write it. You need to know what not to say. You need to know what not to include in the budget. Because otherwise they'll comb through it. Like, it's just, it's really, I don't wanna say it's stupid, but it's annoying. It's annoying. Unless you know how to do it and you only know how to do it by messing up."

"They [family] were waiting for reimbursement. They simply wouldn't be able to get the service, right. So, we've taken on and maybe that's one of the reasons that it works so nicely is that we've been that buffer, right? So, we provide the service. And then we go after Jordan Principle for the reimbursement, for the payment for it. We do that direct invoicing."

Practitioners compensate for time delays and gatekeeping barriers by paying out of pocket to ensure

immediate services, thereby shouldering the burden of delayed reimbursement.

> *"Professionals are recommending equipment and then ISC won't respond at all to phone calls or emails to support, and there's no one to support the family, so I'm personally purchasing their equipment and then being reimbursed months later by Jordan's Principle."*

> *"They got this like complex piece of communications technology, but had no clue how to use it, or set it up. It was purchased through the local First Nation organization, which was amazing, but because they had purchased it, they had to go through this whole rigamarole to ensure the actual parent could have his own account, but then there was no one to support. So again, I ended up supporting with teaching how to use the equipment"*

III.II. Relationship-based practices

Practitioners identify solutions and strategies through relationships with colleagues and patients. In some instances, practitioners learn from First Nations families' experiences of dealing with Jordan's Principle.

> *"And if they really just knew about it, maybe if someone was going through the process of an application, if they could share what that experience was like, they'd feel a lot more comfortable even bringing it up to families"*

Practitioners compensate for the lack of clarity and information from ISC by collecting information through dialogue with those with whom they have established connections and trust. Practitioners rely on their networks to share stories, suggestions and knowledge to navigate the healthcare and federal systems. This strategy echoes Indigenous practices and values, which emphasize that we interact with multifaceted environments (28), privilege interrelationships, and honor language and orality as important knowledge transmission mechanism (29).

> *"I think it's like word of mouth. You know some of these like systems. Yeah, talking to colleagues"*
> *"So,I just moved one of my therapists in into a part time intake coordination position, right? So, we just wrote an e-mail saying, oh, this is [practitioner] and she's going to be interfacing with Jordan's Principle… it really helps to relate on a personal basis"*

In engaging with relationship-based ways of learning, practitioners actively promote anti-colonial practices to circumvent bureaucratic barriers. This further creates space for reciprocity and shared learning with First Nations families and inscribes itself in the long-standing ways in which communities disrupt colonial governmental control.

RECOMMENDATIONS

> *"While ISC staff may be well-intentioned and committed to implementing the Tribunals orders, staff turnover is frequent, the legacy of systemic discrimination runs deep within ISC, challenges due to the confidential nature of Jordan's Principle requests, and concerns of retaliation when staff attempt to address systemic discrimination, all demonstrate the need for independent oversight by a body with expertise in the nature of systemic discrimination faced by Indigenous children and families is in order to ensure that mistakes of the past are not repeated" (30).*

The suggestions provided here are prioritized through the lens of practitioners' experiences and many echo those previously made by the FNCS in 2021 (see Appendix 3 for further timelines and details).

1) **Develop national standards and processes tailored to each province and territory's unique demands**

Different barriers, challenges, facilitators and successes in different provinces and territories can influence the implementation of standards and processes. ISC should develop an understanding of how substantive equality can best be defined and administered within each province and territory taking into account unique features and barriers: e.g., geography, access to healthcare professionals, overall infrastructure. In some regions, the lack of healthcare professionals makes it difficult to obtain standardized or third-party assessments, even if they were deemed safe. Many families have to complete the entire application without obtaining help from an experienced practitioner whereas in other provinces, there is a coordinator to help families circumvent bureaucratic challenges. ISC should understand the variability and shortcomings present across Canada and adapt requirements and standards according to each province and territory's unique demands. These adaptations include:

- Financing for remote travel
- Accounting for the digital divide (internet access) and health literacy levels in relation to the application process
- Simplification and accessibility of forms
- Information required should maintain confidentiality
- Fund and hire Jordan's Principle coordinators to help families go through the application process.
- Remove the requirements for culturally unsafe standardized assessments and unnecessary or unavailable third-party evaluations
- Provide allowances for healthcare professionals to support families throughout the application process
- ISC should provide detailed information about the reason why a request is denied/incomplete and provide a written response as soon as possible

See April 2021 FNCS categories 2, 3, 4, 6, 8,12,13,15,16,17 & CHRT orders 14 & 41

2) **Support practitioners to better access information and improve contact with Indigenous Services Canada**

Supporting practitioners to better access information is another important measure to facilitate navigation of the system, improve efficiency and ensure patients receive services in a timely manner. Information about Jordan's Principle (application processes and other detailed information) should be easily accessible in all healthcare institutions including private organizations. These government websites should be easy to navigate by both families and practitioners. It is the government's responsibility to undertake different methods to ensure accessibility and improve practitioners' knowledge related to Jordan's Principle. These knowledge translation measures may include:

- PowerPoint presentations, video presentations
- Information access through multi-lingual pamphlets
- ISC provided local workshops and training
- Clearly identify contact people at ISC, available via website and phone per province/territory, and simplify province contact emails available on the government website
- Information sessions for families and practitioners

- Develop manuals, toolkits, booklets, online tools to guide practitioners and families
- Update request forms to include a mandatory section to identify the urgency of the case

See April 2021 FNCS categories 1, 4, 7, 9 & 12

3) **Implement community-defined accountability measures to ensure First Nations children are receiving services in a timely and culturally safer manner**

There is a large disparity between how western governments and First Nations communities understand and practice shared accountability(31). For First Nations people to cooperate strictly with a western governments compliance system, they would have to abandon their own systems for one that has failed them (31). To make the systems implemented by the ISC equitable with and for the communities it serves, First Nations must lead the process (31-33). That is, there needs to be a shared understanding of meaningful indicators and culturally relevant accountability mechanisms that evaluate the comparative achievement of substantive equality based on access, fund timing and allocation, harm reduction, and the specific successes and effectiveness of services provided to families with success defined by recipients of services (14). Establishing mechanisms that align with the *United Declaration on the Rights of Indigenous Peoples* to support Indigenous communities' self-determination and governance is an imperative, alongside the implementation of external auditing structures and processes to be able to sanction ISC when failures occur.

See April 2021 FNCS categories 1, 4, 7, 9 & 12

CONCLUSION

"And there's no accountability, you know, uhm, that really like it. It's really frustrating and I'm really hoping that this project can help."

There continues to be a lack of relational and meaningful accountability from ISC when it comes to Jordan's Principle applications across the country, despite recent reviews and audits. The inability for families to easily submit requests and the time it takes for requests to be approved ultimately leads to negative consequences for First Nations children and their families, as well as practitioners. The latter is particularly notable for the risk of burnout and high turnover in a post-pandemic time of healthcare staffing, which is in tension with the imperative to retain knowledgeable and committed practitioners who are engaged in community relationships.

A colonial bureaucracy maintains a lack of Indigenous-led governance and cultural safety in the accessibility of Jordan's Principle across the country. The Canadian government's reproduction of deliberate obscurity leaves frontline practitioners ill-informed and required to circumnavigate the system to best help First Nations families and communities. In many cases, the government gatekeeps their services by requiring practitioners and families to submit multiple documents with supplementary information, leading to unacceptable delays in service provision. It is apparent that the accessibility of Jordan's Principle differs greatly across all provinces and territories. Some regions see more successes while others are waiting months for approvals or reimbursements.

It is clear that there are some easily implemented next steps, such as improving the accessibility and legibility of administrative processes that could quickly simplify and improve clarity and success of applications. It is hoped that ISC's forthcoming Management Control Framework meet some of the concerns identified herein, particularly in relation to transparency and the establishment of Indigenous led accountability indicators and mechanisms. Instead of 'burying in itself', ISC should reveal itself and fulfill the promises of Jordan's Principle to advance substantive equality- and in doing so, finally honor the legacy of Jordan River Anderson.

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APPENDIX 1: RESEARCH METHODS OVERVIEW

This **multi-method qualitative** project used an interpretive description methodology (8) to understand the implementation of Jordan's Principle across Canada from the perspective of practitioners and administrators directly working and interacting with Jordan's Principle. This project did not focus on the lived experiences of Indigenous individuals, families, and communities receiving Jordan's Principle funded equipment or services. The interpretive lens deliberately aligned with an **anti-colonial paradigm** which "recognizes colonialism as a continuing process of imposed and dominating relationships that needs to be both critiqued and resisted" (12). This approach acknowledges that:
1) the systemic problems leading to the curtailed life and death of Jordan River Anderson and the creation of Jordan's Principle are directly tied to the intentions and consequences of colonization, and
2) that barriers in implementing Jordan's Principle need to be understood in the context of a settler-colonial structure.
An anti-colonial ethics means that the explicit intention of this project is to support equitable change in working towards reconciliation (9). It is important to emphasize that this project engaged with the voices of primarily non-Indigenous practitioners and honors their lived experiences and moral engagements.

Group participants included 24 occupational therapists who are members of the Canadian Association of Occupational Therapists (CAOT) OT and Indigenous Health Network with direct and regular experience of applying for Jordan's Principle.

Interview participants included English and/or French speaking key informants, as identified by community partners. They were working in Canada and were directly and currently involved in interfacing with Jordan's Principle in a Canadian province or Indigenous territory for a minimum of 6 months. Practitioners included health care professionals as well as administrators.

A brief description of the project was sent out through the CAOT networks. Practitioners were recruited through the project supervisor, research partners and other professional connections. Snowball sampling and word of mouth was used to further recruit key informants.

Data Collection: Feb 2021 - August 2022
Seventeen practitioners engaged in one-on-one semi-structured interviews between May-August 2022.

There were eight partner story-telling group meetings across 2021-2022. Each meeting lasted 1-1.5 hours with an average of 9-10 members at each meeting and up to 24 members in total. The first two meetings clarified the need and purpose of this project, Meetings 3-6 focused on eliciting partner perspectives and experiences on the challenges and facilitators they experience when accessing Jordan's Principle funding, and meetings 7 & 8 involved member checking in response to emergent themes.

Meetings and interviews were audio and video recorded and transcribed for data analysis. All participants were anonymized, and their codes were kept in a password protected document to maintain confidentiality.

Documents
Four Canadian Human Rights Tribunal legal documents (three Orders and one Notice of Motion)
Five First Nations Child and Family Caring Society documents (3 order information sheets, 2021 Document of concern and the 2022 Letter to Chief General Council)

Data Analysis
Statements identifying challenges and facilitators to accessing Jordan's Principle funding were extracted from the transcripts and were categorized according to themes for each interview and meeting. Preliminary themes were discussed with partners and contextualized in relation to the legal documents. Subsequent refinement of the themes compared themes and deepened understanding in a comparative manner across interviews and meetings. This took place over a 3-month period (Summer 2022) and during the writing of the Policy Report.

Final partner check
The first draft of this report was shared and discussed with the OT-TRC Taskforce in Sept 2022. Further edits and reviews by the OT-TRC Taskforce co-chairs and CAOT Government Relations Manager were incorporated in Summer 2023.

Ethical Approval
This multi-method qualitative study was approved by McGill's Faculty of Medicine and Health Sciences: IRB # A03-B27-22A on 2022/03/09.

APPENDIX 2: KEY FACILITATORS AND CHALLENGES BY PROVINCE AND TERRITORY

Numbers per province reflect the contexts of the 17 interviewees. Findings and were validated by the 24 partners during group meetings.

PROVINCE	FACILITATORS		Challenges	
	Key elements	**Practitioner perspectives**	**Key elements**	**Practitioner perspectives**
AB N=2	• Relationship building and support from the workplace • First Nations Health Consortium has been cited as a good model for reducing delays in reimbursement of out of payment costs.	*"I think it was really positive to have like our teams like such an extensive team, especially in similar communities, to have that as an offering. As opposed to just what they were used to, which was doctors and nurses. I think there is some value in having our Allied health team present and I think it allowed us in some ways, some flexibility in creating more of a community development model."*	• Inconsistent and lack of funding for services • Delayed approvals • Service refusals • Excessive information required for application • Lack of practitioner job security	*"The funding being so inconsistent", "So, then I went to Jordan's principle to see if they could cover kind of the rest of it [rehabilitation equipment] they said no, so that was a bit surprising and frustrating 'cause it was, I think it was close to like $1000"* *"lots of delayed applications that are taking like three months to be processed"* *"Jordan's Principle would always come back and say we need more information"*
BC N=4	• Relationship building with patients and families	*"it seems like as long as the family is interested in still coming, Jordan's Principle will just like keep paying."* *"So, I think that the benefit is you could have like a long-term relationship with the families and the child once they're successfully in the program, as long as there's no other barriers like getting to the site or getting to therapy"*	• Gatekeeping • Culturally unsafe practices • Lack of support • Shortage of practitioners	*"It's a lot of gatekeeping, a lot of declines, a lot of barriers in place that are not effective and unreasonable"* *"they lose applications, it takes like a lot of pushing them and being like where is this application? And then nine months later, they're like we don't have the application, we lost it"* *"You can see a client 3 hours away. Oh, but guess what? Jordan's Principle refuses to pay travel, so they'll only pay you for an hour of time with the client"*
MB N=3	• Every single community has a case manager to help families navigate Jordan's Principle • Practitioners are integrated into the Indigenous community they serve • Minimal barriers for referrals and self-referrals • Screening days improve service promptness	*"They work very hard at planning and the coordination piece and tracking down families and, making sure that we have what we need, and the families have what they need"* *"If I need something or if I have questions, um, I can reach them [ISC case manager] very easily and they respond to emails and phone calls and messages and, and things like that. I know that if I send them a text message they'll probably call me sometime in the next hour"*	• Long wait times • Lack of infrastructure for rehabilitation practitioners • Lack of infrastructure for continuity of care • Increasing caseloads and lack of practitioners • High practitioner turnover • Travel demands to communities	*"One of the challenges that I›ve experienced is the wait times for approvals from Jordan›s Principle. I, think right now it's somewhere between six to eight weeks approval."* *"Even though we can say, look, there's twice as many kids as there were two years ago, they don't have twice as many therapists they did two years ago."* *"Technically, because it's federal funding, we're supposed to be able to stay in the nursing station, accommodations in communities. Most of the time that doesn't happen"*

NB N=2	• Efficient communication between practitioners and Jordan's Principle • Strong interdisciplinary relationships	*"So we have really good relationships with them [ISC] in that we can, we can fight them a little bit. We can challenge them. We can say, no, we're not doing that. But at the end of the day, we have a lot of really great mutual respect for one another and have a lot of communication."*	• Job insecurity & high turnover • Limited resources to support practitioners and to meet the needs of the region • Communities have no say in funding allocation	*"They're not gonna leave the cities to come and work for a 12-month contract. Can I have a three-year contract? And I'm like, Nope, you can have a one-year contract, cuz all the funding is annual […] which is difficult on job security and recruitment, especially in rural New Brunswick"* *"I have accepted that it's high turnover and that when I'm losing my staff, they're going to other community-based positions."* *"And at child and family, there's one person doing the job of two or three people."*
NWT N=1	• Short wait times • Responsive and reachable agents working for Jordan's Principle • Presence of coordinators to help families navigate the system • Adaptive and flexible funding	*"[ISC] has been super responsive, I think we're very fortunate and I think people don't realize how fortunate we are respective to other regions in Canada."* *"Turnaround timelines for getting approvals can happen within a month like that's pretty quick compared to other places."* *"There are Jordan's Principle coordinators within most of the First Nations"* *"Also been pretty responsive about, you know they fund one pocket of approval and being able to adapt it to go OK, we didn't use all of the funding, would it be possible for us to carry it forward for next year"*	• Lack of Indigenous leadership/governance	*"I think it needs to be frank. I think it needs to be run through Indigenous governments directly because I think sometimes, we missed that step because, you know, in education systems they don't always connect with the Indigenous government before applying to Jordan's Principle. I think it would be strengthened by having that funding approval go through Indigenous governments directly […] many of our Indigenous governments want to draw down the authority over their own education system, their own health system, their own child family, service systems and so Jordan's Principle speaks to those Systems and so having that funding go through their Indigenous government, it supports self-determination in those jurisdictional areas."*
ON N=2	• Coordinators to help families navigate Jordan's Principle application process • Reliable Jordan's Principle funding • Job security for practitioners	*"There's a staff member there who's sort of responsible for Jordan principal applications […] They would have like a ton of experience in dealing with individual and possibly even group applications to Jordan's Principle"* *"I mean, no complaints really, the budget allowed for us through Jordan's principle for travel and things like that."*	• Lack of healthcare workers	*"There's lots of Jordan's Principle funding available for respite services and no respite workers. And so there, the money is not the problem, it's the manpower"*

QC N=1	• Accessible services with short wait times • Presence of a dedicated Jordan's Principle coordinator to help families during the process	*"I have a great support with my organization here in [Mohawk territory]"* *"I think at the Quebec region it's really well organized and I have good support from the program officer."* *"Sometimes I'll have an approval the same day. The longest I waited is maybe 48 hours."*	• Excessive proof/ assessments required for application for certain services	*"They were asking for a document from a mental health professional to attest to the mental health effects of not having orthodontics. If the child experienced bullying because of their teeth…you can ask the teacher at school who witnessed bullying because of the child's appearance because of their teeth and that's really stretching it"*
YT N=2	• Ease of application processes and approvals • Abundance of healthcare workers • Accessible and reachable government agents and coordinators	*"Everything is sort of said yes to. And there's like a lot of group funding."* *"They're quite openly funding our request without a lot of demand for standardized assessment or other evidence"* *"They have multiple therapists like 3 OTS and 3 SLPs and mental health counselors and all kinds of things, all funded through Jordan's principle"* *"Healthcare professionals can send requests directly by emails and get approved directly"*	• Approved applications are incomplete • Inefficient organizational coordinators causing delays in the application process • Harmful reimbursement processes • Practitioner job insecurity	*"Jordan's principle will approve the amount, but then there's nobody to order the equipment. The family can't put that money upfront or they don't have the means"* *"Another organization had their own coordinator, and for some reason they would have been quoted at the wrong rates or there'd be a quote approved for a child to be seen in person in a remote community with no travel costs included in the quote"* *"I ended up hiring a finance manager for my clinic because it was taking so much of my personal time just trying to track down and get paid. [It is] Absolutely full-time hassling, which is a little ridiculous, but trying just to get the payments right when she came on took several months. She started last year fall of 2021 and she was going after money from 2019."* *"A lot of our families just don't have [the money]. Like hotel costs could be $800, plus for a week in town with the most reasonable accommodation we can find, and families don't have that to pay up front, right? And so, we've often paid for them. ".* *"It's very tough 'cause you still have to pay for these therapists, practitioners working. Zero of my expenses that can wait right? I have to make payroll. The rent doesn't wait, the landlord isn't Like oh, that's cool, wait for Jordan's Principle right?"*

APPENDIX 3: TIMELINE OF AFFIRMING RIGHTS AND DOCUMENTING FAILURES

The First Nations Child and Family Caring Society (FNCS), whose mission is to "provide reconciliation-based public education, research, and support to promote the safety and wellbeing of First Nations children, young people, families, and nations". The FNCS is recording a timeline of their legal battles to promote Jordan's Principle at the level of the Canadian Human Rights Tribunal (CHRT). The following is a brief summary of key events and findings.

2007: Since February 2007, The Assembly of First Nations (AFN) and the FNCS have fought arduously in legal proceedings for the promise of equitable healthcare for First Nations children. 2007 marks the inception of the first CHRT case on inequitable funding for First Nations children despite the implementation of Jordan's Principle two years prior (4).

2017: A decade later, the Canadian federal government was found to be falling short of the ensuring equitable care for First Nations children through Jordan's Principle, and was mandated by order of the fourteenth CHRT to "ensure substantive equality in the provision of services to the child, to ensure culturally appropriate services and to safeguard the best interests of the child. This requires Canada to provide all First Nations children, on and off reserve, and Indigenous children ordinarily living on reserve, with publicly funded benefits, supports, programs, goods and services in a manner and according to a standard that meets their needs and circumstances, on a substantively equal basis with non-First Nations children" (34).

2021: The FNCS released the "*Concerns with ISC's compliance with the 2017 CHRT Orders on Jordan's Principle*". This document details 24 ways in which Indigenous Services Canada (ISC) remains non-compliant with the CHRT orders in the discriminatory implementation of Jordan's Principle across Canada. The FNCS report clearly outlines facts and experiences from families and professionals. Failures to ensure substantive equality, meet the best interests of the child, uphold privacy rights, and respect CHRT timelines are the primary themes throughout this document. The FNCS also provided a synthesis of solutions at that time.

2022: An Agreement in Principle is reached between the Assembly of First Nations (AFN), class action parties, and the Canadian federal government to provide retroactive compensation to victims of delayed or outright denied child health services under Jordan's Principle since 2007 (5). However, there remains a lack of guarantee on Canada's part to ensure the distribution of compensation for every entitled victim under the tribunal's orders. In March 2022, the CHRT released an order (35) to extend and fund post-majority (up to age 25) healthcare services given that Indigenous youth (0-25) are the fastest growing segment of society in Canada (34).

Resource for further details and recent settlements:
Timeline of Jordan's Principle and First Nations child and family services (2005-2023)