

Jordan's Principle and Children With Disabilities and Special Needs: A Resource Guide and Analysis of Canada's Implementation

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The First Nations Child & Family Caring Society of Canada in partnership with the Wabanaki Council on Disability and Mawita'mk Society



First Nations Child & Family
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INTRODUCTION

Jordan's Principle is a legal rule to ensure First Nations children get the services they need when they need them. The purpose of this resource guide is to provide families, community members, service providers, and policy makers with information about how Jordan's Principle can support First Nations families of children with disabilities and special needs. This includes providing a history of Jordan's Principle, from being passed in the House of Commons to becoming a legal rule through the orders of the Canadian Human Rights Tribunal (CHRT or Tribunal), addressing common questions and also misconceptions about Jordan's Principle, and exploring past studies and reports about the needs of First Nations families of children with disabilities to see how these needs might be addressed through Jordan's Principle.

This resource was created by the First Nations Child & Family Caring Society of Canada (the Caring Society) at the request of the Wabanaki Council on Disability. The Wabanaki Council on Disability advances the economic, social and cultural, spiritual, civil, and political rights of 15,000 Mi'kmaq, Wolastoqey,

Passamaquoddy, Penobscot, Inuit, and Innu persons with disabilities in the Atlantic region. The information in this guide is based on the following:

- the legal orders on Jordan's Principle made by the Canadian Human Rights Tribunal;
- a review of academic and community-based literature on First Nations children with disabilities and special needs in Canada, with a focus on articles and reports since the creation of Jordan's Principle in 2005; and
- conversations (four total) with Jordan's Principle Service Coordinators and others working at the community level about their experiences with Jordan's Principle and families of children with disabilities and special needs, including a meeting with the Atlantic Technical Working Group for Jordan's Principle.

More information about Jordan's Principle is available at jordansprinciple.ca.

HISTORY OF JORDAN'S PRINCIPLE AND COMMONLY ASKED QUESTIONS

What is Jordan's Principle?

Jordan's Principle is a legal rule named in memory of Jordan River Anderson, a Cree child from Norway House Cree Nation in Manitoba. Jordan was born

in 1999 with complex medical needs and spent the first two years of his life in the hospital in Winnipeg. At two years old, Jordan's medical team determined that it was safe for him leave the hospital and move into a family home, providing that the necessary medical equipment and supports were in place.

Tragically, Jordan never left the hospital. The government of Canada refused to pay for Jordan's in-home supports, arguing that health care was a provincial responsibility.

The province of Manitoba also refused to pay, saying that services for First Nations was the responsibility of the federal government. The expenses at issue



Jordan River Anderson

ranged from improvements to make the home more accessible, to small items like a \$30 shower head. Had Jordan not been First Nations, he would have been released from the hospital immediately, with expenses paid, no questions asked (Obomsawin, 2019).

Jordan spent the next two years in the hospital for no reason other than government bureaucracy. He died in hospital in 2005 at the age of 5 years old, without ever having spent a day in a family home.

Jordan's death sparked a movement to ensure that no other child was treated as Jordan had been. The discrimination Jordan experienced was, tragically, not uncommon. In Jordan's community of Norway House Cree Nation alone, there were 37 children with "severe disabilities" needing speech therapy or physiotherapy that governments were refusing to pay for (see Chambers & Burnett, 2007). A national sample of 12 First Nations child and family service agencies found a total of 393 jurisdictional disputes, disagreements between levels of government (provincial or federal) or between government departments, involving services for children in the past year alone (Loxley et al., 2005).

Jordan's family knew that there were many other children being denied services as he was, and gifted his name to the creation of child-first principle to resolving jurisdictional disputes stopping First Nations children from accessing government services. On December 12, 2007, the House of Commons voted unanimously to adopt Jordan's Principle to address the needs of First Nations children. Jordan's father Ernest Anderson and sister Jerlene Anderson were present for the vote, as well as children and families from the community of Norway House Cree Nation, the Chief of Norway House, and the Grand Chief of the Assembly of Manitoba Chiefs (Chambers & Burnett, 2007; Obomsawin, 2019).

Unfortunately, the federal government did not implement Jordan's Principle as the family intended. In the years following the adoption of Jordan's Principle by the House of Commons, First Nations children were still not able to receive help through Jordan's Principle (see for example, Obomsawin, 2019). In fact, the government's implementation of Jordan's Principle was so narrow and restricted that is questionable whether Jordan himself would have qualified. From 2007 to 2016, the federal government's implementation of

Jordan's Principle was restricted to children living on reserve with multiple, professionally assessed disabilities and multiple service providers (Sangster et al., 2019).

Canada's failure to implement Jordan's Principle in the spirit it was intended led the First Nations Child & Family Caring Society (the Caring Society) and the Assembly of First Nations (AFN) to include Jordan's Principle in a human rights complaint they filed against Canada in 2007. The complaint alleged that Canada was racially discriminating against First Nations children by underfunding child welfare on reserve and by failing to implement Jordan's Principle in a manner consistent with the House of Commons motion.

Canada tried on several occasions to have the complaint dismissed on legal technicalities, which delayed the hearings until 2013. During that time, Jordan's family, community, and First Nations leaders and educators worked to raise awareness about the proper implementation of Jordan's Principle. Thousands of people of all ages and diversities signed up to support Jordan's Principle (see jordansprinciple.ca). In 2015, the Truth and Reconciliation Commission (TRC) made full implementation of Jordan's Principle its third Call to Action.

Among the most courageous leaders for Jordan's Principle were Maurina Beadle, her son Jeremy, and their community of Pictou Landing First Nation in Nova Scotia. Jeremy was born with multiple disabilities and required full-time care, which Maurina provided lovingly from birth, until a stroke in 2010 made it impossible for her to do so without help (Chambers & Burnett, 2007). Pictou Landing provided the in-home care that Jeremy needed and asked the federal government to reimburse the costs of his care to the level he would have received from the provincial government if he lived off reserve (Pictou Landing Health Centre, 2013). Canada refused Pictou Landing's request. Rather, the solution proposed by the federal government was to place Jeremy in an institution far from his family and community, the cost of which would actually exceed the cost of in-home care (Pictou Landing Health Centre, 2013).

Maurina and Pictou Landing challenged Canada's decision in Federal Court. In April 2013, the Federal Court of Canada ruled in favour of Pictou Landing, finding that Jordan's Principle was binding on the federal government. Canada was ordered to reimburse Pictou Landing and pay for Jeremy's care. Canada filed for judicial review of the decision, but in the "face

of mounting negative publicity (and an unwinnable case)” the government ultimately dropped the appeal in July 2014 (Chambers & Burnett, 2017, p. 114).

From the beginning, Maurina made clear that the case was not only about Jeremy, but about the proper

implementation of Jordan’s Principle to ensure the care and well-being of all First Nations children. On hearing the decision of the Federal Court, Maurina stated, “I’m overwhelmed with winning the Jordan’s Principle case, knowing the children will finally get the help that is much needed. I have a sense of inner peace knowing that there will be a change for the children across Canada” (Pictou Landing Health Centre, 2013). Sadly, Maurina

passed away in November 2019. She is remembered as a beautiful mother, courageous, selfless, and “a fighter that held the Canadian government to account” (“Remembering Maurina Beadle,” 2019).

On January 26, 2016, almost a decade after the complaint was filed, the Canadian Human Rights

Tribunal (CHRT or Tribunal) ruled in favour of First Nations kids and found that Canada discriminates against First Nations children and their families by underfunding child welfare and failing to implement Jordan’s Principle.



Jordan’s family speak at the Jordan’s Principle Parade in Norway House.

Jordan’s Principle is a legal rule. What does this mean?

As a result of the Tribunal’s decision, Jordan’s Principle is now a legal rule, meaning that the federal government is legally required to implement Jordan’s Principles according to the Tribunal’s orders.

The Tribunal’s decision in January 2016 (2016 CHRT 2) ordered Canada to immediately cease its discriminatory practices regarding First Nations child welfare, to reform the First Nations child welfare program, to cease applying a narrow definition of Jordan’s Principle, and to take measures to implement the full meaning and scope of Jordan’s Principle.

In a press release about the Tribunal's ruling, Canada said it "welcomed the decision" and agreed "we can and must do better" (Indigenous and Northern Affairs Canada, 2016). Just three months later, in April 2016, the CHRT issued its first non-compliance order against Canada for failing to take immediate action to end the discrimination or properly implement Jordan's Principle. As of February 2021, the CHRT has issued 16 additional orders, many of them non-compliance orders against Canada.

The orders issued by the Tribunal are legally binding.

Canada is legally obligated to implement Jordan's Principle as outlined by the Tribunal. If Canada does not follow the Tribunal's orders, legal action can be taken to force Canada's compliance.

What is the proper definition of Jordan's Principle?

Jordan's Principle is a legal obligation on the part of Canada to make sure First Nations children get the services they need, when they need them. It is *not* a government policy or program. The Tribunal has ordered that Canada's implementation must be based on the principles of substantive equality, the best interests of the child, must be needs-based, and

account for distinct community circumstances. These principles work together to inform decision making about Jordan's Principle requests in a holistic way and must be given equal consideration; no one principle is more important than another.

Substantive equality means that First Nations children may need services and supports above the "normative standard" (what is ordinarily provided by the provinces and territories). The Tribunal ruled that substantive equality is needed to address the impacts of Canada's colonial history and discrimination against Indigenous peoples.

In the context of Jordan's Principle, **best interests of the child** reflects that decisions must be based on the needs and interests of the child, and not determined or delayed by government interests like budget cycles, policy questions, or administrative case conferencing (such as conversations between government departments about who should pay).

As of February 2021, the Tribunal has made the following orders related to Jordan's Principle:

- 2016 CHRT 2 (the decision)
- 2016 CHRT 10
- 2016 CHRT 16

- 2017 CHRT 14 and 2017 CHRT 35 (Amendment)
- 2019 CHRT 7
- 2019 CHRT 39
- 2020 CHRT 20
- 2020 CHRT 36

An information sheet about these orders is available on the Caring Society website for Jordan’s Principle at jordansprinciple.ca.

Canada’s failure to properly implement Jordan’s Principle after the Tribunal’s decision in 2016 and the need for the Tribunal to issue additional orders in the case has, unfortunately, led to confusion on the part of communities and some service providers about the proper implementation of Jordan’s Principle, what Jordan’s Principle can do, and how it can be used. Jordan’s Principle Service Coordinators who provided information for this resource say that they “have to deal with an active rumour mill” and are “constantly pushing back” against misinformation. The misconception that Jordan’s Principle is ending (as

if Jordan’s Principle was a government program that can be cut or “sunset”) was cited as common belief among service providers.

The issue of misinformation about Jordan’s Principle is discussed further in the sections on “Findings” and “Gaps and Challenges.”

Does Jordan’s Principle have an end date?

Jordan’s Principle is a legal rule and as a legal rule there is **no end date**. Jordan’s Principle is *not* a government program. It does not have a fixed budget. As more children qualify, the funding pot expands. Approving services for one child does not mean there is less funding for other children.

Does Jordan’s Principle apply to all Indigenous children?

Jordan’s Principle applies to First Nations children. Jordan’s Principle was created by First Nations with the consent of Jordan’s family and became a legal instrument through a human rights case specific to First Nations. There are differences between the

experiences of First Nations, Metis, and Inuit due to the *Indian Act*, which created the reserve system and applies only to First Nations. For these reasons, Jordan's Principle does not apply to Metis or Inuit children and youth. Inuit have worked with Canada to establish a government program called the Inuit Child First Initiative, to ensure Inuit children have access to essential government funded services and supports (see Indigenous Services Canada, 2020). However, the orders of the CHRT do not apply to the implementation of the Inuit Child First Initiative.

Why am I asked *not* to use the acronym "JP"?

Jordan's Principle is a gift from the Anderson family in Jordan's memory. Shortening Jordan's Principle to an acronym reduces it to the level of a government policy, program, or technical term, and dehumanizes Jordan's legacy. The Caring Society has observed that the dehumanization of First Nations children and families through use of acronyms and file numbers is a government pattern that perpetuates discrimination. In honour of Jordan and his family, please do not shorten Jordan's Principle to the acronym "JP."

HOW TO GET HELP THROUGH JORDAN'S PRINCIPLE

Who to contact

Jordan's Principle requests can be made through a community Service Coordinator, a government focal point, or by calling the Jordan's Principle call centre. Indigenous Services Canada (ISC) is the federal government department responsible for the implementation of Jordan's Principle.

Jordan's Principle call centre

ISC has set up a Jordan's Principle call centre, which is staffed 24 hours, seven days a week:

- 1-855-JP-CHILD (1-855-572-4453)
- teletypewriter: 1-866-553-0554

Staff at the call centre will take general details about the request and send the information to a focal point working in the region where you live. The focal point will contact you to gather more information about the request.

Service Coordinators

Service Coordinators are community-based, non-government staff who work with families at the community level to make Jordan's Principle requests. These positions are funded by ISC but staffed by First Nations community agencies, tribal councils, local health authorities, etc. The role of Service Coordinators is to support families in making a Jordan's Principle request. Decisions about the requests themselves are made by ISC. Families should be aware that Service Coordinators do not have the authority to override ISC decisions.

The Assembly of First Nations has a list of Service Coordinators on the Jordan's Principle page of their website, available at afn.ca/policy-sectors/social-secretariat/jordans-principle.

Regional office and focal points

Focal points are ISC (federal government) staff whose job is to receive and work with families on Jordan's Principle requests.

Contact information for focal points in the Atlantic region¹ is:

- 1-833-652-0210
- sac.principedejordanatl-jordansprincipleatl.isc@canada.ca

The above telephone number and email address are specific to the Atlantic region. Contact information for focal points in other parts of the country is available at canada.ca/jordans-principle under “Find a contact person in your region.”

If you are not working with a Service Coordinator, the Caring Society recommends making your request through the 24-hour call centre. The call centre is staffed 24 hours a day, 7 days a week. Regional offices may only be staffed during office hours and callers may be asked to leave a message with no option to speak to an actual staff person. The ISC email address goes to a general email account.

Eligibility and access

Jordan’s Principle applies to First Nations children from birth to the age of majority in their province or territory. The age of majority is the age at which a person becomes an adult under the law. The age of majority under provincial law is 19 in Nova Scotia, New Brunswick, and Newfoundland and Labrador. The age of majority under provincial law is 18 in Prince Edward Island. Unfortunately, there are currently no provisions for post-majority services/ supports under Jordan’s Principle, which is a significant gap for youth with disabilities and special needs and their families. Further discussion about the need for post-majority services can be found in the section on “Gaps and Challenges to Accessing Supports and Services.”

First Nations children meeting any one of the following criteria are eligible for consideration under Jordan’s Principle:

- 1 a child resident on or off reserve who is registered or eligible to be registered under the *Indian Act*, as amended from time to time;

¹ This guide was developed at the request of the Wabanaki Council on Disability, which advances Mi’kmaq, Wolastoqey, Passamaquoddy, Penobscot, Inuit, and Innu persons with disabilities in the Atlantic region. As such, information about Jordan’s Principle contacts in the Atlantic are provided.

- 2 a child resident on or off reserve who has one parent/guardian who is registered or eligible to be registered under the *Indian Act*;
- 3 a child resident on or off reserve who is recognized by their Nation for the purposes of Jordan's Principle; or
- 4 a child who is ordinarily resident on reserve.

The third eligibility criteria refers to First Nations children without *Indian Act* status who are recognized by a First Nation community for the purposes of Jordan's Principle. Recognition by the community is for Jordan's Principle only (does not imply eligibility for band membership, etc). Importantly, recognizing a child for the purposes of Jordan's Principle does not mean less funding for other First Nations children. Canada has a legal obligation to uphold Jordan's Principle, which means the funding pot expands as more children are eligible.

The Tribunal has approved a default process for recognizing children for Jordan's Principle and has also ordered Canada to provide funding for First Nations to implement the default process or to develop their own recognition process for the purposes of Jordan's Principle. For more detailed information, please refer

to the Caring Society's (2021) information sheet about the Tribunal's orders at jordansprinciple.ca² or to the Tribunal's decisions in 2020 CHRT 20 and 2020 CHRT 36.

A timeline of the all the Tribunal's orders is available on the Caring Society website at fncaringsociety.com/chrt-orders.

In December 2020, Canada filed for judicial review, like an appeal, of the Tribunal's rulings on eligibility for Jordan's Principle (2020 CHRT 20 and 2020 CHRT 36). Importantly, the Tribunal's rulings remain in place while the judicial review is underway. Canada must adhere to the Tribunal's orders and provide services to children eligible under one of the four criteria listed above, including children recognized by their Nation for the purposes of Jordan's Principle, pending a decision from the Federal Court.

What services and supports are available under Jordan's Principle?

Jordan's Principle is not a government program with a set list of eligible services and supports. First Nations communities, through the bureaucracy and

2 https://fncaringsociety.com/sites/default/files/jordans_principle_information_sheet_january_2021.pdf

ever-changing nature of government programs like the Non-Insured Health Benefits program, have become accustomed and very good at “making-do” with limited resources. Jordan’s Principle is different.

Requests under Jordan’s Principle made are based on the unique needs of the child or children.

Services and supports received through Jordan’s Principle should not be regarded as benefits but rather rights under the orders of the Canadian Human Rights Tribunal. **The principle of substantive equality means that it does not matter whether the service or support is ordinarily available through the provincial or territorial system.**

Examples of services and supports available through Jordan’s Principle that may be especially relevant to families of children with disabilities special needs **include but are not limited to:**

- adaptive furniture, such as adjustable beds, safety beds and cots, chairs and seating, protective mats and padding;
- allied health services: these are services provided by healthcare professionals in areas other than

nursing, medical or pharmacy (definition as per Vives & Sinha, 2019). Examples include speech therapy and occupational therapy;

- assessments and screenings;
- assistive technology and electronics;
- assistive devices such as hearing aids;
- clothing, shoes and accessories;
- educational support, including educational assistants;
- home modifications and renovations, including outdoor ramps;
- infant formula;
- mental health support³;
- mobility aids, including standing and positioning aids and wheelchairs;
- oral health services;
- personal care items;
- prescription and over the counter medication;
- recreational and cultural activities;
- respite services, including daycare, individual child care, day programs and camps;

3 Research indicates that families may use the term disability to encompass a broad range of behavioural concerns, including suicidal behaviour

- safety equipment and enhanced home security systems;
- sensory and therapeutic items;
- travel costs if families need to travel to access services, including transportation (air, ground, and water), meals and accommodation, and support for escorts. Travel support is available for both medical AND non-medical reasons, such as travel to attend cultural activities; and
- training for families.

Timelines and urgent needs

As ordered by the Tribunal (see First Nations Child & Family Caring Society of Canada, January 2021a)

Canada must determine individual requests within 48 hours and within 12 hours for urgent needs. Canada must determine group requests within one week, and within 48 hours for group requests for urgent needs.

Urgent needs are those where the risk of irremediable harm is reasonably foreseeable, the child is in palliative care, or the child requires urgent assistance.

As per the Tribunal's orders in 2017 CHRT 35, Canada will work proactively in urgent cases to ensure the child is receiving crisis supports until a long-term response can be developed. This means that once a service or support is approved, ISC must also ensure the child has access to it (for example, taking steps to ensure children in remote communities have access to crisis supports by flying in crisis support workers or arranging transportation for the family to another centre if required).

When making a request involving urgent needs, families and Service Coordinators should tell the focal point or staff at the Jordan's Principle call centre that they want the request marked urgent and expect a decision within the 12-hour timeframe ordered by the Tribunal.

ISC views urgent cases and time sensitive cases as different. Time sensitive cases will be triaged, but not necessarily determined in the 12 hour timeframe.

What if the request is denied? (Appeals)

If the request is denied, families have one year to appeal the decision in writing by email or letter. Families have the option to include additional or new information to support the appeal, but this not necessary. Full information about how to appeal should be provided in the letter from Canada denying the request.

Appeals are decided on by senior managers within Jordan's Principle who were not involved with the original decision.

Unfortunately, there are no firm timelines on how long it will take ISC to decide on an appeal.

What are retroactive requests?

The Tribunal has ordered Canada to reimburse parents or caregivers for out-of-pocket costs that would have been provided if the government had implemented Jordan's Principle properly from the beginning.

This includes costs that:

- were submitted to Canada and formally denied; and/or

- were never submitted, either because parents/ caregivers did not know about Jordan's Principle or because families were told or thought the costs were not eligible.

Canada will consider **previously denied requests** dated from April 1, 2007 to November 1, 2017.

Canada will consider **new requests** (requests never submitted) dating back to July 5, 2016.

Retroactive requests can be made by calling the Jordan's Principle call centre, through a focal point, or through a Jordan's Principle Service Coordinator.

In this case, families will be asked to provide proof of payment; however, families are still eligible for reimbursement even if they no longer have the receipts. In this case, families will be asked to sign a form stating that they no longer have the receipts but that the amounts given are true and accurate.

Compensation

In September 2019, the Tribunal ruled that Canada's discriminatory treatment of First Nations children is "willful and reckless," and ordered the federal government to pay the maximum amount allowable

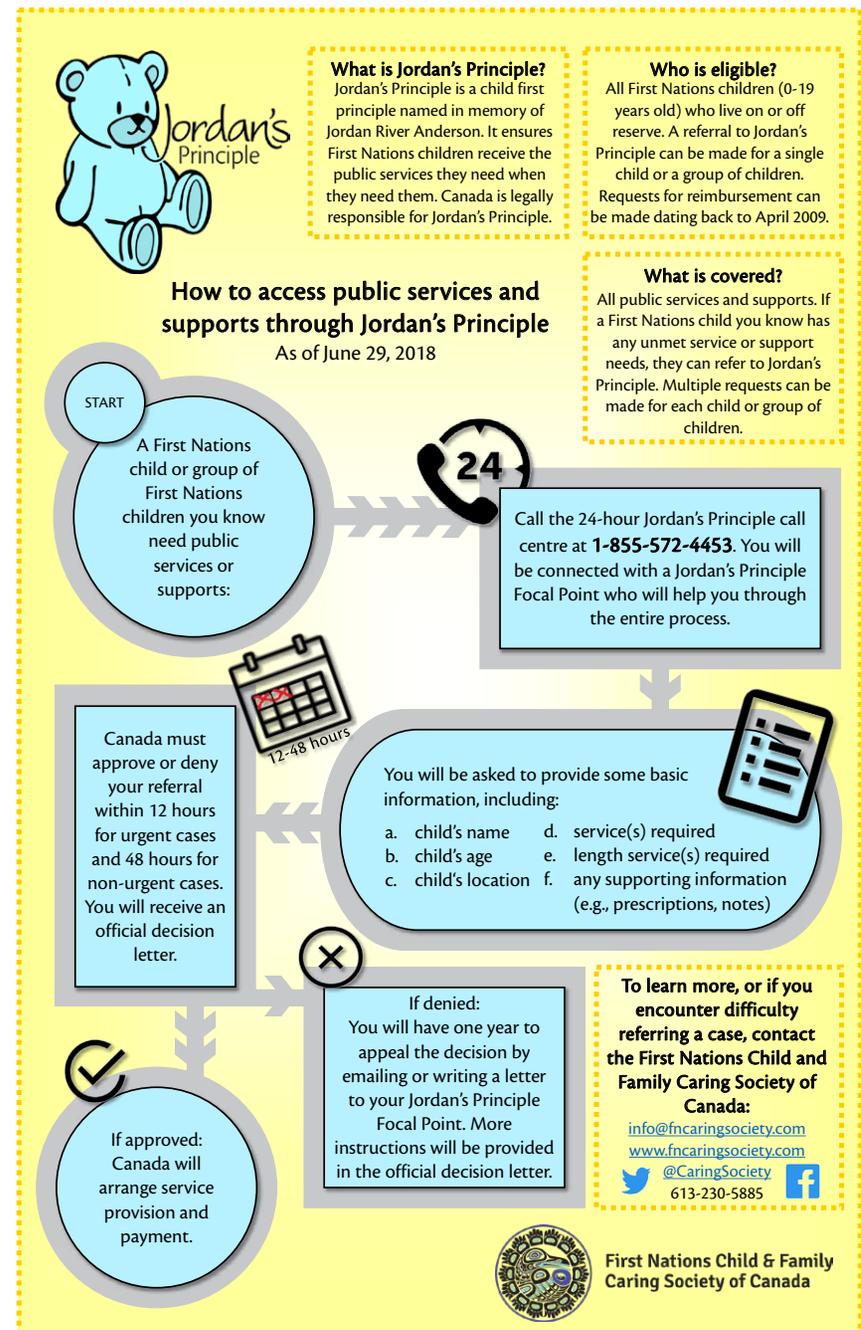
(\$40,000) under the *Canadian Human Rights Act* to compensate certain First Nations children, youth, and families who have been harmed by the child welfare system or were denied or delayed receipt of services due to Canada's discriminatory implementation of Jordan's Principle (see 2019 CHRT 39).

Canada has filed for judicial review (like an appeal) of the Tribunal's decision. No payments can be made until the judicial review is heard and decided on by the Federal Court.

For information about who is eligible for compensation and updates on Canada's judicial review of the please visit fnwitness.ca.

Infographic: How to access services and supports through Jordan's Principle

The opposite infographic is available for free download on the Caring Society website at fncaringsociety.com/information-sheets.



FINDINGS ON JORDAN'S PRINCIPLE AND CHILDREN WITH DISABILITIES AND SPECIAL NEEDS

The following section presents themes from a review of academic and community-based literature on First Nations children with disabilities and special needs in Canada, with a focus on articles and reports since the creation of Jordan's Principle in 2005. The review also includes information shared through four informal conversations with Jordan's Principle Service Coordinators and others working at the community level about their experiences with Jordan's Principle and families of children with disabilities and special needs, including a meeting with the Atlantic Technical Working Group for Jordan's Principle.

The literature needs to “catch up” to the proper implementation of Jordan's Principle

Common throughout the literature were factual errors about the purpose and proper implementation of Jordan's Principle. These errors can be attributed to mixed messaging by Canada about Jordan's Principle

in the years since it was passed by the House of Commons, as well as the evolving legal and policy context due to Canada's failure to implement Jordan's Principle properly without the intervention of the CHRT. The nature of academic literature and some research means that it can be anywhere from months to years after the work is complete before publication (due to the timelines associated with ethics approval and peer review processes, publishing lead times, etc.). As such, the literature has yet to “catch up” with the proper implementation of Jordan's Principle as ordered by the Tribunal.

The most common misconception in the literature is that Jordan's Principle is about ensuring the same level of care as the provincial or territorial standard, when in fact services and supports through Jordan's Principle are determined on the basis of substantive equality. The Tribunal recognized that, as a result of colonialism and Canada's discrimination, the needs of First Nations may go beyond what is normally provided by the provinces and territories. **Substantive equality means that**

First Nations children have a right to services and supports based on their needs. The level of service provided by the province or territory is the *minimum* standard. Services and supports under Jordan’s Principle are to be based on what the child needs, not what the province or territory normally offers.

Inconsistencies in the literature are echoed by Service Coordinators, who say that misinformation about Jordan’s Principle is a huge “stumbling block” and

something they are “constantly fighting against.” The burden of misinformation is felt at the community level by families and Service Coordinators, not by ISC. The theme of misinformation is discussed further under the heading “Gaps and Challenges.”

The table below called “Correcting misinformation about Jordan’s Principle” sets out the errors found in the literature and provides the correct details as ordered by the CHRT.

Table: Correcting misinformation about Jordan’s Principle

Description found in the literature	Proper implementation of Jordan’s Principle
Jordan’s Principle applies only to health services.	Jordan’s Principle requests are based on the needs of the child and include health, social, education, and cultural services and supports.
Jordan’s Principle applies to all Indigenous children, or uses the terms Indigenous and First Nations interchangeably.	Jordan’s Principle applies to First Nations children.
The goal of Jordan’s Principle is to provide First Nations children living on reserve with the same level of care and services as children living off reserve.	Jordan’s Principle applies to First Nations children living on and off reserve. Requests are based on the needs of the child on a substantive equality basis. Substantive equality means that First Nations children may need services and supports above what is ordinarily provided by the provinces and territories.

continued on following page

Table: Correcting misinformation about Jordan’s Principle (continued)

Description found in the literature	Proper implementation of Jordan’s Principle
Jordan’s Principle needs to be ratified by the provinces/ territories to have effect.	The federal government is responsible for the implementation of Jordan’s Principle.
Jordan’s Principle is a policy or guiding principle.	Jordan’s Principle is a legal rule.
Jordan’s Principle funding has an end date.	Jordan’s Principle is a legal obligation on the part of Canada ... there is no end date.

Definitions of disability and special needs

The purpose of this resource is not to define disability and special needs, but rather to affirm the right of children and families to self-identify in terms of how they understand themselves and their needs. Some families may identify as having a child with a disability or special needs, others may prefer to speak in terms of their child’s needs without applying a label. Some families may find value in a diagnosis, others will not. It must be noted, however, that accessing support through Jordan’s Principle requires confirmation of need from a “professional,” such as social worker, medical doctor, psychologist, etc. Unfortunately,

this standard means that children and families must engage with the label of disability and/or other diagnoses to receive support, a process which in many ways overrides the choice of families to self-identify. For this reason, a brief review of definitions of disability and special needs is offered as a matter of context.

The literature reviewed discussed various definitions, types, and models of disability and special needs, including special health needs (see particularly, Dion, 2017; Durst, 2006; Vives & Sinha, 2019; Woodgate, 2013). A study by Gosek et al. (2007) found that parents and service providers used the term disability to refer to a wide range of behavioural concerns such as “suicidal behaviour, oppositional and aggressive

behaviour, and attachment disorder” (p. 155). Durst (2006) stressed the importance of differentiating disability from health: many people with disabilities are healthy (p. 19). Speaking about disability only or primarily as a health care issue erases the social and economic needs of families. The needs of children and families with disabilities include housing, transportation, education, recreation, and home support, among others (Durst, 2006, p. 19). This means that services and supports available through Jordan’s Principle must be similarly broad. This review also identified works by Indigenous scholars on decolonizing disability and examining disability through a decolonial lens (Ineese-Nash, 2020; Weaver, 2015). Common throughout the literature was reference to differences in how Western and Indigenous peoples conceptualize disability and special needs. Dion (2017) writes that “meanings of disability from the Euro-Western definition are based on a perspective of what a person can and cannot do” (p. 6). In contrast, Indigenous worldviews may regard disability as a sign of specialness, as a form of spiritual power (Dion, 2017; Durst, 2006; Gosek et al., 2007; Johnson 2015; Woodgate, 2013). The view of children with disabilities as special was echoed by parents who participated in

Woodgate’s (2013) research. “Child as a gift” was a key theme of the study: “most parents viewed children with disabilities as ‘special people’ who have so much to contribute to their families and society in general. Parents felt that society could learn so much from children with disabilities” (Woodgate, 2013, p. 7).

Key informants in Woodgate’s (2013) study felt that First Nations families have unique perspectives of disability and “are more focused on what children with disabilities can do and not what they are unable

The purpose of this resource is not to define disability and special needs, but rather to affirm the right of children and families to self-identify in terms of how they understand themselves and their needs.

to do” (p. 13). Informants reported being told by some First Nations communities “oh we don’t have any disabilities,” and felt that “First Nations communities “don’t categorize them the same as we would or diagnose them” (p. 13) Gosek et al. (2007) point out that the view of disability as gift can “contribute to valuing and respecting people with disabilities, but it can also mean that some people do

not perceive a need for services” (p. 155). Gosek et al. (2007) also found that parents may “fear being blamed for their child’s disability, especially with a diagnosis of FASD” (p. 155), and that this may lead families to avoid seeking support.

Other differences between Indigenous and Western concepts of disability may be attributed to the holistic nature of Indigenous worldviews, which emphasize the interrelatedness of the physical, mental, emotional, and spiritual dimensions. Drawing on this holistic understanding, Conrad Saulis of the Wabanaki Council on Disability teaches that one might self-identify as having a disability due to colonial policies and practices that denied the transfer of cultural knowledge or the ability to speak one’s language (personal communication, December 9, 2020).

Despite traditional teachings on disability, it must be acknowledged that Indigenous peoples are living and immersed in a societal context that has and continues to view people with disabilities and special needs through a lens of deficiency and otherness. Indigenous peoples are not immune to the power of this discourse. The reality is that Indigenous peoples and communities are not always supportive or welcoming to people

with disabilities (Durst, 2006; Gosek et al., 2007). That fear of discrimination or poor treatment is a reality in Indigenous communities is evidenced by the response of a Service Provider working for an Indigenous agency in major Atlantic urban hub. When asked about barriers to accessing Jordan’s Principle, she suggested that caregiver fear of stigma or discrimination could be an issue; caregivers may be hesitant for people to know that their child has a disability or special needs and therefore prefer to deal with their child’s needs on their own.

What’s missing? Lack of culturally appropriate services and supports for children and their families

Despite important changes as a result of the Tribunal’s orders on child welfare and Jordan’s Principle, First Nations children continue to face systemic barriers in accessing health, education, and social services ordinarily available to other children in Canada (Vives & Sinha, 2019). These barriers are particularly acute for families of children with disabilities and special needs. On reserve, services may be unavailable, or available with less frequency, due to federal underfunding. Gosek, et al. (2007), for example, found that

physiotherapy and occupational therapy were available in some rural and remote communities only once every four months. Parents and caregivers often have no choice but to leave their reserve communities to access health and social services for their children (Durst, 2006; Vives & Sinha, 2019; Woodgate, 2013). Unfortunately, while services are more available in urban centres, they are not necessarily culturally appropriate or supportive to Indigenous families. Woodgate (2013) refers to the lack of supports and services as “disabling environments.” **Disabling environments are found both on and off reserve and refer to the conditions or barriers “that prevent families from having a life,” and include structural (infrastructure, physical environments, transportation), social (such as lack of disability awareness), economic (poverty), and other barriers due to historical trauma and colonialism** (Woodgate, 2013, p. 9). Examples of structural needs on reserve included features like ramps and wider doorways, and funds to address overcrowding (Woodgate, 2013).

Especially troubling were reports in the literature of First Nations children entering child welfare care as a means of accessing services to meet their needs (Chambers & Burnett, 2017; Gosek et al., 2007; Obomsawin, 2019; Vives & Sinha, 2019). While this is a well-established problem, as confirmed by the Tribunal in its finding of discrimination by Canada (2016 CHRT 2 and subsequent orders), the reality of the situation and its impacts on children and families over the years is disturbing. As one example, Gosek et al.’s (2007) study on supporting Aboriginal⁴ children and youth with learning and behaviour disabilities asked First Nations child welfare agencies about the reasons that children entered care. Of the 29 respondent agencies, 21 “affirmed that there are children who come into care primarily because services and supports are unavailable in their communities” (Gosek et al., 2007, p. 150). Two primary reasons were given: serious medical conditions and lack of needed services within communities to keep the child at the home or in the community, especially in northern communities, and behavioural problems that were putting children at risk (Gosek et al., 2007, p. 150). Respondents identified a total of 71 children who were

4 “Aboriginal” appears in this report when it is the term used by the author(s) in their original work. “Aboriginal” and “Indigenous” are both terms to refer collectively to First Nations, Metis, and Inuit.

in care due to a lack of services and supports in their home communities (Gosek et al., 2007, pp. 150–151)—and this is just one study dealing with only a fraction of the total number of First Nations agencies in Canada.

Twelve years later, families in Pinaymootang First Nation reported facing a similar choice, namely to “transfer custody of their child to an Indigenous child and family services agency in hopes they would be able to access better services through the agency” (Vives & Sinha, 2019, p. 13). While none of the families in the study made this decision “some mentioned that service providers outside of Pinaymootang had explicitly asked them to consider it” (Vives & Sinha, 2019, p. 13). The resistance of families to this possibility was a strong theme.

The situation for those living in urban areas is characterized by different challenges. While services are more available, culturally relevant support may be difficult to find (Durst, 2006; Vives & Sinha, 2019; Woodgate, 2013). Despite their “open door

policies,” service providers in mainstream agencies who participated in Durst’s (2006) study admitted that very few Aboriginal people were accessing their services (p. 57). Durst found that a fundamental shift was needed to make mainstream services safe for Aboriginal families: “These professionals need more than cultural awareness but a sound and critical self-examination of their policies and programs, looking for forms of discrimination and racism...The agencies need to take a hard and critical look at themselves” (Durst, 2006, p. 4). Lack of culturally appropriate services is another issue that remains persistent in the literature across time. Almost a decade after Durst’s study, families of children with disabilities continued to voice concerns about mainstream services:

... professionals need more than cultural awareness but a sound and critical self-examination of their policies and programs, looking for forms of discrimination and racism ...

...most of our people won’t access them [support services] because they come into a room and they’re the only brown face and they don’t know how to cope with that, so they don’t come back... we need our own circle to feel safe in order for our voice to be heard...if they’re going have these

support groups they've got to have an outreach worker almost that's going to connect with these parents and make sure these parents you know do have that debriefing...or you know if they didn't get there, well what's the barrier that's keeping them going there...because those are the things that you know mainstream takes for granted.

(Woodgate, 2013, p. 12)

Overall, the literature points both to needs that may be met through Jordan's Principle, as well as broader gaps requiring major systemic reforms and investments. The need for broader reform is discussed further under the heading "The need for systemic change."

Culture, recreation and a "good life"

Common throughout literature was **the importance of providing children with disabilities and special needs the opportunity for recreation, cultural learning, and FUN!** This theme was especially prominent in Woodgate's (2013) study, where "missing out" and *not* missing out were two of the key themes identified by families. Missing out "refers to the many aspects of daily life that contribute to a good life that

First Nations families of children with disabilities have minimal or no access to" (Woodgate's, 2013, p. 9). In addition to service gaps, missing out includes aspects like family time, playing with peers, and the ability to take part in recreational activities that are important to the family, like team sports or boating. Conversely, families also shared examples of *not* missing out—of their children taking part in parades, snowmobiling with parents, and spending time in the bush (Woodgate, 2013). These examples of *not* missing out demonstrate that children with disabilities and special needs are fully capable of participating in many cultural and recreational activities with the right supports in place.

Mentoring programs are one example of how communities can support children and youth with disabilities and special needs to participate in various aspects of life. Mentoring programs can take different forms. Service Coordinators gave the example of a young person who received funding for a community mentor. With their mentor's support, the young person was able to participate in activities, events, and work in the community. Having a community mentor gives young people the chance to build meaningful relationships outside of their immediate family and helps ensure they can participate in community events

and activities safely, and as an equal. Mentoring programs need to be recognized as service to the family as a whole, not just the child or young person.

Another community-based example is that of a cultural mentorship program created at the request of families. Service Coordinators discussed how children with disabilities or special needs spend a lot of time on (for example) assessments, therapy, and other appointments—they often miss out on fun activities. The community’s cultural mentorship program provides the chance to connect with culture, have fun, and do “kid things.” The program engages mentors from a variety of cultures, including Mi’kmaq, Cree, and Inuit, in recognition of the diversity of participants and peoples living the territory.

Support through Jordan’s Principle for cultural and recreational activities includes transportation costs, if needed. This is important for families to know, as Durst’s (2006) study found that the “costs of transportation and the amount of time involved in arranging, planning and waiting for rides” was a barrier to participation (p. 59). The costs of

participating in even subsidized activities can be a barrier in the context of limited means, where even “the smallest fee is a major decision” (Durst, 2006, p. 59).

Early intervention services and accessible education

Early childhood development is one of 14 mutually interdependent determinants of health in Canada, which also include Aboriginal status, disability and education (see Vives & Sinha, 2019, p. 1). Early intervention services and accessible education were discussed across the literature as important to the well-being of First Nations children with disabilities and special needs. A First Nations policy advisor who contributed to this guide summed it up well, saying: “the earlier the better [when it comes to supporting children, families and child development] is my philosophy.”

Unfortunately, the literature also pointed to systemic barriers in accessing early intervention supports. A study conducted by Vives and Sinha (2019) in partnership with Pinaymootang First Nation in Manitoba found the greatest discrimination in service accessibility to be in the area of allied health services.

Allied health services are services provided by health professionals in areas other than medicine, nursing, or pharmacy, such as speech therapy and occupational therapy.

As of 2016, there were no early intervention services available on reserve in Pinaymootang for children before the age of six (Vives & Sinha, 2019). In addition, difficulties in getting assessments prevented most children in this age group from receiving early intervention services off reserve. Canada's

funding terms dictated that older children with special health needs were expected to access allied health services, such as speech and language therapy,

through the local school, yet the study found that the range and frequency of these services was "vastly insufficient" to meet the needs of the community (Vives & Sinha, 2019, p. 8).

Vives and Sinha (2019) state that lack of early interventions services can impact the ability of children with special needs to "communicate, socialize, and develop normally" (p. 11). Their study gave the example of a child in the community with a severe hearing

impairment who was unable to access American Sign Language training until he was four years old "and only then because his mother decided to temporarily relocate to Winnipeg to access this service. Until then, this child was only able to communicate with this mother and in a very rudimentary way" (p. 11). Delays in accessing diagnostic and assessment services, particularly for children with neurodevelopmental disorders such as autism, meant that children were

often not diagnosed until they started school. Citing the work of numerous scholars, Vives and Sinha (2019) assert, "Access to early intervention is essential to support the development

of children with autism and improve their social and daily living skills, decrease the frequency and intensity of autism symptoms and improve cognitive skills" (p. 12).

Importantly, Vives and Sinha (2019) found that "the difficulty in accessing allied health services...was not the result of geography or remoteness" but the result of administrative divisions between services provided by the federal and provincial governments" (p. 9).

The study found that services available to children

Accessibility encompasses not just the range of services available but also factors like physical access (infrastructure) and whether the service is culturally relevant.

living in a rural but non-First Nations community were comparable to those offered in Winnipeg, despite the fact that the rural school was significantly further from Winnipeg than the Pinaymootang school (Vives & Sinha, 2019). The fact that barriers to services were administrative rather than geographic, rooted in funding discrepancies, is significant; it confirms the problem to be one of political will.

Accessibility encompasses not just the range of services available but also factors like physical access (infrastructure) and whether the service is culturally relevant. Woodgate's (2013) study with First Nations families of children with disabilities refers to this as the need to "promote landscapes that promote meaningful participation of families" (p. 16).

Accessibility was also discussed by Dion (2017), who lists three specific ways that school can be inaccessible for children with disabilities:

- 1 the infrastructure of the school itself prevents a child with physical disabilities from entering the building;
- 2 the curriculum is not adapted to the child's needs or teachers do not have the necessary resources to make the adaptations; and

- 3 the child requires additional or specialized support inside or outside of the classroom. (pp. 28–29)

Dion (2017) also refers to the power of technology in facilitating participation, which highlights the need to ensure families are aware that assistive technologies are available through Jordan's Principle: "Technology has been recognised for helping children with disabilities take their place in the community and contribute to it" (p. 10). Echoing Dion, Vives and Sinha (2019) found that a lack of appropriate services at school led some parents to keep their children with special health needs at home, indefinitely.

While noting the limitations of their research as a case study of one community, Vives and Sinha (2019) assert that "aspects of the Pinaymootang experience may resonate with other First Nations communities" (p. 21). Certainly, this was reflected in the experiences of Service Coordinators and others who provided information for this guide. Similar to the situation in Pinaymootang, Service Coordinators discussed the policy constraints that deny eligibility of public services to people who live on reserve, including family supports for children with disabilities, early intervention, and

daycare assistance. In some cases, First Nations have been able to replicate these programs on reserve, and in fact improve on their delivery by “making them our own” (making them culturally relevant). However, funding constraints remain a barrier.

Information and support for caregivers

Proper implementation of Jordan’s Principle needs to understand that the well-being of children with disabilities and special needs is tied to the well-being of their parents or caregivers (Dion, 2017; Gosek et al., 2007; Vives & Sinha, 2019; Woodgate, 2013). Woodgate’s (2013) study in particular identifies several themes related to the difficulties of caring for a child with disabilities, including: life is hard, intense parenting, harnessing resources, parenting in a fishbowl, and marginalization. As stated by Woodgate:

Parents struggle to provide a good life for their children in environments that are lacking the appropriate resources and services. “Having a life” for these families required significant physical, mental, psychological, and spiritual work by parents. At times, the personal resources of parents

were so taxed that the possibility for meaningful participation in everyday life was something less than what they desired. (emphasis added, p. 17)

The themes of Woodgate’s (2013) study were echoed by caregivers in Pinaymootang First Nation, who reported feeling overwhelmed and anxious due to lack of appropriate support and the “demands of constant travel” to access services (Vives & Sinha, 2019, p. 12). Some were sleep deprived due to their child having an irregular sleep schedule. Vives and Sinha (2019) also pointed to the significant financial pressure felt by families due to caregiving responsibilities: “If the child lived with his or her parents, at least one of them had to give up his or her job to take care of their child” (p. 13). From this it follows that the situation for single parents may be even more precarious. Caregivers in Pinaymootang pointed to the need for respite, as well as “training opportunities that would allow able and willing relatives to fill in for them if needed. Without properly trained respite care, children’s lives were dependent on their primary caregiver’s constant physical presence” (Vives & Sinha, 2019, p. 12). Promoting the physical and mental health of families as a unit, including that of siblings, was a major recommendation of Woodgate’s (2013) study as well.

In addition to physical and emotional support, information for parents and caregivers about the *kinds* of services that exist, especially in regard to the help available through Jordan's Principle, emerged as another important need. As explained by a policy advisor who provided feedback for this guide, many families are unaware of the range of services that exist to support children with disabilities and special needs. Long-term underfunding by the federal government has meant that services on reserve are far less than what is available provincially. The result is that people may not know specialities like speech therapy or occupational therapy exist; these supports and others are "brand new," in the sense that people simply "don't know about them." Educational training for parents and caregivers was also a recommendation of the study by Gosek et al. (2007).

"Lunch and learns" were cited by the above policy advisor as a good way to let parents and caregivers know about Jordan's Principle: "If you feed them, they will come." Communities in her region have had great success hosting lunch and learns (before

Information for caregivers about the kinds of services that exist for children with disabilities and special needs was an important theme.

the COVID-19 pandemic) to educate families about services that they otherwise might not know exist. Similarly, the lower number of Jordan's Principle requests in some areas or communities may be attributed to lack of awareness about Jordan's Principle, pointing to the need for more information for caregivers and potentially service providers as well. Considering that many families rely on service providers as their point of access for information, increased efforts by ISC are needed to raise awareness about Jordan's Principle with this group. Though most of the people who provided feedback for this guide were Service Coordinators, we did have the opportunity to speak with a service provider/manager working in a major urban hub. She stated that she had learned about Jordan's Principle through her own research. Though certainly familiar with Jordan's Principle in a general sense, she was unaware of some important details, such as the 24-hour phone line, that Service Coordinators are available in her province, or the possibility of group requests—indicating that further outreach to service providing organizations in urban areas may be useful.

Community approaches

Both the literature and research conversations indicated a strong commitment by First Nations to serving and supporting families of children with disabilities and special needs. First Nations want to help their children flourish, and to develop services and systems that focus on the strengths of families (Gosek et al., 2007; Vives & Sinha, 2019; Woodgate, 2013). This commitment is evident in the community-based approaches established by Service Coordinators to ensure children and youth receive the help they need through Jordan's Principle.

Faced with "horrendous wait times of two to five years" for provincial services, Service Coordinators in one Atlantic region sought to build relationships and establish service agreements with local providers to facilitate access to frequently needed supports, such as developmental assessments, speech therapy, and occupational therapy. This has worked very well. In developing agreements, service providers are asked to sign a contract confirming their fee level, which is good for one year. This allows Jordan's Principle Service Coordinators to budget accordingly when helping families submit requests. Three and half

years later, they have a consistent, familiar group of service providers who are culturally sensitive and knowledgeable about Jordan's Principle. Given issues of racism in health care and other services (see for example, Allan & Smylie, 2015; Durst, 2006; Turpel-Lafond, 2020; Vives & Sinha, 2019), having a trusted group of service providers for families to choose from is key.

Another community approach discussed by the same Service Coordinators is the "circle of care." This approach was developed to assist families who know their child needs support, but have no or only limited access to professionals (for example, only a doctor). Service Coordinators request an assessment through Jordan's Principle, which is done by a trusted social worker. The social worker collaborates with families on a plan of action that suits the child. As part of the circle of care approach, the social worker follows up with families every three to six months to see how the plan is working and adapt or make changes as necessary.

A third community approach discussed by Service Coordinators is the hiring of a "procurement specialist" due to the "nightmare" of finding equipment.

Health professionals will often make general recommendations for products or equipment, but there are many brands and models available. The role of the procurement specialist is to find right item(s) for the child. Service Coordinators say that working with a procurement specialist “has been a fantastic move”—it frees up their time to focus on helping families and ensures that the items purchased are the right ones. Procurement is a specialty! In addition to finding items, the procurement specialist works with families to trial the item(s), helps with fitting children to the item, and also builds the item if required.

GAPS AND CHALLENGES TO ACCESSING SUPPORTS AND SERVICES

The following are gaps and challenges that emerged through discussions with Service Coordinators and others, as well as an analysis of the literature on the needs of families of First Nations children with disabilities and special needs, and how these needs relate to Canada's implementation of Jordan's Principle.

Group requests

Group requests are requests for funding to provide needed services or support to a group of children. If a service is provided by the province and not the federal government on reserve, group requests appear to be a timely means through which to address this discrimination in service provision. Off reserve, group requests might be used to establish culturally based services, in response to the racism that is sometimes present in mainstream service organizations. The Tribunal ruled that Canada must decide on group requests within 48 hours for urgent

requests and within one week for non-urgent requests. Group requests were envisioned by the parties to the CHRT case as way to meet the needs of multiple children quickly and in a manner not constrained by usual bureaucratic processes, which the Auditor General of Canada (2011) has found to be burdensome and ineffective.

Unfortunately, the Service Coordinators who contributed to this guide have found the process of group requests to be similarly burdensome. Group request were described as very difficult to manage, as a lot of work, and as having "many moving parts." It was stated that group requests require detailed workplans: "it's basically like writing a proposal." Some Service Coordinators in the Atlantic have essentially stopped doing group requests because they involve so much work and no one really has the time. The example was given of a group request that was successful. Funding was received for a cultural support program. The program was extremely needed

and has been a wonderful success. However, the request was only possible because someone from another community agency was keen to help and was experienced in proposal writing. Service Coordinators would not have had the time to manage the process without help.

Service Coordinators further explained that group requests are difficult in large part because funding is determined on a per child basis. Per capita funding means that once monies are received, someone needs to keep track of who attends in order to ensure attendance matches the data that was submitted to ISC. Concerns were raised about the ramifications if the numbers submitted in the request are different from the make-up of the actual program, for example, what if the request was to run a program for 40 children and only 32 end up taking part? Conversely, because funding is based on the predicated number of children, the only way to ensure that funds are sufficient is to cap the service/program. This means that if interest or need is high, children could be turned away or denied access, which violates the spirit of Jordan's Principle. Closely related to these concerns were questions and worries about responsibility for ensuring the roll-out of funded programming

or services matches the overall terms of the group request. For instance, if the request was submitted on behalf of a community agency, who is responsible for tracking the kids and meeting the outcomes stated in the request? Is it the Service Coordinator agency or the agency providing the service?

The complexity of group requests ("so many moving parts") can lead to miscommunications, which then need to be addressed and are stressful for all involved. It was stated that the stress and workload involved with group requests can make it feel "almost not worth it" as it takes away from time spent helping families in other ways.

Lack of post-majority services

The lack of post-majority support is a major concern about Canada's implementation of Jordan's Principle (see First Nations Child & Family Caring Society of Canada, 2020), and this gap is felt particularly by young people with disabilities and special needs. The needs of young people and their right to a good life do not suddenly disappear when they reach the age of majority. As was stated in one of the conversations for this guide: "Once these young people turn 19 or 20, where do they go?"

Who supports them? Parents are wondering what to do as their child approaches the age cut-off.” Worries about the care of young people as they transitioned to adulthood was a strong theme in the literature as well (Gosek et al., 2007; Obomsawin, 2019; Vives & Sinha, 2019; Woodgate, 2013). Unfortunately, information from Service Coordinators indicates that Canada currently provides no support or suggestions for transition planning. Service Coordinators report scrambling to figure out solutions for young people set to “age out” of Jordan’s Principle support.

The needs of young people and their right to a good life do not suddenly disappear when they reach the age of majority.

In many cases, it appears to be the provinces stepping in to provide continued care. Two Service Coordinators from different provinces shared examples of young people requiring 24/7 care who Canada would no longer support once they reached the age of majority. Despite knowing that these young people had no means of private support, no plan was offered by Canada as to how care would be maintained. Thankfully, in both cases, provincial departments eventually agreed to assume funding at the same level to ensure continued care. While these arrangements are indefinite and the

commitment seems strong, both agreements are informal. In one of these case examples, it was decided that service providers would meet with the province every three months to confirm that care was still needed. It has now been one and a half years; however, the absence of a formal commitment leaves young people and their families at the mercy of changing political wills.

Communities are doing their best to figure out how to continue care when young people “age out” of Jordan’s Principle. Service Coordinators noted that

while there are some provincial programs available, these are usually based on income and/or the eligibility is quite narrow. Support through these programs is by no means guaranteed. Some communities have started to establish their own tripartite tables (with federal/provincial/First Nations representation) to explore options for continuing care and other issues. It was stated by one Service Coordinator that their province has informally agreed to review young people aging out of Jordan’s Principle who need 24/7 care on a case-by-case basis.

Another example given was that of a community-based response. In this case, the community was able to come together, pool resources, and develop a plan to provide wrap-around services for a young person who was about to “age out” of Jordan’s Principle care. When asked if the community had been able continue this support over the long-term, it was explained that Service Coordinators do not receive funding to follow-up with families once the child or young person is no longer receiving services through Jordan’s Principle; as a result, the Service Coordinator lost contact with the family and is not sure how the young person is doing now. Service Coordinators talked about the difficulty of losing contact with families when the young person is no longer eligible for services: “It’s hard because you spend so much time with a family and you have no ability to follow-up.”

The final example given was that of a young person who was receiving funding for a community mentor (as described above under the heading “Culture, recreation and a ‘good life’”). With the support of their mentor, this young person was able to participate in activities, events, and work in the community. Unfortunately, the opportunity ended when the young person “aged out” of Jordan’s Principle.

Capital funding

As discussed above, upgrades to, or in some cases, new infrastructure is often needed to support the well-being of children with disabilities and special needs. The literature cites physical accessibility as a major concern for families, especially on reserve. Barriers include inaccessible homes and community buildings, lack of proper transportation, and no options for independent housing (Dion, 2007; Durst, 2006; Gosek et al., 2007; Woodgate, 2013). A family in Woodgate’s (2013) study shared the unsettling example of the beginnings of an accessible washroom in a family home that was never completed and left to “mould away” as a storage space (p. 9). Unfortunately, Service Coordinators in the Atlantic report difficulty in accessing funds for recommended capital (infrastructure) improvements. The process was described as “not easy, with a lot of hoops to jump through.” While requests for capital can be done successfully, “it requires a lot of back and forth.” Service Coordinators were unclear as to Canada’s policies and commitments to capital improvements under Jordan’s Principle. In her cross-examination before the Tribunal on May 7, 2019, Dr. Valerie Gideon

(now Senior Assistant Deputy Minister, First Nations and Inuit Health Branch, Indigenous Services Canada) confirmed that **Jordan’s Principle has the authority to approve capital expenditures for improvements associated with a child’s specific needs related to their direct living environment.**

Requests must directly address the needs of the child(ren). New builds or even modifications/renovations not directly related to the needs of children (expanding a health centre was the example given in transcripts) is not something ISC has the authority to do. In the same transcript, Dr. Gideon indicated that there is no cap on major capital requests.

Unfortunately, the terms discussed by Dr. Gideon do not seem to be accessible in practice. Service Coordinators state that approval for capital improvements is generally limited to minor renovations, such as modifications to a bathroom or funds to widen doorways. In some cases, ISC has required that costs for capital improvements be split with the First Nations community.

Canada’s “old mindset”: Renewing requests and problematic funding approaches

The Caring Society (2020) has observed that ISC will sometimes require families to re-apply for previously approved supports or services, will impose sunset dates on approvals, or will periodically require families to submit a professional “re-evaluations” or assessments to indicate that services are still needed. It is not clear, however, if this is a requirement writ large (i.e., if it is a policy) or if it is a regional practice with terms that vary across the country. ISC’s approach to renewing approved supports and services overlooks the lived realities of First Nations families of children with disabilities and special needs. Children with disabilities and special needs, including special health needs, typically require multiple services over a long period of time; gaps in these services can impact their chances of reaching their full potential, diminish their quality of life, and even put their lives at risk (Vives & Sinha, 2019, p. 4). As a result of this requirement to re-apply, the Caring Society has observed that ISC will sometimes reduce services that were previously

approved, even when the child's needs or situation remains the same or, in some cases, their needs have increased.

The requirement by ISC to re-apply or renew previously approved requests ignores the reality of children with disabilities and special needs and places an unnecessary burden on families. Further, requiring all families to reapply for services, no matter the nature of the situation or request, suggests that ISC continues to prioritize the needs and interests of the government over the needs of children, an approach that the Tribunal has referred to as "Canada's old mindset" and found to be discriminatory (see First Nations Child & Family Caring Society of Canada, 2021). Reducing the level of support when the needs of the child are the same (or their needs have increased) violates the Tribunal's orders that Jordan's Principle decisions must be based in substantive equality, the best interests of the child, must be needs-based, and account for distinct community circumstances. Decisions that

The requirement to re-apply or renew previously approved requests ignores the reality of children with disabilities and special needs.

cut or deny previously approved requests require immediate attention and re-evaluation by ISC and families are encouraged to appeal.

The continued influence of Canada's old mindset is also evident in ISC's approach to funding in-school supports, which is based on the fiscal year and not the school year. School boards hire staff based on the school calendar. For example, a child may receive funding for an educational assistant or special education teacher through Jordan's Principle, but the approval only lasts to March 31 (the end of the fiscal year). Service Coordinators say that schools have raised serious concerns about this approach, which effectively leaves the school board responsible for continuing to fund the positions if the agreement is not renewed. Canada may make verbal commitments regarding an extension but without a funding agreement in place monies are not truly guaranteed and schools may see hiring with Jordan's Principle funds as a risk. Service Coordinators state that these concerns are amplified by Canada's continued legal challenges to the Tribunal's orders, which give

service providers and community organizations the impression that funding through Jordan's Principle may not be "stable."

Canada's policy of funding Service Coordinators based on the population size of the communities served is another issue raised in conversations for this guide.

The example was given of an agency that initially qualified for funding for only one Service Coordinator due to population. They were eventually able to advocate for funds for four Service Coordinators.

Today (as of February 2021) they have caseload of 660 Jordan's Principle requests. The agency has been able to handle the huge numbers because of their team approach; the work is shared with other positions, such as Family Support Workers. They would never turn families away, but at a certain point, the need becomes unmanageable with the resources they have.

It was further explained by Service Coordinators that Canada provides funding for case management only, and zero dollars for things like policy development (for example, privacy policies), data management, or outcome tracking. **The issue of per capita and insufficient funding to meet the demands of the job is further evidence of Canada's "old mindset."**

The Tribunal found that Canada has consistently failed

to provide First Nations child welfare agencies with the funds needed to meet their responsibilities and the actual needs of children. To see this pattern replicated in the context of Jordan's Principle is concerning and needs to be addressed.

Evolving legal and policy context

The rapidly evolving legal and policy contexts surrounding Jordan's Principle were cited both by Service Coordinators and in the literature (Sangster et al., 2019; Vives & Sinha, 2019) as an area of challenge and concern. While grateful for the Tribunal's orders, which continue to affirm that Jordan's Principle must be based on substantive equality, the best interests of the child, must be needs-based, and account for distinct community circumstances, the changes can be difficult to navigate and integrate into service coordination, particularly when the messaging from ISC is inconsistent. For example, on the release of 2020 CHRT 36, which confirms the eligibility of children without *Indian Act* status who are recognized by their communities, some Service Coordinators were told by ISC that they needed to get a letter from Chief and Council each time a child without status applies to Jordan's Principle. They later learned that

an email or fax would suffice. While this distinction may seem minor, in the context of high workloads and competing demands, the administrative burden between an official letter and an email is significant and makes a real difference in how quickly things get done and, by extension, how quickly the request is approved and the child gets the service they need.

The evolving legal and policy context surrounding Jordan’s Principle is the result of Canada’s non-compliance to the Tribunal’s decision, which has resulted in many subsequent orders, as well as Canada’s continued legal challenges.

Service Coordinators say that organizations and service providers see Canada filing appeals and question whether the government’s commitment to Jordan’s Principle is permanent or reliable. As explained by one Service Coordinator, “they see the government pushing back and think, ‘You guys [Jordan’s Principle Service Coordinators] aren’t stable. We don’t know what’s happening with you.’” This has led to an ongoing and troubling issue in which communities and organizations hesitate to partner through Jordan’s Principle funding because of the perceived uncertainty. As reported by Service Coordinators, “communities and organizations say,

‘we don’t want to partner with you to start up a program for kids, only to risk having it taken away from them when funding ends.’”

The need for systemic change

Both the literature and information provided by Service Coordinators and others are clear about the systemic inequities experienced by First Nations children with disabilities and special needs. Families having to leave their reserve communities to access services and the need for increased and consistent funding for services on reserve were recurring themes in publications ranging from 2006 to 2019. Barriers to culturally appropriate services off reserve, including racism, were present across the timespan of the literature reviewed as well. The Tribunal has characterized Jordan’s Principle as a means of remedying Canada’s discrimination against First Nations children, and the impact of the Tribunal’s orders can be seen in the continued rise in number of requests (for statistics see Iamsees, 2020; Indigenous Services Canada, 2021). The Tribunal’s orders have ensured Jordan’s Principle responds to children and families in a way that is timely, needs-based, accounts for distinct community circumstances, and reflects the

principles of substantive equality and the best interests of the child. Unfortunately, Jordan's Principle is the only avenue of government support in which Canada is legally obligated to uphold these standards. The First Nations Child & Family Caring Society of Canada (2020) has argued that "the large volume of Jordan's Principle requests is directly related to the ongoing barriers and discrimination in all other federal services for First Nations children" (p. 22). This analysis is seconded by the Yellowhead Institute, a First Nations–led research centre out of Ryerson University, which argues that the "incredibly high application rate [for Jordan's Principle] should also be viewed as a failure of government leaders and decision makers to effectively change how programs and services are delivered to First Nations children" (Iamsees, 2020, Troubling Trends section, para. 4).

Unless Canada commits to ending the inequalities in public services for First Nations children, youth, and families, requests for support through Jordan's Principle are likely to remain high. Developed by the Caring Society and endorsed by the Assembly of First Nations, **the Spirit Bear Plan sets out concrete steps that Canada can take to end the inequalities in public services.** Even if the process

for group requests through Jordan's Principle is changed to address the burdens described above, the extent of the inequity is too wide-spread and too ingrained to fix in a piecemeal way. In the area of education alone, for example, the Parliamentary Budget Officer calculated that the "shortfall between

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provincial school funding across Canada and that of federally funded First Nations–operated schools was between \$365 million and \$666 million in 2016" (Vives & Sinha, 2019, p. 14). Jordan's Principle is not a substitute for systemic reform. Canada needs to move beyond the standard of basic survival for First Nations children to a landscape that enables First Nations children to "flourish" (Woodgate, 2003, p. 12).

For more information about the Spirit Bear Plan, visit fncaringsociety.com/spirit-bear-plan.

CLOSING WORDS: “JORDAN’S PRINCIPLE HAS BEEN TRANSFORMATIVE”

While gaps and challenges remain, the Service Coordinators and others who contributed to this guide were adamant that Jordan’s Principle has been “transformative” for children and families. There are “so many success stories”: a child who was struggling with literacy and jumped four grade levels in a month after receiving personal school support. Or a child who got 100% on their math exam. One Service Coordinator talked about receiving an email from a mom who said without help through Jordan’s Principle, she would not have known what to do during the COVID-19 pandemic. Another talked about a family who now has accessible transportation. These are only a few of the many children helped by

Jordan’s legacy. Collaboration across organizations in community (health, social, education, etc.), increasing community capacity in various ways, increasing access to services across sectors, improving health, social, and educational outcomes for First Nations children are all positive changes described by Service Coordinators as a result of Jordan’s Principle.

Jordan’s Principle has been transformative, but the government’s implementation of the Tribunal’s orders remains lacking, and these shortcomings have a particular impact on children with disabilities and special needs. Further work is required to ensure these children and their families receive the proper support for sustained well-being.

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