Implementing Jordan's Principle in paediatric practice and advocacy: Barriers and solutions

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First Nations Child & Family Caring Society of Canada Société de soutien à l'enfance et à la famille des Premières Nations du Canada



Jordan's Principle ensures First Nations children have access to the services they need free of any discrimination or red tape.

A legal rule per the orders of the Canadian Human Rights Tribunal (2016 – present).

Please do not use the acronym "JP" – reduces Jordan's Principe to the level of a government policy, program, or technical term, and dehumanizes Jordan's legacy.

Read more at JordansPrinciple.ca

CPSP: Jordan's Principle Study (2020)

- Do Canadian paedatricians access supports and services for First Nations children and youth through Jordan's Principle? A survey of knowledge, behaviour, and experiences
- PI: Dr. Radha Jetty
- Co-ls: Dr. Ryan Giroux, Elizabeth Moreau, Dr. Brett
 Schrewe
- Collaborators: Cindy Blackstock, Nick Barrowman, Dennis
 Newhook, Jennifer King

CPSP: Jordan's Principle study results

- 265 Respondents
- 232 provided medical care for First Nations children or youth of which 90% were aware of Jordan's Principle
- Only 59% of 219 respondents had ever tried to access services for an eligible patient

Eligibility

- 63% were not familiar or only somewhat familiar with eligibility criteria
- Biggest unknown: eligibility criteria, particularly for First Nations children and youth without Indian Act status, living off reserve and recognized by their nations (47% unaware of this criteria)
- Categories of eligibility confirmed by the Canadian Human Rights Tribunal in 2020 CHRT 36

Application challenges

- 26% reported that they had challenges trying to make contact with someone to discuss an application
- Most common barriers included difficulty reaching someone (78%) which included both at the program level and at the community level

Application challenges 2

- 39% reported that they (or delegate or patient) encountered difficulty in accessing funding on at least one case
- Most common barriers included difficulty reaching someone to assist (60%), excessively time-consuming (53%), difficulty in navigation of the process (50%), or an unreasonable amount of information requested (47%)

Delays and denials

- For non-urgent cases, 69% of respondents said they had no cases that were processed within the 48 hour standard, with 32% reporting longer than 7 days
- 34% have had at least one denial, with 23% reporting one-quarter or more of their applications were denied

Delays and Harm

- 28% reported that there was a negative outcome for a patient or family due to a delay in accessing Jordan's Principle
- Some of the common impacts included developmental/educational, medical complication, worsened mental health, unnecessary separation from the family, delay of therapy, and prolonged hospitalization

The literature needs to catch up with the proper implementation of 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.
Jordan's Principle needs to be ratified by the provinces/territories to have effect.	The federal government is responsible for the implementation of the Canadian Human Rights Tribunal orders on 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.

From Jordan's Principle and Children With Disabilities and Special Needs (2021)



Back to Basics Approach (B2B)

B2B is an implementation guideline that Indigenous Services Canada (ISC) staff must follow, as of early 2022.

- Substantive equality is presumed. Reference to normative standards cannot be used to deny requests.
- It is presumed that professionals and Elders/knowledge holders are acting within their area of expertise, and also that the request is specific to the child and their needs.
- Minimum information is required for ISC to approve an urgent request + risk mitigation plans must be put in place where the request is unlikely to be determined within CHRT timeframes.
- Examples of urgent requests include end-of-life care, risk of the child entering the child welfare system, physical safety concerns, no access to basic necessities, and mention of suicide.



Back to Basics Approach (B2B) cont.

Documentation should not be a barrier to children accessing supports through Jordan's Principle.

- 1 letter from a professional or Elder/knowledge holder is the presumed requirement.
- ISC does not require a letter for every requested product, service, or support. A letter can speak to multiple needs within the recommending professional's scope.
- Quotes, cost estimates, and length of service are not required for ISC to decide on the request.
- ISC staff will review previous requests for the child and any relevant letters already on file to support new requests that are clearly linked.

Case scenarios - Questions to consider

- What are the biggest barriers identified in the scenario? Is the federal government meeting its legal obligation to First Nations children and families?
- What can you do if this situation happened to a patient or family of yours?
- How might your personal advocacy look in the following spheres:
 * Within your own clinic, hospital, or institution
 - * Within medical education or continuing education for pediatricians
 - * The work of the CPS
 - * The federal government or public at large

Case 1 (Eligibility)

You are part of the care team who is assisting Shayla, a 11-year-old Cree girl whom you are following for Autism Spectrum Disorder and Intellectual Disability. She recently moved to the city you are working in with her parents and younger brother because many of the services that her parents wanted to access, including extra school supports, autism services, and behavioural interventions, were not available on reserve in a neighbouring province.

You determine that Shayla would benefit from a psychoeducational assessment as well as additional Occupational Therapy and Speech-Language Therapy. Recently, her tablet that she uses to communicate broke, and this has led to her becoming increasingly frustrated that she cannot communicate.

Shayla's provincial funding for Autism services has not been approved, and her family calls your team to help with getting these services. They heard about Jordan's Principle, but when they asked a local Indigenous community centre about it, they said that Shayla isn't eligible because she is non-status.



Eligibility per 2020 CHRT 36

Children meeting **any one** of the following criteria are eligible for consideration:

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

Case 2 (Substantive Equality)

You're part of the care team who is assisting Zayne (they/them), a 15 year old gender non-binary Mohawk teenager who is currently living in a very small and remote rural community. You see them once every two months when you make trips up to their community as part of an outreach pediatric team, but there are nurses and family doctors who also assist with Zayne's healthcare when you cannot be there.

Over the past 4 visits, Zayne has been disclosing serious events of bullying in their school. They don't feel safe in the bathroom, they have been forced to change in a communal locker room for gym class, and their teachers are constantly misgendering them. Their parents are supportive, but feel that the school isn't listening to their concerns. Zayne has disclosed suicidal ideation and self-harm in the past because of their bullying.

Zayne has met a few Trans and non-binary teenagers through TikTok who live in a larger city in their province, and feels that their life would be significantly better if their school environment was different. In fact, Zayne wishes to become a pediatrician to help take care of gender non-conforming youth, but their grades keep slipping due to their experiences at school. Zayne's parents are supportive of what Zayne needs, but don't know how to help. They've heard of Jordan's Principle before and they know they're eligible, but they ask you if it's at all relevant to this.

Case 3 (Communication and Support with Requests)

You're part of the care team who is assisting Brent, a 12-year-old Gitxsan boy who recently moved across the country to a new city with his mom. Housing in the new city is incredibly expensive and the family is only able to afford a second floor apartment in an old building that is suspected to have mold. Brent has a history of prematurity with chronic lung disease, and now has moderate to severe asthma, along with environmental allergies. After connecting them to Respirology services in the new city, his Mom asks if you could assist them in getting a humidifier for Brent's room, as this has helped him significantly in the past when they've dealt with forest fire smoke that aggravated his asthma in the past, and she thinks it will help with the mold in their new home, while they wait for the housing corporation to fix the issue.

You wrote a letter of support and mom submitted the request via an Ontario Focal Point. Three weeks later, you come into your clinic to find out that mom had called for an immediate appointment due to Brent's asthma symptoms getting worse. At the appointment, you learn mom has not heard anything back about the request and feels like giving up. She doesn't know what to do next.



How to Access Services and Supports Through Jordan's Principle

As of April, 2023

What is covered?

Any service, support or

item that a First Nations

child needs. Multiple

requests can be made

for each child or group

of children. Supports

may be above what is

normally provided in

the province/territory.

XX

Canada must approve

within 12 hours

within 48 hours

GROUP REQUESTS:

these timelines:

INDIVIDUAL

REQUESTS:

Non-urgent:

Urgent.

or deny requests within

What is Jordan's Principle?

Step 1

supports

Step 2

24

A First Nations child or

a group of First Nations

children needs services or

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Jordan's

centre at

(1-855-JP-CHILD). You will be

Principle Focal Point who will

help you through the entire

process. If the request is

urgent, let the call centre

know. Examples of urgent

requests include: end-of-life

care, risk of child entering

child welfare system, safety

concerns. If a situation changes to become urgent call back to update the

First Nations Service

Coordinators are in some

You do not need to work

communities and agencies to

assist families with requests.

with Coordinator to make a

First Nations Child & **Family Caring Society**

fncaringsociety.com

request.

request.

connected with a lordan's

Call the 24-hour

1-855-572-4453

Principle call

Jordan's Principle is a legal rule and child-first principle named in memory of Jordan River Anderson. It ensures First Nations children receive the services and supports they need when they need them. Canada is legally responsible for implementing Jordan's Principle.

First Nations children from birth to age of majority in the province/territory of residence who meet any one of the following criteria: 1. The child or one parent/guardian has Indian Act status or is eligible for status.

- 2. The child is recognized by their Nation for the purposes of Jordan's Principle.
- 3. The child ordinarily lives on reserve.

Who is eligible?

Step 3 You will be asked to provide some basic information. including: 1. Child's name 2. One referral from a professional or Fider/ knowledge holder 3. Parent/guardian consent 4. Confirmation of eligibility Quotes, cost estimates and length of service are not

Urgent. within 48 hours parent/guardian is needed; documentation can follow after the immediate needs

are met. In all cases, documentation should not be a barrier to accessing supports through Jordan's Principle.

IF APPROVED:

Canada will

provide payment and reimbursement details.

required for Canada to decide on the request. In urgent cases, only verbal or written consent from the

Non-urgent: within 1 week You will receive an official decision

letter.

IF DENIED:

You will have one

year to appeal the

decision by emailing or

writing a letter to your

Jordan's Principle Focal

Point. Full instructions

will be in the official

decision letter.

Learn more at JordansPrinciple.ca • 24-hour Jordan's Principle line: 1-855-JP- CHILD 1-833-PJ-ENFAN

- Regional Focal Points
- First Nations Service Coordinators/Navigators
- Let ISC know what will happen to the child should services not be determined/provided

Case 4 (Approvals and Denials)

You're part of the care team who is assisting Christina, an eight-year-old Anishinaabe girl with Autism Spectrum Disorder (Level 3). The family lives on reserve but due to services being limited in the community has sought pediatric care at your clinic in the city. Over the past six months, you have been successful in applying for funding for additional time with an in-home occupational therapist.

Recently, the family has had concerns about Christina's safety. The family's house is near a river and a wooded area and submitted a request to Jordan's Principle for a fence so that Christina can play outside safely, as she has attempted to leave the yard on multiple occasions to explore, and once nearly walked onto a road with traffic. You submitted a letter supporting the request explaining that Christina does not fully understand the risks of leaving the yard to explore the river and woods and that an unfenced yard is not safe for her. The request was denied on the grounds that a fence for the family's yard is not child-specific. The family is very disappointed and says they are gathering assessments relating to Christina's autism diagnosis to support an appeal. What do you say?



Re-reviews, denials & appeals

- Requesters have the right to ask for a re-review of a decision, where the response by ISC is clearly not in keeping with the B2B approach or CRHT orders.
- If denied, requesters have one year to appeal the decision in writing by email or letter to their Focal Point.
- Option to include additional or new information, but this not necessary.
- Underscore why/how the request is required to meet the needs and best interests of the child, their distinct community circumstances, and ensure substantive equality.
- Key question: consequences if the product, service, or support is not received by the child?
- Appeals are heard by an arm-length Committee made up of health, education, or social services professionals from outside the Government.



Progress is measured at the level of kids. We are long past accepting "best efforts" by Canada.

Systemic concerns should be brought to the attention of Valerie Gideon, Assistant Deputy Minister in charge of Jordan's Principle (cc: Assembly of First Nations + the Caring Society).

Caring Society can try to assist in urgent situations where there is non-compliance by Canada.



Caring Society Resources

Back-to-Basics approach for Improving Outcomes Under Jordan's Principle. (2023, May). <u>https://fncaringsociety.com/publications/back-basics-approach-improving-outcomes-under-jordans-principle</u>

Jordan's Principle: Ensuring First Nations Children Receive the Supports They Need When They Need Them. (2023, May). <u>http://www.fncaringsociety.com/publications/jordans-</u> <u>principle-information-sheet</u>

How to Access Services and Supports Through Jordan's Principle. (2023, April). <u>https://fncaringsociety.com/publications/jordans-principle-poster</u>

Jordan's Principle and Children With Disabilities and Special Needs (2021, May). <u>https://fncaringsociety.com/publications/jordans-principle-and-children-disabilities-and-special-needs-resource-guide-and</u>

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