

# Survey of paediatricians' knowledge and use of Jordan's Principle

# Background

Jordan's Principle is a legal rule named in memory of Jordan River Anderson, a First Nations child from Norway House Cree Nation in Manitoba. It is a child-first principle to ensure First Nations children can access the products, services and supports they need, when they need them. Jordan's Principle is a legal rule that stems from the Canadian Human Rights Tribunal's 2016 finding that the federal government was racially discriminating against First Nations children. The Tribunal ordered the federal government to fully implement Jordan's Principle.

In Canada, paediatricians often take care of children who have additional health and educational needs, including First Nations children. Paediatricians and paediatricians-in-training (residents) need to understand Jordan's Principle so that they can help children and their families access the supports they need.

The Canadian Paediatric Society (CPS) is a national professional organization involved in professional education and knowledge translation on child and youth health. In 2022, the CPS undertook to:

- whether and to what degree paediatricians and residents understand Jordan's Principle
- understand their comfort and ability to support First Nations children and their families to access and receive the services and supports they need and deserve.

The CPS First Nations, Inuit, and Métis Health Committee partnered with the Children's Hospital of Eastern Ontario's Research Institute to survey 2,920 Canadian paediatricians and paediatric residents about their awareness and experiences of accessing supports through Jordan's Principle. This was done through a 25-item questionnaire in English and French.

# Study highlights

#### Respondent profile

- 219 paediatricians and residents (collectively referred to as "respondents") who care for First Nations children completed the survey.
- All provinces and territories except Nunavut were represented with at least one respondent.
- Practice locations included dedicated pediatric academic teaching hospitals, community hospitals, private office-based practices, and other practice settings.

#### Knowledge gaps for paediatricians were common

- 90% of respondents indicated they were aware of Jordan's Principle before completing the survey, but only about half could correctly identify eligibility criteria.
- Only 59% had ever tried to access services or supports through Jordan's Principle for an
  eligible patient. Of the 41% who had never attempted, the most common reasons cited
  were not knowing what services may be covered, not knowing how to access funding, or
  believing that none of their patients needed any eligible services.
- Some respondents noted that, in certain areas, some families knew how to access Jordan's Principle themselves and did not require a physician's help.
- Respondents reported requesting several types of supports through Jordan's Principle to address their patients' health, school, or cultural needs. The most common included allied health (such as speech therapy, physiotherapy, dieticians, etc.), school supports, and mental health services. Medications (especially for First Nations children without non-insured health benefits coverage), housing, formula, and grocery support were the most reported supports in the category of "Other." See Figure 1 for more detail.

Allied health/therapeutic specialists 64% 50% Services or supports for the school setting 50% Mental health services (i.e., psychology,counselling) Medical or rehabilitation equipment or supplies 48% 40% Transportation (e.g. to medical appts, to school) 33% Respite care for patient's family Homecare, nursing, or personal support worker services 25% 20% Specialized programs based on cultural beliefs/practices Long-term care for children with special needs 14% 8% Traditional healing or services from elders 21% Other

Figure 1. Types of supports and services requested through Jordan's Principle

## Many respondents reported challenges

The 129 respondents who attempted to access supports reported many challenges. Over one-quarter reported difficulty reaching someone to discuss a request. Among their comments:

"With almost every application (I have now stopped even trying to access Jordan's Principle) it is a complete waste of time. Emails get ignored. Phone calls ignored. Requests get only approved until 'fiscal' year end."

"Very different experiences depending on location - in [one province or territory], relatively seamless and straightforward process. In [another province or territory] - marked challenges with access, extremely slow turnaround times and large numbers of refusals."

"While someone may get back to you relatively quickly, i.e., 5-7 days, getting actual funding approved and then getting the actual services in place takes MONTHS and in some cases just never gets completed at all."

Thirty respondents provided additional information about barriers to accessing services or supports through Jordan's Principle. The most common included: difficulty reaching someone; excessively time-consuming; difficulty navigating the process; or being asked for an unreasonable amount of information.

#### Delays were common and resulted in negative outcomes

Delays were very common, especially for urgent cases. Of the 22 respondents who responded to a question about urgent cases, only 3 (14%) had ever such a case processed within the 12-hour standard agreed to by the federal government. For non-urgent cases (77 respondents), only 24 respondents (31%) said a case was responded to within the 48-hour standard.

Delays in services for children can lead to negative outcomes. Of the 99 respondents who responded to a question about implications of delays accessing Jordan's Principle, 28 reported a negative outcome for a patient or family. These included: developmental/educational impacts; medical complications; worsened mental health; unnecessary separation from family; delay of therapy; and prolonged hospitalization. For example:

"Poor blood sugar control in a pediatric diabetes patient who was waiting for access to technology to assist in monitoring."

"Prolonged hospital stays (for months, recurrently) while trying to get services into the rural/remote home. Family unable to be there in hospital frequently due to other child care responsibilities, so our young patients are unattended and institutionalized instead of receiving care in their homes..."

"Delays caused further delays in development as therapies were slow to start."

"Inability to access respite services resulting in caregiver burnout and family separation."

"If we had to rely on Jordan's Principle only, and not the kind actions of a community pharmacist, the child would not have received medications on time, and would have required emergency airplane transport out of his community and hospital admission."

"I have a patient who has been living in the city for 2-3 months awaiting approval of a request to modify the home environment to be accessible for his special needs."

Unfortunately, denials were common. One-third of respondents experienced at least one denial, and 23% reported that one-quarter or more of their applications were denied.

# Where do we go from here?

Paediatricians and paediatric residents provided valuable insight into physicians' awareness and knowledge of Jordan's Principle, as well as the barriers to accessing supports and services. The CPS will continue to educate its members about Jordan's Principle as a legal rule and how, when properly implemented by the federal government, it can support First Nations children and families. We will also continue to advocate for changes in Jordan's Principle to ensure that no First Nations child experiences unnecessary denials, delays, or disruption in receiving the care that they need.

## For more information

To make a request through Jordan's Principle, visit Indigenous Services Canada's website.

Learn more about Jordan's Principle through the First Nations Child and Family Caring Society.

## In memory of Jordan River Anderson

The family of Jordan River Anderson provided the gift of his name to be used to support other First Nations children. Because of this, it is important that we always use the full term "Jordan's Principle" instead of acronyms or shortened forms.

#### Study team

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