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## Which Comes First: Child or Politics?

### Accessibility and care for First Nations children

Imagine a wheelchair-bound young child unable to attend the only daycare facility in his community because the facility is not wheelchair accessible. The community does not have paved roads and it is, therefore, difficult for him to accompany his mother on a walk outside because of the many potholes in the road that have become too difficult to navigate. His family is unable to afford specialized transportation for him and as a result he is, for the most part, house-bound. These and similar circumstances are a common reality faced by many children with special needs. Even more disturbing is that these services would be more accessible and more quickly provided if the child were not of First Nations status and did not have to live the experience of jurisdictional conflict.

First Nations children are the fastest growing segment of the Aboriginal population in Canada. Astonishingly, the rate of disabilities among First Nations children is almost double than that for Canadian children in general (7.8% vs. 4.4%). This rate is quite high, particularly considering that the figure is based solely on those disabilities asked about in both the First Nations Regional Longitudinal Health Survey (RHS) and the Canadian National Population Health Survey. In addition, about one in

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eight Aboriginal children (12%) had one or more of the disabilities listed in the survey.

In *A Canada Fit for Children* (Government of Canada 2004) the federal government outlined its commitment to improving the conditions faced by children, *including those with disabilities*.<sup>1</sup> Policy developments such as this have highlighted the importance of early childhood development and the investments that result in improved outcomes for children later in life. These investments are even more important when a child has special needs. Children are considered to have *special needs* if they require services and supports beyond what is provided through regular maternal, infant and early childhood development programming.

Children with special needs often require a wide range of services and supports in order to participate with their peers. These services may include (but not be limited to) screening, assessment, behavioural interventions, remedial speech, occupational therapy, nursing or psychological counselling; depending on the complexity of their disability, the condition that creates these special needs, or the special needs themselves. In addition,



A parade held in support of Jordan's Principle, Norway House Cree Nation, August 2008.

children with special needs may also require transportation, medical supplies and equipment or pharmaceuticals to be able to participate meaningfully in society.

Children with special needs, in most cases, require additional public or private resources beyond those usually required to support healthy development because of: exceptional gifts and talents, mental health issues, problems related to social, linguistic, or family factors, and physical, sensory, cognitive and learning challenges.<sup>2</sup>

Early childhood development is closely linked to special needs and has an impact on a child's development and school readiness. It is essential that supports and services be present within the communities to provide the required resources for screening, assessment and ongoing follow-up for children with special needs. Early diagnosis is the key to providing children with special needs the resources to develop, learn, live and grow.

Over 40% of Canada's young people live in communities with less than 100,000 people. This includes all children in Nunavut, the Yukon, Northwest Territories and PEI. In addition, over 60% of youth in Newfoundland/Labrador, Nova Scotia, New Brunswick and Saskatchewan live in small communities. As a result, children with special needs in these areas face unique challenges just because of where they live.<sup>3</sup> This creates even greater obstacles for First Nations communities, given that many have a population of less than 2,000.

First Nations children with special needs face even greater barrier than those mentioned above. Jurisdictional conflicts between provincial/territorial health systems and the federal system is unique to First Nations and Inuit people and often results in the lack or absence of services that are available to other Canadian residents. Health care services in Canada are paid for and legislated by provincial/territorial governments. However, the majority of health services received by First Nations individuals are provided through the federal government's fiduciary responsibility to fund these services to First Nations children on reserve. Jurisdictional disputes arise when federal and provincial governments engage in intergovernmental and interdepartmental conflict over payment for the cost of these services. In other words:

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Children with similar needs and medical problems who are deemed to be a provincial responsibility do not face the jurisdictional disputes that First Nations children from reserves do. Thus, children living off reserve have much quicker accessibility to supports and services that promote healthier developmental well-being. The average Canadian gets services from federal, provincial, and municipal governments at an amount that is almost two and a half times greater than that received by First Nations citizens.<sup>4</sup>

For many parents of First Nations children with complex medical needs that require ongoing health services, jurisdictional disputes can delay receiving the care needed so desperately by these children. In these cases, parents are often faced with the difficult decision of placing the child in foster care to receive the needed medical services in a timely manner. The story of Jordan River Anderson is one such case that has received national attention and as a result has led to the development of Jordan's Principle, a child-first principle.

Jordan was born in 1999 with a complex genetic disorder and required a number of specialized medical services including a ventilator for breathing, a tracheotomy, and a gastrostomy tube for feeding. He had a severe developmental delay, was nonverbal, and required the use of a wheelchair for mobility. Similar to many other First Nations children with special needs, Jordan was the victim of jurisdictional squabbling between federal and provincial governments as to who would cover the costs for his medical needs. In addition to the ongoing battle between governments for essential medical services for Jordan, his family was also faced with the difficult decision of placing him in child welfare care, for no other reason than to obtain the medical services required to sustain Jordan's life. For many federally-funded First Nations status children with complex medical needs who live on reserve, the multitude of services they require are often not available within their community. Therefore, in order to meet the medical needs of these children, their parents are frequently faced with the grueling decision to place their child in the care of child welfare services off reserve to access essential medical supports and services.

Jordan's health eventually stabilized and the hospital team responsible for his care recommended that he be discharged to a

specialized foster home closer to his community. Despite this recommendation, the federal and provincial governments were unable to come to an agreement on who would cover the costs for Jordan's home care. For three years, bureaucrats quarreled over the payment of Jordan's care, including such minute details as the cost of a special showerhead required for a wheelchair-accessible shower. Throughout the course of the governments' squabbling, Jordan remained in hospital until his death at age four, never having lived outside the hospital walls.

Jordan's story is not unique. Unfortunately, many First Nations children across Canada have experienced similar struggles. In honor of Jordan and his family, child advocates, such as the First Nations Child and Family Caring Society, have proposed the development of Jordan's Principle.

Under this principle, where a jurisdictional dispute arises between two government parties (provincial/territorial or federal) or between two departments or ministries of the same government, regarding payment for services for a Status Indian child which are otherwise available to other Canadian children, the government or ministry/department of first contact must pay for the services without delay or disruption. The paying government party can then refer the matter to jurisdictional dispute mechanisms. In this way, the needs of the child get met first while still allowing for the jurisdictional dispute to be resolved.<sup>5</sup>

Despite new policies and initiatives put forth by the federal government, many gaps remain and the struggle to implement Jordan's Principle is ongoing. On December 12, 2007, a unanimous Private Members Motion (296) was passed in the House of Commons in support of Jordan's Principle. However, despite this move, as well as reports that the federal and provincial governments have been trying to develop a dispute resolution process for the implementation of Jordan's Principle, there has not been any indication that a process has been adopted or is in practice in any of the provinces. Furthermore, First Nations have not been invited to participate in these discussions affecting the wellbeing of their children. In addition, there is the lack of a coordinated approach from federal programs and departments for First Nations children and youth with special needs. Due to the multitude of issues encompassed by First Nations children with

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special needs, there is no one federal body, such as INAC, HRSDC, or FNIHB, mandated to coordinate the continuum of services and supports to ensure these children's wellbeing.

As a result of these ongoing circumstances, many First Nations children have and will continue to fall through the cracks. When governments continue to put their needs before those of the children, parents will have to continue to put their children in care to obtain needed health services. The high costs of placing a child in care inevitably results in the often-used response that funding is not available to ensure that essential health services are provided in First Nations communities. Subsequently, without the systemic change that is so clearly necessary, many other children will experience the same devastating fate as Jordan's, a fate that no child or parent should endure.

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<sup>2</sup> O'Sullivan, J. Bowd, A., Boone, M., Clinesmith, J., Greenwood, M., Kienapple, K., Malcom, L., and McSorley, A. (2006) *Distance Learning on Special Needs for Early Childhood Educator Workers in Aboriginal Communities, Phase I*. Distance Learning on Special Needs for Early

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<sup>3</sup> O'Sullivan, J. Bowd, A., Boone, M., Clinesmith, J., Greenwood, M., Kienapple, K., Malcom, L., and McSorley, A. (2006) *Distance Learning on Special Needs for Early Childhood Educator Workers in Aboriginal Communities*, Phase I. Distance Learning on Special Needs for Early Childhood Educator Workers in Aboriginal Communities, Phase 1, *Addendum to Section 3.*

<sup>4</sup> Lavallee, Trudy. Honoring Jordan: Putting First Nations children first and funding fights second. *Journal of Paediatric Child Health*, Vol 10 No 9 (November 2005). Canada: 527.

<sup>5</sup> First Nations Child and Family Caring Society of Canada. "Joint Declaration of Support for Jordan's Principle to Resolving Jurisdictional Disputes Affecting Services to First Nations Children". (<http://www.fncaringsociety.com/more/jordansPrinciple.ph>)