# Honouring Jordan: Putting First Nations children first and funding fights second

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This is Jordan's story. Jordan was a First Nations boy from a northern Manitoba reserve who spent his entire life living in an institutional hospital setting until he succumbed to his illness at four years of age. He never had the opportunity to experience life in a loving family home environment, where the sights, senses and sounds of home would have provided him with the dignity, integrity and sense of belonging that he so deserved. The tragedy is that he did not have to stay in the hospital for medical reasons: he remained there for two years because government departments could not settle on which one would pay for his foster home care. Government needs came before Jordan's needs. However important the jurisdictional dispute must have seemed to the government bureaucrats involved, it seems so small compared with Jordan's sacrifice.

To begin, let us introduce him. To protect his anonymity, we will kindly refer to him by his first name, Jordan. Jordan was born in 1999 with a complex genetic disorder and severe developmental delay. He had a tracheotomy, was ventilator-dependent and was fed through a gastrostomy tube. He was nonverbal and required a wheelchair for mobility. Jordan was formally diagnosed with Carey-Fineman-Ziter syndrome.

Jordan was like so many other particularly vulnerable First Nations children with special needs, who continue to be the innocent victims of constant federal and provincial jurisdictional and funding disputes. Jordan suffered the impact of intergovernmental and interdepartmental wrangling around responsibility to pay for his home care. Sadly for Jordan, this 'wrangling' resulted in the federal government refusing to come to an agreement to approve the costs for his release to a specialized foster home before his death. 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 (1).

For Jordan and his biological family, very difficult decisions had to be made after his birth. Federally funded First Nations-status children with complex medical needs, without the full scope of services in their on-reserve communities, most often must live away from home to have their health needs met. Many of these children, similar to Jordan, are brought into child welfare care under the Manitoba Child and Family Services Act for the sole purpose of accessing essential medical supports and services.

In Manitoba, First Nations child and family services agencies were established under tripartite agreements between the province of Manitoba, Canada and First Nations in the early 1980s. There are 13 fully mandated First Nations child and family services agencies that provide statutory services under the Child and Family Services Act of Manitoba, both on and off reserve. Those original tripartite agreements have since expired and been replaced by annual bilateral funding agreements. Both types of agreements recognized that the province has constitutional responsibility over the provision of child and family services and that the federal government has a fiduciary responsibility to fund services to First Nations children on reserve. This funding must be adequate to support First Nations children to receive full benefits under provincial legislation, standards and policy.

Over the past 10 years in Manitoba, there have been ongoing jurisdictional disputes between the federal departments of Indian Affairs and Health Canada and the Province of Manitoba over who has or does not have the authority to pay the costs of First Nations children on reserve who are in the care of child welfare services. The Department of Indian Affairs states that they do not have the authority to cover any medically related costs because noninsured health benefits and costs for status Indians fall under the First Nations and Inuit Health Branch (FNIHB) of Health Canada. The FNIHB indicates that it does not have funding authority for certain medical items because they no longer fall within the noninsured health benefit criteria. The FNIHB also states that because the child is under the care of a First Nations child and family services agency, the Department of Indian Affairs should pay because it is expected to fund child welfare according to provincial legislation. The two federal departments also assert that the provincial health system should pay because it already receives federal health transfer dollars for both insured and noninsured health benefits. The federal departments also state that the provincial department of family services

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should pay because it has constitutional authority, pursuant to Section 92 of the *Constitution Act, 1867* (2), for the delivery of child and family services. The province, of course, views this federal stance as federal off-loading. The province argues that the federal government is responsible for the funding of these children because the Department of Indian Affairs is signatory to the child welfare agreements and has committed to fund according to the provincial legislation. The province also argues that the FNIHB has federal authority to cover noninsured health benefits for status Indians. The provincial and territorial governments argue, " … that the federal government has a constitutional, historical, fiduciary and Treaty responsibility for and to Aboriginal peoples, both on reserve and off" (3).

Although the medical team from the hospital recommended Jordan's discharge from hospital in 2001, the government partners were unable to come to an agreement on who would pay for his home care. The governments sat at a negotiating table for three years, disputing and rejecting responsibility over a whole slew of itemized costs included in the foster care per diem rate, foster care training and equipping the home so that Jordan's needs could be met. The governments disagreed about some of the most basic costs, such as who would fund a showerhead, transportation to medical appointments and special food – and all the while, Jordan remained in hospital. The failure to resolve even some of the most trivial costs amplified the disagreements about covering the costs of ongoing medical supplies and a wheelchair ramp for the foster home.

If the use of public funds in a responsible manner were at the centre of the storm of government disagreements, it was not evident because they paid the hospital twice the rate of what it would have cost to place him in a foster home. Moreover, as the lengthy negotiation process dragged on between the governments, concern grew among child welfare authorities that the very specialized and medically trained foster home would be unavailable for Jordan because other children were in need and could be placed more quickly.

If this had been a child off reserve, the entire per diem cost would have been covered by the non-Aboriginal child welfare agency, with reassurance that full reimbursement from the province was forthcoming. The child's needs would have been met first and not put aside while government negotiations regarding who was going to pay dragged on for three years.

Frustration grew among First Nations leaders in Manitoba, the First Nations agency, family, community, children's advocates and medical teams because it appeared that the 'system' was unable to arrange funding for placement for Jordan (4). The governments simply could not come to an agreement on the expense coverage for this child. Because funding could not be secured, the First Nations agency was reluctant – understandably so – to sign a voluntary placement agreement for fear of not being reimbursed by the Department of Indian Affairs and the FNIHB (5).

Despite these serious jurisdictional problems, the Department of Indian Affairs and Health Canada continue to introduce new policies and apply for Treasury Board authorities that further limit their authority and/or ability to cover child welfare activities and medical costs for federal First Nations children. The Department of Indian Affairs recently released its new funding manual (6) for First Nations child and family services that articulates the Department's lack of funding authority to cover costs, such as a wheelchair ramp to a foster home, for First Nations children on reserve that it is legally responsible for.

In the past, there have been several attempts by First Nations to address this issue, demonstrate program effectiveness and find solutions to ensure that these children do not 'fall through the cracks'. In 1999, the Awasis Agency of Northern Manitoba developed a pilot program with 18 months of funding from the Department of Indian Affairs, Health Canada and the provincial health department to study the effectiveness of community-based supports for children with complex medical needs. The pilot was initially funded on the basis of 16 cases. Funding ended once those specific cases closed. There are only seven children left within the pilot program. Current funding is very sparse and no additional funding has been provided despite the fact that the Awasis Agency continues to receive requests from northern First Nations families to get help accessing services for their disabled children (Project Manager of Children with Lifelong Complex Medical Needs Program, Awasis Agency of Northern Manitoba, personal communication). In the midterm evaluation of the Social Union Framework Agreement (2003), federal Minister Jane Stewart told the world that the Awasis Pilot is recognized as a 'best practice', yet federal funding continues to be diminished.

In Manitoba alone, it was reported in 2002 that 955 First Nations children were identified with either severe or profound disabilities (7). The demand for culturally based and effective supports comparable with those provided to children off reserve is there. Why is the federal government not listening? The First Nations Child and Family Caring Society of Canada has expressed these concerns to the international community through such forums as the United Nations Committee on the Rights of the Child (8). The issue has been politicized through Assembly of Manitoba Chiefs' correspondence to the Prime Minister and is now being dealt with through legal means.

The Assembly of Manitoba Chiefs has received support from the Public Interest Law Centre of Manitoba to further explore this issue and develop a legal opinion. It is apparent that a good case can be built that intergovernmental jurisdictional wrangling violates the rights of these children according to certain sections of the Canadian Charter of Rights and international human rights conventions, such as the Convention on the Rights of the Child. Ironically, Canada is signatory to this convention but apparently failed to implement the nondiscrimination and 'child best interests' concepts that the Convention

embodies. Further, as these children are unnecessarily kept in hospitals and other institutional environments, their physical and psychological integrity is severely affected. In reference to Jordan, it was stated that, "The extended hospital stay with limited social contact with family will influence this child's (Jordan) development. This issue of attachment and the residual implications will affect this child throughout his life" (9).

Jordan's story is true, and it happens every day in this country. First Nations children on reserve are set aside while governments figure out who will pay. Sadly, Jordan never had the opportunity to realize his potential in life. He was held back to live his life in an institutional setting because of ongoing government jurisdictional disputes. Jordan could have lived in a specialized foster home – surrounded by the sights, senses and sounds of home – but he did not get that chance. Never again should a government place their need to resolve a jurisdictional dispute before the needs of a child. To adopt a 'child first' principle, where a status Indian child on reserve would receive services that are otherwise available to non-Aboriginal children without delay or disruption, would cost governments nothing. They could sort out who pays afterward. Most important, children would not have to pay either.

In Jordan's memory, we ask that the federal and provincial governments immediately adopt a 'child first' policy – call it 'Jordan's Principle', in his honour. First Nations people will continue to fight to ensure that their children, now and in future generations, do not become victims to discriminatory practices demonstrated by government policies.

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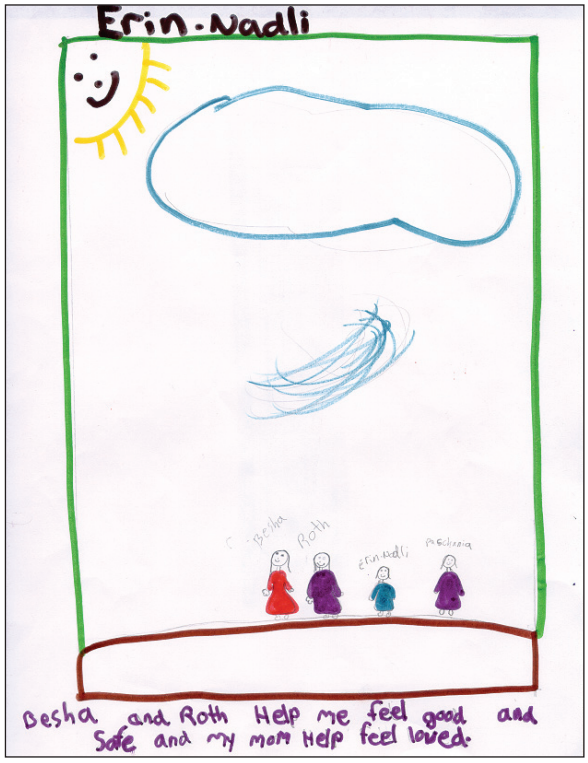


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