

The Impact of Jordan's Principle on Children with Fetal Alcohol Spectrum Disorder

Kelly D. Coons, PhD & Marnie Makela, PhD

Canada FASD Research Network

Issue: Jordan's Principle is a child-first principle meant to prevent First Nations children from being deprived of essential public services or experiencing delays in receiving them (Government of Canada, 2017). Jordan's Principle declares that where a jurisdictional dispute arises, such as between two government parties (i.e., provincial/territorial or federal) or between two government departments of the same ministries, for the payment of any services to a First Nations child, that the government ministry or department with first contact must pay for the services without delay or disruption (Blackstock, 2011; Government of Canada, 2017; Wekerle, Bennett, & Fuchs, 2009). Thus, the needs of the First Nations child are immediately addressed, while still allowing the dispute to be resolved at a later time.

Background: Jordan's Principle is named in honour of Jordan River Anderson (Canadian Paediatric Society, 2016; UNICEF Canada, 2009), a First Nations boy from Norway House Cree Nation, Manitoba. Jordan was born in 1999 with complex medical needs and a rare disorder that required hospitalization from birth. In Jordan's situation, the federal and provincial governments could not resolve who was financially responsible for the necessary at-home care expenses. Consequently, Jordan never left the hospital, never received treatment at home, and died in the hospital in 2005 without ever having spent a day in his family home. The services that Jordan needed would have been available and would have been provided if he was non-Aboriginal (UNICEF Canada, 2009). Jordan Anderson's legacy is Jordan's Principle.

Jordan's Principle was unanimously passed by the House of Commons in 2007 and has been adopted by most provinces and territories. However, its implementation has been limited and inconsistent (Canadian Paediatric Society, 2016; The Jordan's Principle Working Group, 2015). Jurisdictional confusion among provincial, territorial, and federal governments still results in First Nations children being denied care, and that true spirit of Jordan's Principle is not being appropriately applied. Recently, attention has been drawn to Jordan's Principle and the Truth and Reconciliation Commission Calls to Action, two of which (#33 and #34) deal specifically with increasing community resources to diagnose, support, and prevent FASD. The Truth and Reconciliation Commission recognized that Jordan's Principle is critical for health equity and in redressing the legacy of residential schools, and called for the full implementation of Jordan's Principle. The Canadian Human Rights Tribunal issued its latest ruling on Jordan's Principle on May 26, 2017 and the Government of Canada is taking steps to implement the Human Rights Tribunal's orders (Government of Canada, 2017). Jordan's Principle is reflective of the non-discrimination provisions of the United Nations Convention on the Rights of the Child (The United Nations, 1989, art. 15) and Canadian domestic law that does not allow differential treatment on the basis of race or ethnic origin (Canadian Human Rights Act, 1985).

Honouring Jordan's Principle:

First Nations children are significantly overrepresented amongst children in the child welfare system (Fuchs, Burnside, Marchenski, & Mudry, 2009). In recent history, there have been notable increases in the number and proportion of First Nations children coming into the child welfare system with chronic conditions and disabilities, including children with FASD (Bennett, Wekerle, & Zangench, 2010). Service gaps exist for First Nation families and children with special needs, including FASD (Bennett et al., 2010). Previous research has suggested that more FASD training is needed in First Nations communities to ensure community-based awareness and primary prevention, and to support the delivery of comprehensive and sustainable services for individual with FASD of all ages along with their families and caregivers (First Nations Child and Family Caring Society & Paukuutit Inuit Women of Canada, 2006). Some examples of services recommended for children after they receive a diagnosis of FASD include community-based recreation programs, educational assessment and intervention, developmental therapy, caregiver respite, child counseling, psychiatric services, sleep evaluation, genetic workup or consultation, mental health services, occupational therapy assessment or intervention, speech language therapy assessment or intervention, and substance abuse prevention (Jirikowic, Gelo, & Astely, 2010; Pei, Baugh, Andrew, & Rasmussen, 2017). However, it remains unclear to what extent the application of (or lack thereof) Jordan's Principle may impact care for children with FASD.

One recent example of the application of Jordan's Principle comes from a collaborative research project in Manitoba. *Honouring Jordan's Principle* (Vines, Sinha, Burnet, & Lach, in collaboration with Pinaymootang First Nation, 2017) is a report outlining the obstacles to accessing equitable health and social services for First Nations children with special health care needs living in Pinaymootang, Manitoba. In 2015, Pinaymootang First Nation partnered with McGill University to document the experience of Pinaymootang First Nation families and service providers in accessing services for children with special needs. Interviews with families, service providers, and representatives from Indigenous organizations revealed severe funding disparities for services provided on reserve, which were due to a number of factors including ambiguous and vague bureaucratic guidelines and procedures regarding provincial vs. federal responsibility, unequal funding between provincial and federal programs, and the mere distance Pinaymootang First Nation is from a service hub.

First Nations children in Pinaymootang First Nation experienced service disparities compared to Manitoba children living off reserve. In particular, children on reserve experienced disparities in accessing allied health services (e.g., occupational therapy, physiotherapy, speech and language therapy, and counselling), a reduction in access to a range of prescription medications and assistive devices, and faced several limitations in primary and specialized medical services because of shortages of qualified personnel and rurality. While other children in Manitoba had regular access to these services, children with special healthcare needs living in Pinaymootang experienced denials, delays, and disruptions in services. This disparity affected the proper

management of their medical and developmental conditions, their quality of life, and their ability to reach their maximum potential.

Additionally, the lack of support services placed emotional and financial strain on the families and there were very limited support services for caregivers who felt overwhelmed, isolated, and frustrated. In fact, it was through the research project that families in very similar situations first learned of each other and the health care facility started bi-weekly family support meetings. Families were faced with 3 scenarios to meet the needs of their children with complex health care needs: (1) stay where they were without access to services; (2) relocate to Winnipeg and move away from their support networks; or (3) transfer custody of their children to Child and Family Services. The school and health care centre work hard to collaborate with other organizations and apply for grants in order to provide services to its community members. Many of their programs are delivered outside of core funding without certainty of continued funding, which hinders long-term strategies to address community needs.

Recommendations:

There is a continued need for the full and proper implementation of the spirit of Jordan's Principle. Jordan's Principle should be realized by all levels of government and should be proclaimed as best practice for child-centred care (Stout & Harp, 2009). This governmental response should be consistent with the vision of Jordan's Principle raised by First Nations and endorsed by the House of Commons. Given the on-going gaps in knowledge, service delivery, and access to care for First Nations youth, including those with disabilities, special needs, and mental health concerns, there is also a critical need for continuous monitoring of the implementation of Jordan's Principle (Canadian Council of Child and Youth Advocates, 2011).

There is a need for on-going, culturally safe research projects (Canadian Institutes of Health Research, 2013) that support First Nations communities. Regarding FASD, this should include provisions for culturally and linguistically congruent FASD training and materials, and First Nations communities and organizations should be supported to provide the full spectrum of FASD services that are essential to community well being (Wemigwans, 2008). Further research and monitoring in this area will also provide a better understanding of the issues and challenges faced by the health sector and child welfare sector in servicing First Nations children with special needs, such as FASD, to better address why and where service gaps may exist.

In line with the recommendations put forward by *Honouring Jordan's Principle*, we also recommend the swift and immediate addressing of disparities in funding, community capacity building, and collaboration across governmental jurisdictions. Some of the recommendations from *Honouring Jordan's Principle* include:

- All future decisions on the implementation of Jordan's Principle on reserve should be made in ongoing consultation with First Nations.

- Known and documented disparities in the services available to on reserve First Nations children and those ordinarily available to other children should be immediately and systematically remedied.
- Funds to support the identification of community needs, and the development and implementation of programs to address those needs, should be allocated as core funding (not be conditional or grant-based).
- Investments in capacity building need to be made immediately. These investments should support both short-term (e.g., additional training on speech and language basics for case workers already working in communities) and long-term (e.g., funding the training of local First Nations workers in the allied health professions) capacity development.
- Mechanisms should be put in place to improve communication and collaboration between the three levels of government (federal, provincial, and First Nations), as well as among departments within the same level of government.
- Policy and services must be designed and implemented to address the needs of youth with disabilities and/or special healthcare needs as they transition into adulthood.

To read more about *Honouring Jordan's Principle*, please refer to the Pinaymootang Health Centre publications, available here:

http://www.pfnhealth.com/_mndata/phc/uploaded_files/Pinaymootang_Honouring_Jordans_Principle_web_20170714.pdf

References:

Bennett, M., Wekerle, C., & Zangench, M. (2010). Aboriginal health - The overlap among child maltreatment, mental health, and addictive behaviours - The way forward. *International Journal of Mental Health & Addiction*, 8, 127-134. doi:10.1007/s11469-010-9273-6

Blackstock, C. (2011). *Reconciliation means not saying sorry twice: How inequalities in federal government child welfare funding, and benefit, on reserves drive First Nations children into foster care*. Ottawa, ON: First Nations Child & Family Caring Society of Canada. Retrieved from <https://fncaresociety.com/sites/default/files/fnwitness/FNCFCS-submission-status-of-women.pdf>.

Canadian Council of Child and Youth Advocates. (2011). *Special report. Aboriginal children: Canada must do better: Today and tomorrow*. Toronto, ON: Canadian Council of Child & Youth Advocates Retrieved from http://www.cdpcj.gc.ca/Documents/CCCYA_UN_Report-final.pdf.

Canadian Human Rights Act, R.S.C., 1985, c. H-6. Retrieved from <http://laws-lois.justice.gc.ca/PDF/H-6.pdf>

- Canadian Institutes of Health Research. (2013). *Internal assessment for 2011 international review - CIHR Institute of Aboriginal Peoples' Health*. Ottawa, ON: Canadian Institutes of Health Research Retrieved from <http://www.cihir-irsc.gc.ca/e/43686.html>.
- Canadian Paediatric Society. Are we doing enough? A status report on Canadian public policy and child and youth health: Jordan's Principle. Retrieved from <http://www.cps.ca/en/status-report/jordans-principle>
- First Nations Child and Family Caring Society & Paukuutit Inuit Women of Canada. (2006). *FASD training study: Final report*. Ottawa, ON: First Nations Child and Family Caring Society of Canada Retrieved from <https://fncaringociety.com/sites/default/files/27.pdf>.
- Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2009). Children with FASD involved with the Manitoba child welfare system: The need for passionate action. In S. McKay, D. Fuchs, & I. Brown (Eds.), *Passion for action in child and family services: Voices from the prairies* (pp. 185-206). Regina, SK: Canadian Plains Research Center. Retrieved from <http://cwrp.ca/sites/default/files/publications/prairiebook2009/Chapter9.pdf>
- Government of Canada. (2017). About Jordan's Principle. Retrieved from <https://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879>
- Jirikowic, T., Gelo, J., & Astley, S. (2010). Children and youth with Fetal Alcohol Spectrum Disorders: summary of intervention recommendations after clinical diagnosis. *Intellectual and Developmental Disabilities, 48*, 330-344.
- Pei, J., Baugh, L., Andrew, G., & Rasmussen, C. (2017). Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. *Research in Developmental Disabilities, 60*, 176-186. doi: 10.1016/j.ridd.2016.11.007
- Stout, R., & Harp, R. (2009). *Aboriginal maternal and infant health in Canada: Review of on-reserve programming*. Winnipeg, MB: Indigena Creative Group. Retrieved from http://www.pwhce.ca/pdf/AborigMaternal_programmes.pdf.
- The Jordan's Principle Working Group. (2015). *Without denial, delay, or disruption: Ensuring First Nations children's access to equitable services through Jordan's Principle*. Ottawa, ON: Assembly of First Nations Retrieved from http://www.afn.ca/uploads/files/jordans_principle-report.pdf.
- The United Nations. (1989). Convention on the Rights of the Child. *Treaty Series, 1577*, 3. Retrieved from <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>

UNICEF Canada. (2009). *Canadian supplement to The State of the World's Children 2009. Aboriginal children's health: Leaving no child behind*. Toronto, ON: Canadian UNICEF Committee Retrieved from <http://www.nccah-cnca.ca/docs/nccah%20partner%20documents/UNICEF%20Report,%20English.pdf>.

Vives, L., Sinha, V., Burnet, E., Lach, L., in collaboration with Pinaymootang First Nation. (2017). *Honouring Jordan's Principle: Obstacles to accessing equitable health and social services for First Nation children with special healthcare needs living in Pinaymootang, Manitoba*. Fairford, MB: Pinaymootang First Nation, Canada. Retrieved from http://www.pfnhealth.com/_mndata/phc/uploaded_files/Pinaymootang_Honouring_Jordan's_Principle_web_20170714.pdf.

Wekerle, C., Bennett, M., & Fuchs, D. (2009). Editorial: The legacy of a child: Jordan's Principle. *First Peoples Child & Family Review*, 4(1), 5-7. Retrieved from <http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/viewFile/69/105>

Wemigwans, J. (2008). *FASD tool kit for Aboriginal families*. Toronto, ON: Ontario Federation of Indian Friendship Centres Retrieved from <http://www.ofifc.org/sites/default/files/docs/FASD%20Toolkit%20-%202008-01.pdf>