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Falling Through the Cracks: Canadian Indigenous Children with Disabilities

International Human Rights Internships Program - Working Paper Series

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Abstract

This paper discusses Indigenous children with disabilities in Canada and examines their experiences with federal and provincial jurisdictional and funding disputes. It explores Canada's adversarial legal and policy techniques to delay implementation and funding of Jordan's Principle, the effects of the Canadian Human Rights Tribunal decision, and the recommendations of a recent independent Canadian research project. Finally, it suggests ways to advance Jordan's Principle in Canada as well as other alternatives to improve the situation of Indigenous children with disabilities.

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Indigeneity in Context

Although Indigenous peoples are accorded the same rights as everyone else in the states in which they live, they also have certain rights that aim to protect and promote their rights as Indigenous persons. However, there is a large controversy concerning who can be beneficiary of these rights ascending from the long struggle of defining the term Indigenous.[1] To this day, there is no universal accepted definition. Nonetheless, the UN Working Group on Indigenous Populations provide a definition for the term "indigenous":

Indigenous communities, peoples, and nations are those which having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop, and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions, and legal systems.[2]

This broader conception of Indigenous identity is in line with the principle of self-defining one's identity and eliminates the narrow characteristics approach to defining Indigenous people. This definition of the term "indigenous" contributes to the contentious debate about the notion of self-determination.[3] Indeed, the issue of self-determination is a challenge for post-colonial governments where the colonised Indigenous persons are the minority and a history has prevented a relationship on equal terms. States, including Canada, have been unwilling to implement self-determination because of the fear for the rise of new political sovereignties. Yet, without self-determination Indigenous persons' identity is at risk.[4]

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[1] Maya Sabatello & Marianne Schulze, eds, *Human Rights and Disability Advocacy* (Philadelphia: University of Pennsylvania Press, 2014) at 159.

[2] *Ibid.*

[3] *Ibid* at 160.

[4] *Ibid.*

Considering Canada's lack of recognition and endorsement of the notion of self-determination, the terms Indigenous and First Nations are used interchangeable in this paper to describe the political reality of those individuals who hold status under the *Indian Act* and are under the fiduciary responsibility of the the federal governments.[5] Nevertheless, the issue of self-determination should be kept in mind and one wants to consider that if Canada continues to attribute Indian status the way they do now, demographers predict that there will be no status Indians in 200 years absolving Canada from any obligations towards Indigenous people.[6]

Disabilities in Context

The cultural conceptualisation and understanding of the notion of disability within Indigenous communities is under researched.[7] The definition and perception of disability within the Aboriginal community is different from that of mainstream Canada. Consequently, it can be difficult to reconcile traditional Indigenous teachings with contemporary political realities.[8] Disabilities within Aboriginal communities tend to be considered special gifts or powers which enable people to communicate with the spiritual world.[9] An example are the traditional teachings of the Cree First Nations, which guide beliefs and values that children born with disabilities are special:

The old man said, to have been born imperfect was a sign of specialness… The old man explained carefully that in the old days, if a child came with a hare-shorn lip, it wasn't a terrible thing or a hurtful thing; it meant the child's soul was still in touch with the Spirit World.[10]

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[5] *Indian Act*, RSC 1985, c I-5.

[6] Cindy Blackstock, "The Canadian Human Rights Tribunal on First Nations Child Welfare: Why if Canada wins, equality and justice lose" 33:1 (2011) Children and Youth Services Review, 187 at 188 [Blackstock "Canadian Human Rights Tribunal"].

[7] Sabatello & Schulze, *supra* note 1 at 161.

[8] Shelly Johnson, "Jordan's Principle and Indigenous Children with Disabilities in Canada: Jurisdiction, Advocacy, and Research" 14:3 (2015) Journal of Social Work in Disability & Rehabilitation 233 at 237.

[9] Yvonne Johnson, *Stolen Life, The Journey of a Cree Woman* (Toronto: A. A. Knopf Canada, 1998) at 423.

[10] *Ibid.*

Such an understanding and perspective on disabilities is quite the contrary to the western perception of a disability. That is, the meanings of disability from the Euro-Western definition are based on a perspective of what a person can and cannot do: whether or not a person can support him/herself, the degree and type of work that the individual can complete, and the degree of inability.[11]

Following the Cree's traditional perception, children living with disabilities should be treasured.[12] However, the reality for Indigenous children with disabilities living on reserves in Canada is far from being alongside anything "special". These children and their families are constantly in the middle of jurisdictional and political disputes, which can lead to "social, physical, and economic exclusion, discrimination, and racism, nothing that supports a belief about being 'special'".[13]

In this paper, the term "children with disabilities" is used throughout this paper to refer to children with physical, intellectual, developmental, cognitive and/or psycho-social disabilities. Children with physical disabilities have an acquired or congenital physical and/or moto impairment such as cerebral palsy, spina bifida, muscular dystrophy, arthritis, developmental coordination disorder, amputations, or genetic disorders.[14] Children with intellectual disabilities generally have greater difficulty than other children with their intellectual and adaptive functioning and development due to a long-term condition that arises at birth or during childhood.[15] Developmental disability includes intellectual disability, as well as children with other developmental challenges including cerebral palsy, autism spectrum disorder and fetal alcohol spectrum disorder. Cognitive disability refers to difficulties with learning and processing

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[11] Sabatello & Schulze, *supra* note 1 at 161

[12] S Johnson, *supra* note 8 at 239.

[13] *Ibid.*

[14] Natasha Graham, "Children with Disabilities" Paper commissioned for Fixing the Broken Promise of Education for All: Findings from the Global Initiative on Out-of-School Children (UIS/UNICEF, 2015), Montreal: UNESCO Institute for Statistics (UIS) at 11.

[15] Mental Disability Advocacy Centre, "Access to Justice for Children with Mental Disabilities: Project Summary Report" (2015) at 6.

information. Children with psycho-social disabilities are those who experience mental health issues.[16]

Introduction

> "A child with disability has his or her own specific needs, and the families have specific needs too. Support for families at home should be available and accessible to every family that needs it."[17]
>
> A Mom, whose 4-year-old daughter has profound multiple disabilities and was denied services by the Slovak government. October 2015.

Every child should be given the tools and resources to achieve their full potential and capabilities. Regardless of a child's cultural background and beliefs; regardless of a child's status; regardless of his sex, his age and his needs, every child with a disability should receive equal services and be supported in his development. As such, Canadian children with disabilities should all have access to the same health services, support, apparatus and education opportunities as other children. It should not matter whether a child is on or off reserve, services should be equal with basic and essential needs being met.

Research consistently shows that the most prominent health disparities in Canada are those existing between Indigenous people and the rest of the Canadian population.[18] Moreover, the

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[16] *Ibid.*

[17] After the government refused to pay for in-home support, the Mental Disability Advocacy Centre (MDAC) in Budapest took on this little girl's case to the Bratislava Regional Court. The decision quashed the decision of the local authority and made it clear that the law requires community support services such as in-home care must be available for children with disabilities. Although I did not work on this case during my time at MDAC, I was involved with a multitude of other cases involving children over the summer. This little girl's mother's words resonated with me throughout my internship and led to an internal reflection about my own country's treatment of of children with disabilities nation-wide. Even if I have positive thoughts about community supports and health services in Canada for children with disabilities, I realised that they were not applied fairly. This realisation sensitised me to learn more about my own country's weaknesses and led to my commitment for the fair and equal treatment of Indigenous children with disabilities. See http://www.mdac.info/en/news/slovakia-first-time-litigation-helps-4-year-old-girl-being-institutionalised for the case MDAC defended.

[18] First Nations Families of Children with Disabilities Summit, *Understanding the Disability Trajectory of First Nations*

disability rate among Indigenous children was found to be twice that of the general population.[19] Demas explores the concept of triple jeopardy in her description of Indigenous Women with disabilities. [20] This analogy can also be used to describe the situation for Indigenous children with disabilities: they live in a situation of extreme disadvantage and vulnerability due to the triple jeopardy of inequities experienced by Indigenous people, being a child, and living with a disability.

As research and studies about Indigenous children with disabilities is limited, this paper's aim is to contribute to the understanding of the barriers and challenges they are faced with. First, the context for the marginalisation of children with disabilities will be considered and the effects of indigeneity and disability on a child will be explored. Then, Canada's legal and policy framework will be analysed including landmark cases for indigenous children with disabilities, the advancement of Jordan's principal and the effects of the Canadian Human Right's Tribunal 2016 decision. Finally, recommendations of solutions will be made to improve the situation of Canadian Indigenous children with disabilities.

Part I: Equal Rights for Children with Disabilities: a Paradigm Shift

The so called 'paradigm' shift' in disability policy is often described as a shift in viewing persons with disabilities from objects to subjects.[21] This signifies a move from charity to a rights-based approach and from paternalism to empowerment.[22]

Families of Children with Disabilities: Advancing Jordan's Principle, 20 June 2013, at 3.

[19] *Ibid.*

[20] Doreen Demas, "Triple jeopardy: Native women with disabilities" 13:4 (1993) Canadian Woman Studies 53; see also Douglas Durst, *Urban Aboriginal Persons with Disabilities: Triple Jeopardy* (Regina: Social Policy Research Unit, University of Regina, 2001).

[21] Sabatello & Schulze, *supra* note 1 at 20.

[22] *Ibid.* See also Donald W Shackel, "The Experience of First Nations People with Disabilities and Their Families in Receiving Services and Supports in First Nations Communities in Manitoba – Honouring the Stories" (2008) *Department of Disability Studies, University of Manitoba* at 9.

A. Understanding disability in the human rights context

This paradigm shift permeates the notion of disability in the human rights context.[23] The *Convention on the Rights of Persons with Disabilities* (CRPD) affirms that disability is a consequence of the interaction between persons with impairments and the environment.[24] It is only when the environment fails to accommodate the needs of the child that disability occurs.[25] This way of understanding disability is fundamentally different from viewing disability as a consequence of the individual's impairment. In the past, disability was interpreted as a medical model, which means that disability was linked to various medical conditions.[26] In some regions, for example in Central and Eastern Europe, disability is still largely treated as a medical condition with little differentiation made between impairment, illness and disability.[27]

However, Canada, has distanced itself from the medical model of disability and is adopting the social model, which is the model promoted in the *CRPD*. With this view, Canada conceptualises disability as arising from the interactions of a person's functional status with the political, physical, and cultural environments.[28] Nonetheless, to fully adopt the understanding of disability in the human rights context, Canada has yet to acknowledge that it is its failure to create an inclusive environment that disables children rather than any mental or intellectual conditions attached to the person.[29]

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[23] *Ibid.*

[24] *Convention on the Rights of Persons with Disabilities*, 2515 UNTS 3, 30 March 2007 (entered into force 3 May 2008, accession by Canada 11 March 2010) [*CRPD*].

[25] *Ibid* at art 1 & preamble (e).

[26] Graham, *supra* note 14.

[27] UNICEF and UIS. 2013a. "Forward". Education Equity Now! A Regional Analysis of the Situation of Out of School Children in Central and Eastern Europe and the Commonwealth of Independent States- Summary brochure, Geneva, UNICEF Regional Office for Central and Eastern Europe and Commonwealth of Independent States (CEE/CIS). UNICEF, Geneva, 2013, at 2.

[28] Shackel, *supra* note 8 at 20.

[29] Sabatello & Schulze, *supra* note 1 at 18.

Ultimately, if a child's environment does not favour inclusion of people with disabilities, the marginalisation and discrimination that they will face will be greater.[30] The State of the World's Children Report highlights that "children with disabilities encounter different forms of exclusion and are affected by them to varying degrees, depending on factors such as the type of disability they have, where they live and the culture or class to which they belong".[31] Regardless of these differing forms and degrees of exclusion, children with disabilities relate to the feeling and the experience of being defined and judged by what they lack rather than by what they have. These children are very recurrently exposed to a greater vulnerability than other children because their (in)capacities are often regarded as inferior to other children. [32] Such attitude and perception of children with disabilities results in discrimination, marginalisation from resources, services and decision-making.[33]

Childhood deprivations can have lasting effects including limitations on education opportunities, gainful employment and inclusion in social and political affairs of society. These effects can be avoided or reversed with access to adequate supportive services. Technology has been recognised for helping children with disabilities take their place in the community and contribute to it because it inhibits them with the confidence and tools they need.[34] That is why by placing the 'problem' of disability in the (inaccessible) environment, the solution is to be found there as well. The paradigm shift calls for legal, attitudinal, and environmental changes. Existing barriers preventing children from receiving the same series and care on an equal basis with others needs to be removed and new systems should be developed. Considering that it is the environment that contributes to children's disabilities, impoverished First Nations

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[30] Louise Hanvey, "Children with Disabilities and Their Families in Canada" (2002) Commissioned by the National Children's Alliance for the First National Roundtable on Children with Disabilities at 5.

[31] UNICEF, "Children with Disabilities" (2013) *The State of the World's Children Report* at 1 [UNICEF "Children with Disabilities"]

[32] *Ibid* at 2.

[33] Lisa Jones et al, "Prevalence and Risk of Violence against Children with Disabilities: A systematic review and meta-analysis of observational studies" 380:9845 (2012) The Lancet 899 at 902; World Health Organization and the World Bank, "World Report on Disability" (2011) WHO, Geneva at 59.

[34] UNICEF "Children with Disabilities", *supra* note 17 at 2.

communities, jurisdictional health wrangling, and funding inequities further create a disadvantage to Indigenous children's environments, perpetuating their disabilities.[35]

B. Contributing factors to the disabling environments on reserves

Poverty, disease, alcoholism and unemployment among Canadian Indigenous persons; lack of appropriate services; lack of adequate funds for existing services; jurisdictional disputes about service provision: these are only a few of the common barriers that affect health and service provider for Indigenous children with disabilities.[36]

Poverty, disease, alcoholism and unemployment among Indigenous Canadians continue to be an issue.[37] The statistics are dismal and disgraceful. Children raised in this environment have more physical and emotional problems than other children and are more likely to become disabled or become chronically ill before than children from the general population.[38] Estimates indicate that nearly 80 percent of all disabling conditions among Indigenous communities are preventable.[39] Occasionally a bright, dedicated and aggressive individual will appear on the scene like a ray of sunshine, but after a few years of struggling against the disabling environments alone, they burn out. Health service agencies struggling with this problem have begun to realise the value of cooperative programs, cost sharing and networking in getting difficult jobs accomplished without provider burnouts.[40]

The lack of appropriate services is evident in many rural areas and reservations as well as in urban areas.[41] Moreover, appropriate usually means culturally appropriate, which is what

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[35] UNICEF "Aboriginal children's health: Leaving no child behind" (2009) *Canadian Supplement to the State of the World's Children* at 5 [UNICEF "Aboriginal children's health"].

[36] *Ibid.*

[37] *Ibid*; Karen Bennett, "Aboriginal Children and Youth in Canada: Canada Must do Better" (2010) Canadian Council of Provincial Child and Youth Advocates at 5.

[38] Lindsay Gething, "Aboriginality and disability" 18:3 (1994) Aboriginal and Islander health worker journal 29 at 30; Bennett, *supra* note 30 at 8.

[39] John Swain, Sally French, Colin Barnes & Carol Thomas, *Disabling Barriers, Enabling Environments*, 3rd ed (London: Sage Publications, 2014) at 14.

[40] *Ibid* at 16.

[41] Douglas Durst, "Urban Aboriginal families of children with disabilities: Social inclusion or exclusion?", *Participatory research: Working together for the inclusion of Aboriginal families of children with disabilities* (Ottawa: National

services to any minority group should be but often is not. Appropriate services might include establishing an Independent Living Centre in rural areas and on reserves, providing accessible reservation housing, arranging equipment purchase and repair, and providing transportation to and from remote areas to services in urban areas or making such services available in remote areas.[42]

Jurisdictional disputes about service provision actually lead the list of major headaches for Indigenous communities. Such disputes are the source of some of the most inhumane acts ever committed against innocent people, all carried out within "the letter of the law".[43] These situations come about because each agency declares itself the "provider of last resort", which means it is not going to provide the "first dollar" for a service if another agency might provide it.[44] For Indigenous people who have multiple providers (Indian Health Service, Bureau of Indian Affairs, provincial services, federal programs and tribal programs), the last-resort declaration is a nightmare.[45] When there is a stalemate between Indian Health Service, Bureau of Indian Affairs and a state agency, each declaring that a particular service (e.g., providing a wheel chair) is the jurisdiction of another agency, the Indigenous child needing that service is caught in a no-win situation and usually ends up without any service at all.[46] The continuing horror stories arising from this situation are countless. The issue with jurisdictional disputes is rooted in funding problems. Agencies have budgets and priorities that are seldom established with the involvement of the population they serve, and Indigenous communities are rarely any agencies priority.[47]

Association of Friendship Centres, 2006) at 50 [Durst "Urban Aboriginal families"].

[42] Gething, *supra* note 38 at 32; Bennett, *supra* note 30 at 9.

[43] Linda Simon, "Portrait of First Nations in Quebec Living with Disability or Having Special Needs" (2013) First Nations of Quebec and Labrador Health and Social Services Commission at 74.

[44] Jordan's Principle Working Group, "Without denial, delay, or disruption: Ensuring First Nations children's access to equitable services through Jordan's Principle" (Ottawa: Assembly of First Nations, 2015) at 8.

[45] *Ibid.*

[46] Durst "Urban Aboriginal Families", *supra* note 41 at 4.

[47] Jordan's Principle Working Group, *supra* note 44 at 11.

C. Situating the health inequalities in the overall human development indicators

Indigenous people in Canada suffer persistent health inequalities as a result of individual and structural uncertainty.[48] Over time, the progress in the health and well-being of Indigenous populations, compared to non-Indigenous populations, has been inconsistent.[49] The health inequalities faced by Indigenous Communities in Canada can be situated in the overall human development indicators. By applying the United Nations Development Programme's Human Development Index (HDI) to Indigenous people in Canada and by examining the trends in the HDI scores, a difference can be noted between their score compared to Canada as a whole.[50] HDI measures average wellbeing in a country by considering health, education and income, but does not measure the disparities between different regions or groups within a country.[51] The difference between the HDI score of non-Indigenous and Indigenous Canadians fell is significant when considering the discrepancy between the overall ranking of Canada's HDI and Canada's Indigenous people's HDI. Canada's HDI grants them the eighth rank in the world while Canada's Indigenous Population ranks 33.[52] This disparity highlights the inequality of the overall health and socioeconomic status of Indigenous communities in Canada versus the rest of the Canadian population.

The recent improvement in overall HDI scores for Indigenous peoples in Canada marks the recent progress achieved by the nation.[53] Nonetheless, considering Canadian Indigenous Population ranked 25 spots lower than the rest of the country proves that further improvements

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[48] Carlos R Quiñonez & Josée G Lavoie, "Existing on a boundary: the delivery of socially uninsured health services to Aboriginal groups in Canada" 33 (2009) Humanity & Society 35 at 40.

[49] Martin Cooke, Francis Mitrou, David Lawrence, Eric Guimond & Dan Beavon, "Indigenous well-being in four countries: An application of the UNDP'S Human Development Index to Indigenous Peoples in Australia, Canada, New Zealand, and the United States" (30 May 2007), online: <https://bmcinthealthhumrights.biomedcentral.com/articles/10.1186/1472-698X-7-9>.

[50] *Ibid.*

[51] United Nations Development Programme, "Human Development Index", online: < http://hdr.undp.org/en/content/human-development-index-hdi >.

[52] Cooke, *supra* note 35.

[53] The difference between the HDI score of non-Indigenous and Indigenous Canadians fell from 0.103 in 1991 to 0.085 in 2001 (*ibid*).

in the social, economic, and physical health of Indigenous peoples are necessary.[54] The resulting picture is best described as one of inconsistent progress. These improvements cannot be taken for granted and to witness the gap further closing between the two HDI calculations in the future, additional efforts have to be made.

Part II: Canadian Legal Framework and Policy Techniques

A. International Conventions to which Canada is a Signatory

Canada is a signatory to the *UN Convention on the Rights of the Child* (*CRC*).[55] The *CRC* recognises the rights of children with disabilities. It recognises their right to protection and promotion of equality; their right to special care, including family support, early education, child care and early intervention; their right to access services, including education, employment training, health care and rehabilitation; and their right to recreation and play.[56] Of particular importance to this topic, Article 23 of the CRC states: "...that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".[57] This article also recognizes the rights of children with disabilities to assistance for the child or parents to care for the child and to ensure the child has

> ...effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.[58]

Furthermore, Canada is also a signatory to the *CRPD*, which articulates a human rights framework for addressing the exclusion and lack of access people with disabilities have

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[54] *Ibid.*

[55] *Convention on the Rights of the Child*, 1577 UNTS 3, 20 November 1989 (entered into force 2 September 1990, accession by Canada 13 December 1991) [*CRC*].

[56] *Ibid.*

[57] *Ibid*, art 23.

[58] *Ibid*, art 23(3).

encountered in Canada and in all societies.[59] The initial draft text of the CRPD did include a specific article on children with disabilities, modeled largely on the text of Article 23 of the *CRC*.[60] It was, however, recognised soon to be unsatisfactory because it focuses on the special needs of children with disabilities whereas the philosophy of the CRPD is focused strongly on a social model of disability and the need to remove the barriers impeding the realisation of the rights.[61] Beyond the specific article on children with disabilities, and an article on education, the Working Group text included little recognition of their rights at all.[62]

However, considering Canada is a signatory to both the *CRC* and the *CRPD*, one would expect that these two conventions would complement one another and that the implementation of both in Canada would resolve a lot of injustices children with disabilities face. Although there has been a positive change in Canada for most children with disabilities, little or no difference was perceived by Indigenous communities living with children with disabilities.[63] One would have hoped that the *UN Declaration of the Rights for Indigenous Peoples* (*DRIP*) would have balanced the inequality Indigenous children with disabilities were still facing.[64] Although Canada voted against the adoption of the *DRIP*, as a member state of the United Nations, the Declaration is binding on Canada.[65] Nonetheless, this has yet to happen. Considering Canada is a signatory to three conventions that specifically address the rights and needs of Indigenous children, the lack of compliance to the intersection of these three Conventions is disappointing.

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[59] *CRPD*, *supra* note 10.

[60] Sabatello & Schulze, *supra* note 1 at 98.

[61] *Ibid.*

[62] *Ibid.*

[63] UNICEF "Aboriginal children's health", *supra* note 21 at 5.

[64] *Declaration on the Rights of Indigenous Peoples*, (adopted on 13 September 2007).

[65] United Nations Human Rights Office of the High Commissioner, "Declaration on the rights of indigenous peoples", online: < http://www.ohchr.org/EN/Issues/IPeoples/Pages/Declaration.aspx>.

B. National Laws and Policies for Disability Rights

Federally, the *Canadian Charter of Rights and Freedoms* (*Charter*) ensures some protections for people with disabilities.[66] Article 15 of the *Charter* guarantees equality before and under the law for people with a disability.[67] The issue of disability has become a policy priority in Canada, evident in several policy papers.[68] Moreover, the *Canadian Human Rights Act* prohibits discriminatory practices.[69] Though more general, this provision ensures that no one in Canada be denied good, services, facility or accommodation on the basis of discriminatory practices.[70] This shows Canada's commitment to people with disabilities and intention to treat all Canadians equally, despite of their differences. However, Indigenous children with disabilities are overlooked because of the lack of intersectionality between these laws and conventions.[71] While these conventions and federal laws should be implemented in parallel, they are rather read narrowly and individually, with no reference to each other. The lack of clear implementation of these laws becomes even more problematic when jurisdictional disputes interfere with the implementation of Indigenous people's rights. Jordan's story illustrates how this conflict affects Indigenous children with disabilities.

Jordan's Story: How one boy inspired a world of change

Jordan was a young boy from Norway House Cree Nation in Manitoba who was born in 1999 with multiple disabilities. He lived for more than two years in a hospital because federal and provincial governments could not concede on who would pay for his at-home care.[72] In

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[66] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

[67] *Ibid* s 15.

[68] See e.g. "In Unison: A Canadian Approach to Disability Issues" (1998); "Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship" (1999) which presented a government agenda to meet the needs of this group and highlighted the "acute needs of Aboriginal people with disabilities (at 11); "Advancing the Inclusion of Persons with Disabilities" (Social Development Canada, 2004), recognizing that poverty is more than low income.

[69] *Canadian Human Rights Act*, RSC, 1985, c H-6, s5.

[70] *Ibid*, s 5(a).

[71] Sabatello & Schulze, *supra* note 1 at 163.

[72] Cindy Blackstock, "Jordan's Principle: Canada's broken promise to First Nations children?" 17 (2012) Paediatrics and Child Health 368 at 368 [Blackstock "Jordan's Principle"].

Jordan's case, the Manitoba and federal governments fought for who should pay for his at home care. Consequently, Jordan was deprived of receiving the services he deserves until the governments established the payment issue.[73]

The explanation behind this debate is that responsibility for services to First Nations children is often shared by federal, provincial/territorial and First Nations governments.[74] In contrast, funding and delivery of these same services to most other children in Canada falls solely under provincial and territorial jurisdiction.[75] Accordingly, First Nations children face unique challenges in accessing services, and their rights under the *CRC*, *CRPD*, *DRIP*, the *Charter,* and the *Human Rights Act* are neglected because of bureaucratic disputes on funding and services for Indigenous communities. Jordan's wait for a resolution to settle the federal and provincial jurisdictional disagreement ended when he died in a Winnipeg hospital on February 2, 2005, at 5 years old, hundreds of kilometres away from his family's community and before Jordan could experience living in a loving home.[76]

Jordan's death exemplified the severity of the inequality, challenges and disparity Indigenous children with disabilities face and stressed the need for a mechanism for ensuring their human, constitutional, and treaty rights. Consequently, a new child-first principle for Indigenous children – a principle that is consistent with government commitments set out in the CRC and the *Charter* – was unanimously voted in favour by members of Parliament in 2007: Jordan's Principle.[77]

C. Jordan's Principle

This principle requires First Nations children to receive the same services other children in Canada receive, notwithstanding any jurisdictional dispute that might erupt for the payment of

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[73] Blackstock "Canadian Human Rights Tribunal", *supra* note 6 at 192.

[74] Also referred to as Band government, which are small groups of people joined together or tribal Councils, which are larger regional groupings (Sabatello & Schulze, *supra* note 1 at 159).

[75] Jordan's Principle Working Group, *supra* note 44 at 8.

[76] S Johnson, *supra* note 8 at 235.

[77] Blackstock "Jordan's Principle", *supra* note 72 at 368.

that service.[78] The principle applies for all government services available to children, youth and their families. The goal of this principle is to ensure that children living on reserves receive the same level of care, support and services as Canadian children living off reserves.[79] Given that Jordan's Principle is a child-first standard, it is crucial that legislatures address and meet the needs of the child as a first priority. The commitment to address the needs of the child ought to always supersede government interests to arrange jurisdictional dispute procedures or implementation of policies.[80]

Unfortunately, even with the implementation of Jordan's Principle, Jordan's experience was not the last struggle for Indigenous children with disabilities. Jurisdictional disputes continue to arise and continue to affect the lives of other Indigenous children living with a disability on a land reserve in Canada. Jeremy Weawagige's story highlights another example of obstacles faced in accessing health and social services as quickly as other children due to continuing bureaucratic confusion.[81]

D. Key Case for the Rights of Indigenous Children with Disabilities in Canada: Pictou Landing Band Council (PLBC) v Canada (Attorney General)

Maurina and her son Jeremy are Mi'kmaq members of Pictou Landing First Nation (PLFN) in Nova Scotia. In 2010, Maurina was a single mother providing care for her 15-year-old son, who lives with complex health needs including microcephalus, cerebral palsy, curvature of the spine, and autism.[82] Jeremy is only minimally verbal and he requires total personal care. His mother had been providing all his home care until she suffered a stroke and became unable to provide full-time care.[83] Since then, the PLFN had been providing home care for Jeremy to supplement the care his family is able to provide. The cost of that home care used a majority of

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[78] Blackstock "Canadian Human Rights Tribunal", *supra* note 6 at 192; First Nations Families of Children with Disabilities Summit, *supra* note 18 at 4.

[79] S Johnson, *supra* note 8 at 234.

[80] Blackstock "Jordan's Principle", *supra* note 58 at 368; Jordan's Principle Working Group, *supra* note 44.

[81] S Johnson, *supra* note 8 at 234.

[82] *Ibid* at 236.

[83] *Pictou Landing Band Council v Canada (Attorney General)*, 2013 FC 342 at para 8, [2013] FCJ No 367 (QL) [*Pictou*].

the First Nation's total health care funding from the Federal government.[84] Therefore, the Health Director at the PLFN Health Care Centre contacted the Atlantic Regional Home and Community Care Coordinator at Health Canada as she believed Jeremy's case met the criteria's of Jordan's Principle. The First Nation requested that federal government reimburse the PLFN for its expenses, on the basis that Jeremy would be entitled to this level of care if he lived off-reserve.[85]

However, the federal government denied the First Nation reimbursement of the costs of Jeremy's home care, saying that Jeremy would not have been entitled to that level of care from the province of Nava Scotia if he lived off reserve. Both the federal and provincial governments agreed there was a funding cap set at a maximum of $2,200 per month.[86] The Federal Court's ruling said that Aboriginal Affairs and Northern Development Canada (AANDC – today's Indigenous and Northern Affairs Canada) was unreasonable when it made its decision that the First Nation should not be reimbursed for its costs.[87]

In response to the Manager's decision, the PLBC and Ms. Beadle (Applicants) filed an application for judicial review. The Applicants presented many arguments against the Manager's decision. Firstly, the Applicants argued that the Manager erred in law when she disregarded the decision in *Nova Scotia (Department of Community Services) v Boudreau* (*Boudreau*), when applying the *Nova Scotia Social Assistance Act* to the case at hand.[88]

The Court ruled, just like in Nova Scotia's Court decision in *Boudreau*, that in exceptional circumstances home care expenses will be provided to individuals residing off-reserve, in amounts exceeding the maximum. The Court found that the First Nation was complying with the provincial legislation when it provided home care to Jeremy in excess of the maximum. Justice Mandamin said that Jordan's Principle should not be read narrowly to exclude this kind

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[84] *Ibid* at paras 9–11.

[85] *Ibid at paras 16–18*.

[86] *Ibid at paras 21, 23*.

[87] *Ibid.*

[88] *Ibid*, at paras 32 –34; *Nova Scotia (Department of Community Services) v Boudreau*, 2011 NSSC 126, 302 NSR (2d) 50.

of dispute between levels of government.[89] Thus, the First Nation is entitled to be reimbursed for its expenses providing care to Jeremy, because Jordan's Principle binds the Federal government to do so.[90]

Although each case involving providing comparable health care services will depend on the factual circumstances of the case, this case is the first time that the courts have said that Jordan's Principle is binding on the Government of Canada and is not to be read narrowly.[91] Although this decision should have assisted other families and First Nations seeking health care services funding that is comparable to provincial services, Canada appealed the April 4, 2013 decision by Justice Mandamin.

On May 6, 2013, the Attorney General of Canada appealed the decision in *PLBC v Canada* to the Federal Court of Appeal. Canada argued that the judge erred in the interpretation and application of Jordan's principle, the decision was unreasonable, the remedy the judge granted was incorrect, and other grounds to be determined.[92] On July 11, 2014, two months before the scheduled hearing for the appeal, Canada announced its decision to drop its appeal and filed a discontinuance in the Pictou Landing Band Council case.[93]

Although the appeal has been dismissed, this serves as an example of the legal struggle for the full implementation of Jordan's Principle. It is necessary to resolve the complex jurisdictional issues of governments because it is one of the core reasons why Indigenous children with disabilities are still not receiving the proper care they require. Jordan's Principle Working Group shares the same opinion:

> Health and social services program fragmentation among various government levels and agencies is a major barrier to access. The situation is confusing and frustrating and many persons simply give up, and therefore are not accessing services or programs to which they are fully entitled. The first step that should begin immediately is

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[89] *Pictou*, *supra* note 83 at paras 95–97.

[90] *Ibid* at para 127.

[91] S Johnson, *supra* note 8 at 236.

[92] Department of Justice, *Notice of appeal,* (6 May 2013).

[93] *Canada (Attorney General) v Pictou First Nation*, 2014 FCA 21.

addressing the complex jurisdictional issues of government departments.[94]

E. Poor Implementation of Jordan's Principle Lead to a Canadian Human Rights Tribunal Decision

The government's poor implementation of Jordan's Principles gave rise to both Indigenous and non-Indigenous peoples, political and research organisations collaborating together to respond to Canada's efforts "to control, deny, minimise and delay funding to vulnerable Indigenous children". [95] Namely, Cindy Blackstock, the Executive Director of the First Nations Child & Family Caring Society of Canada (FNCFCSC), cooperated with the Assembly of First Nations (AFN) to challenge Canada's decision to fund on reserve First Nations child welfare services at a 22 percent reduced rate as compared to services for children living off reserves.[96] Together, they asked the Canadian Human Rights Tribunal to rule on whether this was a discriminatory practice according to Canada's own *Human Rights Act*.[97] This was followed by a second challenge filed with the Canadian Human Rights Tribunal compelling Canada to fund and implement Jordan's Principle. The FNCFCSC and Amnesty International found that the current interpretation of Jordan's Principle was "narrow, restrictive, ambiguous, unlawful and discriminatory, causing denial and delay of services to children in need".[98]

This critique of Jordan's Principle is justified by its limited scope, inefficient repayment procedures, and lack of accountability, transparency and stakeholder participation. First, the children who can be protected by this principle must satisfy very specific conditions including the requirements to be "on-reserve, Status or Status-eligible children who have been professionally diagnosed as having multiple disabilities requiring multiple service providers".[99] The Canadian government also narrows the operational definition of jurisdictional disputes to

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[94] Durst "Urban Aboriginal families, *supra* note 41 at 6.

[95] S Johnson, *supra* note 8 at 239.

[96] *Ibid* at 239, as cited in Blackstock "Jordan's Principle", *supra* note 58.

[97] *Canadian Human Rights Act*, *supra* note 55.

[98] S Johnson, *supra* note 8 at 240.

[99] Jordan's Principle Working Group, *supra* note 44 at 14.

exclude intra-governmental disputes. That is, disputes occurring between two federal government departments cannot make grounds for a case to be considered under Jordan's Principle. In addition, it fails to consider existing formal payment disputes as the primary indicator of a jurisdictional dispute thus eliminating all cases that involve service gaps that are already identified and widely known.[100]

Second, the procedure to apply for Jordan's Principle lacks a consistent mechanism for repayment of costs incurred by the family or organisations providing interim services.[101] The family needs to be involved in a local case conferencing process and have the situation brought to the attention of a government employee appointed to oversee Jordan's Principle cases. Following the local case conferencing, the family must take part in a multi-step formal case conferencing process, that can potentially be lengthy.[102] The costs of services required will only be covered after normative provincial/territorial standards have been assessed and a jurisdictional dispute has been formally declared by both levels of government. While this procedure is undertaken, the child may go without the needed services.[103]

Third, on the systemic level, documentation reveals a severe lack of accountability, transparency, and stakeholder participation. First Nations have been fully excluded from the discourse, development and implementation of Jordan's Principle. Publication of Jordan's Principle processes are not made accessible to the public and there are no mechanisms aside from going to court to appeal decisions made in Jordan's Principle cases.[104]

F. Canadian Human Rights Tribunal Decision

On January 26, 2016, the Canadian Human Rights Tribunal (CHRT or Tribunal) released its decision substantiating all aspects of the claim and ordering Canada to immediately cease its

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[100] *Ibid.*

[101] *Ibid.* See e.g. *Pictou*, *supra* note 83.

[102] *Jordan's Principle Working Group*, *supra* note 44 at 15.

[103] *Ibid.*

[104] Ibid page 15.

discriminatory conduct.[105] The Tribunal retained jurisdiction and ordered Canada to provide compliance reports. The CHRT, consisting of a three-member panel, found that Canada's flawed and inequitable provision of First Nations child and family services is discriminatory pursuant to the section 5 of the *Human Rights Act* on the grounds of race and national ethnic origin.[106] The Tribunal also found that Canada's failure to ensure First Nations children can access government services on the same terms as other children via Jordan's Principle was also discriminatory and contrary to the law. Consequently, it ordered the federal government to "immediately implement the full meaning and scope of Jordan's Principle.[107] Canada had to stop applying the discriminatory definition of Jordan's Principle and finally ensure to immediately take measures to implement the full definition of Jordan's Principle like it was advanced by First Nations and endorsed by the House of Commons.[108]

Unsatisfied with Canada's progress, the Tribunal issued a compliance order on April 26, 2016. This order found that the federal government was not respecting the January 2016 judgment delivered by the Tribunal regarding the full implementation of Jordan' s Principle.[109] It also noted that the discussions the federal government was having with partners and stakeholders were developing rather slowly. Again, the Panel ordered Indigenous and Northern Affairs of Canada (INAC) to "immediately consider Jordan's Principle as including all jurisdictional disputes (this includes disputes between federal government departments) and involving all First Nations children (not only those children with multiple disabilities)".[110] Going forward, the government organisation to be contacted first must pay for the service the child needs without policy review or case conferencing.[111] Finally, the order granted the INAC until

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[105] *First Nations Child and Family Caring Society of Canada et al v Attorney General of Canada (*for the Minister of Indian and Northern Affairs Canada*)*, 2016 CHRT 2, T1340/7.

[106] *Ibid* at para 468.

[107] *Ibid* at para 481.

[108] *Ibid.*

[109] *First Nations Child and Family Caring Society of Canada v Attorney Canada (*for the Minister of Indian and Northern Affairs Canada*)*, 2016 CHRT 10, T1340/7008.

[110] *Ibid* at para 33.

[111] *Ibid.*

May 10, 2016 to report on the long-term plan for the definition and full implementation of Jordan's Principle, including a confirmation that this order was implemented.[112]

Government Response to the Compliance Order

INAC's May 10, 2016 report outlined five steps the government has taken since the January 26, 2016 decision.[113] First, it eliminated the requirement for a child to have multiple disabilities. Second, it expanded Jordan's Principle to include disputes within the federal government departments and applies to all jurisdictional disputes. Third, it ensured that services for any Jordan's Principle case will not "be delayed due to case conferencing or policy review", confirming that services or suite of services will be implemented in a timely manner.[114] The government generally stated in the fourth step that "Canada committed to provide the necessary resources to implement Jordan's Principle".[115] Finally, the report stated that INAC had initiated discussions with the provinces/territories on Jordan's Principle.[116]

Although INAC complied with the order and respected its two-week delay to respond to the April 26, 2016 decision, the report was rather disappointing. Considering the length and detail of the two Tribunal's decision, the INAC's two-page response is inadequate to address the scope and seriousness of the issue. They did not care to elaborate further on the mechanisms and strategies they would implement to ensure the orders were complied with. A simple reiteration of the Tribunal's requests is not progress.

A more comprehensive response to the Tribunal's decisions would have provided more details on how the federal government was going to ensure implementing the full meaning and scope of Jordan's Principle. Rather, the government's steps do the contrary. It seems as though things were purposely left out to ensure INAC still had discretion with regards to certain aspects of Jordan's Principle. For example, although the internal federal departments are included, the

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[112] *Ibid* at para 34.

[113] Department of Justice Canada, Re: First Nations Child and Family Caring Society, et al. v. Attorney General of Canada Tribunal File: T1340/7008 (10 May 2016).

[114] *Ibid* at 2.

[115] *Ibid.*

[116] *Ibid.*

report did not specifically say the federal government is applying Jordan's Principle to all jurisdictions. Moreover, even if the criteria of "multiple disabilities getting services from multiple providers" would stop, the report did not specifically confirm that Jordan's Principle will apply to all First Nations children.[117] Providing exactly what resources Canada committed to in order for Jordan's Principle to be fully implemented should have been elaborated upon. Making such a broad statement is artificial in nature and suggests an insincere commitment to realising the order. Lastly, while it is positive that INAC initiated discussions with provinces and territories, it makes no mention how, or if, First Nations and First Nations Child and Family service agencies would be engaged in those discussions or what the nature of those discussions would have been.

Since then, the Tribunal released a second compliance order in which it is made clear that "it rests on INAC and the federal government to implement the Tribunal's findings and orders and to clearly communicate how it is doing so, including providing a rationale for their actions and any supporting data and/or documentation, ensures the Panel and the parties that this is indeed the case."[118] The Tribunal finds that the federal government has not addressed the most egregious discriminatory effects of its child welfare program pending longer term reform despite knowing about solutions to fix many of the problems over a decade. According to the Tribunal, Canada's failure to deal promptly with key findings of the Tribunal's January decision in a timely manner is "reflective of INAC's old mindset that spurred this complaint" and "this may imply that INAC is still informed by information and policies that fall within this old mindset and that led to discrimination".[119] While Jordan's Principle's implementation is yet to be achieved as requested by the Tribunal, other measures can be taken simultaneously to respond to the urgent needs of Indigenous children with disabilities in Canada.

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[117] Anishinabek News, "Human Rights Tribunal decision confirms non-compliance by Canadian government" online:<http://anishinabeknews.ca/2016/09/16/human-rights-tribunal-decision-confirms-non-compliance-by-canadian-government/>.

[118] *Ibid.*

[119] *Ibid.*

Part III: The Way Forward

A. Provincial/Territorial Ombudsmen Offices for Families of Children with Disabilities

The existence of jurisdictional tensions and divisions between federal, provincial, and band governments results in an overall lack of leadership and responsibility for Indigenous children and youth with disabilities.[120] The jurisdictional issues are one of the fundamental problems affecting service planning and provision. It results in inadequate levels of funding, limited availability and access to support services (particularly culturally appropriate services). The inadequacy of funding also means that children and their families on-reserve do not receive support comparable to the standard of children off-reserve. This does not comply with Article 23 of the *CRC*.[121]

These jurisdictional disputes are partially generated by the absence of a centralised agency responsible for Indigenous persons with disability, nor is there an ombudsman or advocate for their rights. There is a need for greater coordination of policy at the federal and provincial levels as many of these issues cross programs and are separated in Indigenous departments or divisions within government.[122] There are segments of federal programs dedicated to the disabled, but there is no single program for Indigenous persons with disabilities designed to meet their needs for education, social integration, health care and other services.

In order to address this problem, the creation of a personal ombudsmen would be a good example to showcase advocacy for the rights of Indigenous children with disabilities. For example, Sweden established the personal ombudsmen support model for people with disabilities because their existing legal capacity systems did not meet the needs of many people with psychosocial disabilities who were pushed between authorities and unable to access their

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[120] Alex Wright, Diane Hiebert-Murphy & Gwen Gosek, "Final Report: Supporting Aboriginal children and Youth with Learning and/or Behavioural Disabilities in the Care of Aboriginal Child Welfare Agencies" (2005) Faculty of Social Work, University of Mantioba.

[121] *Ibid* 45.

[122] *Ibid 48*.

rights. Although this system was established in a European country for legal capacity challenges, the idea can be used in parallel for Indigenous children with disabilities because just like Swedish persons with disabilities, Canadian Indigenous children with disabilities are pushed between authorities and caught up in jurisdictional disputes.[123]

The ombudsman is a professional who works 100 percent on the commission of the individual, and for the individual only. The ombudsman has no commitments or responsibilities vis-à-vis the medical or social services, or any to her authority or person. The ombudsman only acts when the clients wants him to do so.[124] It may take a long time before the ombudsman and the individual have developed a trustful relationship where the individual wants to talk about what kind of support he wants, but the ombudsman needs to wait, even if the client's life may appear chaotic.[125] This type of support has been successful in helping also those who are most hard to reach and who have previously often been left without support. This includes persons diagnosed with schizophrenia, persons experiencing delusions and psychosis, and those who are homeless or live very isolated avoiding all contact with the authorities. To reach this group, the ombudsman has to actively seek contact on the individual's terms. A number of characteristics have contributed to the success of the personal ombudsman model. These characteristics include that there is no bureaucratic procedure to get an ombudsman. Requirements to fill in forms would prevent many who need the ombudsman, to get one. A simple yes to the question from an ombudsman to the client if he wants an ombudsman is enough.[126]

The ombudsman does not work ordinary office hours but holds flexible hours and is prepared to have contact with his clients also in the evenings or on weekends. The ombudsman is comfortable to support the client in a number of matters. The priorities of the individual are not always the same as the priorities of the authorities or the relatives. The client's first priorities

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[123] Durst "Urban Aboriginal families", *supra* note 41 at 61.

[124] Mental Disability Advocacy Centre, *supra* note 15.

[125] *Ibid.*

[126] *Ibid.*

may not concern housing or occupation but relationships or existential matters. An ombudsman must be able to discuss such matters as walk and not just 'fix' things.

B. Accessing Inclusive Education for Indigenous Children with Disabilities

The Global Partnership for Education notes that "education is one of the most effective ways to break the cycle of discrimination and poverty that children with disabilities often face".[127] However, Indigenous are often segregated from the education the rest of the community receives.[128] *In the Matter of the Children NP and BP*, the custody of the children was granted to a non-Indigenous couple rather than their Indigenous uncle, because the Court "afforded significant weight to the 'greater understanding' of the non-First Nations couple of the special educational needs of children suffering learning disorders.[129] Comparatively, little consideration was accorded to the presumably far greater understanding of the First Nations aunt and uncle of the special cultural needs of First Nations children and their education.[130]

Another struggle towards accessing inclusive education for Indigenous children is the lack of accessibility.[131] There are three ways that a school could be inaccessible for a student. First, it can be that the infrastructure of the school itself prevents a child with a physical disability to enter the building.[132] Second, a child who is able to access the school premise might be excluded from learning because the curriculum is not adapted to his needs or teachers do not have the resources make the necessary adaptations.[133] Finally, the third way a child can be prevented for receiving an inclusive education is that because of his severe disability, he requires additional

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[127] Global Partnership for Education, "Children with Disabilities", online: <http://www.globalpartnership.org/focus-areas/children-with-disabilities>.

[128] Ardith Walkem, "Wrapping Our Ways Around Them: Aboriginal Communities and the Child, Family and Community Service Act Guidebook", ShchEma-mee.tkt Project (Nlaka'pamux Nation Tribal Council at 39.

[129]Philip Lynch, "Keeping Them Home: The Best Interests of Indigenous Children and Communities in Canada and Australia" 23 (2001) Sydney L Rev 501 at 524 citing In the matter of the children NP and BP: NP and SM v. the Director of Child, Family and Community Service (BCSC Prince George Registry 03998, 1999).

[130] *Ibid.*

[131] See UNICEF "Children with Disabilities", *supra* note 24, for a comprehensive understanding of inclusive education.

[132] Global Partnership for Education, *supra* note 110.

[133] *Ibid.*

and specialised support either in the classroom or outside the classroom.[134] These factors are especially present on Canadian Indigenous Reserves.[135] Thus, one of the core solutions to empower Indigenous children with disabilities is to ensure that funding is specifically allocated for schools to make necessary changes to improve accessibility of inclusive education. While providing a solution to allocate funds for school infrastructures falls beyond the scope of this paper, providing teachers with the proper training to teach children with disabilities and to train other professionals specifically to support children with severe disabilities in schools can be solved with the following recommendation.

C. Training and educating Community Members to Provide Services

This paper highlights the lack of support services that are available for children with disabilities and their families. The services that are lacking include: (a) respite, (b) financial assistance for families caring for children with disabilities, (c) parent/foster parent training and support groups, (d) community-based therapeutic services (e.g., speech therapy, occupational therapy, physiotherapy, psychological services, child development counselors), (e) early diagnosis and intervention services, and (f) services for youth with disabilities when they reach adulthood.[136] Considering the improvements and recommendations are followed by the Canadian government, the issue at core is still being ignored. That is, these services offered stem from the Canadian perspective on disability while it is important to consider how disability is or can be defined from an Indigenous perspective.[137]

As a result of the lack of support services available on reserves, children with disabilities are placed in agency care.[138] This is in line with the *National Household Survey (2011)* that found that 48% of youth in foster care across Canada are Indigenous children, even though Indigenous

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[134] *Ibid.*

[135] Walkem, *supra* note 11.

[136] Wright, *supra* note 120 at 49.

[137] Sabatello & Schulze, *supra* note 1 at 159.

[138] Aboriginal Children in Care Working Group, "Aboriginal Children in Care: Report to Canada's Premiers" (July 2015) at 7.

peoples account for only 4.3 percent of the Canadian population.[139] Moreover, 50 percent of parents said that it was because of a lack of respite that their child was in alternate care (including institutions).[140] No child should be placed in care in order to receive disability services. Indigenous Community members should receive training and education to be able to offer the necessary services in their communities. For example, training could be provided in various professions such as psychology, occupational therapy, physiotherapy, and speech therapy. While these opportunities would increase the available services on reserves, it would also decrease unemployment in the community and would help employ other community members. All in all, ongoing education and training is one the of crucial ingredient for capacity building in First Nations communities. The solution of equipping community members to provide the services that are lacking on reserves would simultaneously address the issue of losing contact with their cultural and family supports when Indigenous children with disabilities receive care.

D. National Indigenous Controlled Child welfare, Health and Social services

Although it is beyond the scope of this paper to recommend a structural arrangement based on Indigenous people's right to self-governance, reconciling the two aforementioned recommendations relating to education and training would be the first step in the right direction. It is still important to consider the right to self-government over Indigenous internal affairs and governance when considering the interests of Indigenous children with disabilities. Although Canada has yet to see the implementation of Indigenous self-government on a national scale, there are numerous examples of smaller community-led projects in the fields of criminal justice, health and social welfare can serve as an example of how this can serve for Indigenous children with disabilities.[141] The community's sense of control and ownership over these initiatives, as promised more generally with the implementation of self-government, has proved vitally important to its success. For example, a number of communities have taken control over the

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[139] *Ibid.*

[140] Wright *supra* note 12 at 47.

[141] Sonia Harris-Short, *Aboriginal Child Welfare, Self-Government and the rights of Indigenous Children: Protecting the Vulnerable Under International Law* (Padstow: *University of Birmingham*, 2012) at 11. See also Don Fuchs, Linda Burnside, Shelagh Marchenski & Andria Mudry, "Children with Disabilities: Receiving Services from Child Welfare Agencies in Manitoba" (2005) University of Manitoba, for a province specific approach.

problem of substance and alcohol use, initiating the process of individual and community healing.[142] Essentially, the solutions to the problems surrounding Indigenous welfare for children with disabilities will have to come from within the communities themselves. This change can only be achieved if those communities are empowered and are recognised to have the ultimate responsibility for their children.[143]

Empowering Indigenous communities to take responsibility for their children will be easier if the Band is also granted with the power to control services for their children. Moreover, Indigenous leadership is necessary for the advocacy for the rights of Indigenous children with disabilities to reinstate and reinforce the Indigenous perspective on disability that was discussed in the context section of this paper.[144] An intermediate solution, somewhere in between self-government and the Canadian government alienating Indigenous communities, is to consider creating Indigenous National bodies to monitor and control the heal and social services of Indigenous children. Durst suggests to expand the National Aboriginal Health Organisation's mandate to include both health and social services. The alternative to expanding this organisation is to expand the mandate of the National Association of Friendship Centres to include comprehensive health and social services.[145] Although this centres are currently small, their facilities could be expanded in the eventuality of mandate reforms[146].

E. Expand Research and Knowledge about Indigenous Children with Disabilities

It is necessary for the federal government to conduct more research about the areas of need identified in this paper. The field of Indigenous children with disabilities is under-researched. With a lack of research, it is impossible to know the accuracy of the number of Indigenous children with disabilities and the varying and urgent needs they have. While no further research

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142 *Ibid* at 125.

143 *Ibid* at page 123

144 See page 5–6 of this paper.

145 Durst "Urban Aboriginal families", *supra* note 41 at 62.

146 *Ibid.*

is conducted, Indigenous children with disabilities continue to be invisible. It is primordial to be able to find these children to be able to include them in services and programs.

Furthermore, expanded research will be able to help settle issues of the understanding of "inclusion" from different perspectives.[147] While the inclusion of children with disabilities is a widely held value, inclusion can mean a variety of things. It can signify being included in social and cultural life of the community, or it can be inclusion with other persons and children with disabilities. While inclusion should be understood in its largest sense, a clear and cohesive comprehension of the scope of inclusion will facilitate closing the inequality gaps.

Conclusion

Indigenous children with disabilities are one of the most oppressed and marginalised groups in Canada. This paper highlights and reveals that First Nations families of children with disabilities have many needs that are not adequately addressed. Parents struggle to provide a good life for their children in environments that are lacking the appropriate resources and services. The commitment of First Nations families to children with disabilities is clear that they strive to provide a good life for their children and do so with an engagement to family and children's human potential.[148]

> "Get to know him ... he is a member of the community ... he needs supports to utilize his talents to be a contributing member of the community. Any money spent on him is an investment in the community."[149]

Every child deserves the right to live a childhood that is granted with the same opportunities as other children. Cultural backgrounds and beliefs; a child's status; sex, age or capabilities are not valid reasons to differentiate a child's treatment and potential. Indigenous

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[147] Durst "Urban Aboriginal families", *supra* note 41 at 60.

[148] First Nations Families of Children with Disabilities Summit, *supra* note 18 at 17.

[149] A Mom, from the "Beyond the Limits: Mothers Caring for Children with Disabilities" Roeher Institute Study (2000); Hanvey, *supra* note 23 at 3.

children with disabilities have bene neglected and only certain communities in Canada have recognised their unfair access to care and services.

This paper served to provide a clearer understanding of the struggles and challenges Indigenous children with disabilities face in Canada. The root of many of those challenges relate to federal and provincial jurisdictional and funding disputes. Moreover, Canada's adversarial legal and policy techniques to delay implementation and funding of Jordan's Principle go against the clear ruling in Canadian Human Rights Tribunal decision. Until the Tribunal's orders are specifically implemented by INAC, Canada will not be complying with the *CRC* and *CRPD*. Considering that Canada committed to these Conventions, it is inexcusable that it is not fully committed to see its equal implementation nation-wide.

Although the situation of Indigenous children with disabilities in Canada commands for serious changes and improvements, the potential in certain solutions and recommendations is promising. From the creation of Ombudsmen offices, to improvements in education for Indigenous children with disabilities and community members, a positive change is possible. These recommendations should not be ignored or shelved, the needs must be addressed; the *Charter* and *the Canadian Human Rights Act* require nothing less. In applying Jordan's Principle, the needs for rehabilitation, training and employment, regardless of legal responsibility, should be assured for First Nations children living with a disability.

To ensure these recommendations and actions are implemented successfully, a national awareness and recognition of the problem is the first step. In Canada, there is a lot of denial of unequal treatment of the Indigenous community and without admitting to it as a nation, no change will ever be possible. ***The old man said, to have been born imperfect was a sign of specialness... as Canadians, where have we gone wrong? It is time to start to right the wrongs.***[150]

[150] Durst "Urban Aboriginal families", *supra* note 41 at 63.

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