

For Michael Charlie: Including girls and boys with disabilities in the global South/North

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Recognizing that there are pockets of the global South in the global North, I illustrate in this paper how Indigenous and northern children with disabilities and their relationships with their care providers have been rendered invisible and excluded by jurisdictional disputes between levels of government, an ongoing drive to institutionalize children with disabilities and longstanding colonial and capitalist values and systems. The paper highlights how Jordan's Principle, an Indigenous child-first response offers a small first step in ensuring children with disabilities in Indigenous and northern communities in Canada, access to necessary services in their communities.

Keywords: Indigenous; Canada; children with disabilities; colonization, Jordan's Principle

Introduction

Invisibility is often used to describe the situation of children and adults with disabilities in the global South. Nirmala Erevelles (2011) argues that disabled people are made invisible by their segregation in institutions, long-term care homes, special education classrooms and sheltered workshops. Those who live in the global South, which she argues has been designated as a space of terror, 'run the risk of almost complete erasure, and subsequently, face the most extreme dehumanization on account of this non-recognition' (122) in these segregated spaces. While in some countries with conflict or war, recently disabled veterans or children may have some visibility, many disabled people are at the edges of their communities and invisible (Rohweder 2013; Trani et al. 2011; Berghs and Dos Santos-Zingale, 2011). Children, and especially girls with disabilities are among those missing from broad attempts to ensure education for all (UNICEF, 2012, 2013; Trani et al. 2011). Development projects often treat people with disabilities as victims rather than as contributors to their country's development or reconstruction processes (Berghs, 2010).

In developing this article on children with disabilities in the global South/North, I wondered about this invisibility for girls and boys with disabilities, especially those who are Indigenous

and live in Canada's North. How do they experience disability? Does invisibility render them unseen and their needs unaddressed? To what extent do they, their families and communities illustrate agency in response to perceptions and assumptions around disability?

Many years ago as a teenager, I volunteered in a children's rehabilitation hospital in Edmonton, Canada. My job as a 'volunteer' was to spend time with the children on the wards and provide peer company. Many of the children who lived in the hospital came from northern Indigenous communities and attended the hospital school. They were unable to participate in the schools in their communities because their communities were not able to provide the supports they needed to be included in their local schools. This gap was (and continues to be) a result of long-standing colonial practices that fail to provide adequate funding for services in northern communities, devalue community-based Indigenous education, and force families of children with disabilities to choose between keeping their community and cultural connections or accessing disability-related services.

Michael Charlie was one of the children in the hospital. He came from a northern Alberta First Nations¹ community, but lived in the hospital because his family could not get the services they needed to keep him in their home. He lived with muscular dystrophy and was a wheelchair user. We did homework together, played wheelchair basketball, but most importantly to me, I considered him my friend. When I had to leave my position, I promised him that he would not be forgotten, that despite his invisibility on a ward of a hospital, I promised I would work to keep him and his experiences visible. Over the following years, various research projects (Shackel, 2008; Stienstra and Kellerman, 1999) have reminded me that his experiences are not unique and continue to this day.

In this article, I argue that disability/ableism together with colonization and global capitalism work together to render girls and boys with disabilities invisible and primarily as victims in communities of the global South found in Canada. To make this argument, I suggest that when we consider global development and the global South, we need also to address the global South found in countries of the global North, including Indigenous and northern communities in Canada. But several key initiatives taken primarily by and in Indigenous communities, including Jordan's Principle and the recent court victory of the Pictou Landing First Nations, highlight forms of resistance to this invisibility. The stories of particular Indigenous children with disabilities in their access to services, together with their families and their communities, challenge the dominant portrayal of girls and boys with disabilities and, in so doing, teach us more about Indigenous ways of knowing around disability and childhood.

Global South in the Global North

Global or international development studies are often focused on examining global

inequalities with an emphasis on the poorest, particularly those found in countries of the global South. This is an important area of studies that until recently has neglected those with disabilities. To address disability in the global South is essential since two-thirds of those experiencing disabilities are located in the global South (WHO, 2011). But it remains difficult because much of the study of disability and global development has proceeded from a Northern perspective and Northern ways of knowing (Grech, 2011; Grech and Soldatic, 2014).

Much of the emergent disability studies dichotomizes the global North as the colonizer and the global South as the colonized. Some of the complexities within countries of the global North remain cloaked by this stark contrast. Some recognize that Indigenous peoples in countries of the global North have long and current histories of colonization (Connell, 2011; Meekosha, 2011). These accounts often lump Indigenous peoples together describing a legacy of poverty and disproportionate illness. Meekosha (2011) argues from an Australian perspective that these experiences are not well served by existing disability studies analysis since they often deal with survival rather than issues of independent living or care. These accounts often portray Indigenous people primarily as victims of colonization, rather than actors in a world shaped by colonization and there is little to help us understand how disability is understood in Indigenous worldviews.

Beginning to understand experiences of disability from an Indigenous worldview may require a different starting point. So little has been written from an Indigenous perspective around disability, although there is an increasing recognition of the importance of this perspective including through the discussions at the United Nations (2013) which suggested that disability as a concept is foreign to some Indigenous cultures and languages. Shackel (2008) illustrates this among some Indigenous nations in Canada. The United Nations report also draws the link between colonization and Western (global Northern) models of development and a shift in attitudes towards people with disabilities among some Indigenous societies:

In some places, the perception of what was once seen as a gift, a source of wisdom or a welcome contact with the spirits or the spiritual or philosophical life has changed because of the rupture of social systems resulting from a Western model of development. It is extremely important to strengthen Indigenous institutions to regain or build this inclusion. Just as disability is an evolving concept, Indigenous cultures and worldviews are also not static and can affect persons with disabilities positively or negatively (UN, 2013: 6).

The emerging literature on disability and the global South also does not address experiences in the periphery parts of the global North, including the northern parts of Canada. Many of the remote areas of Canada experience historical and long-lasting effects of core/periphery inequalities especially in terms of access to services, displacement as well as having their land, water and communities 'developed' through resource extraction or global military

contributions (Stienstra, forthcoming). With a desire to illustrate that the global South is complex and includes pockets of the global North that have experienced colonization and exploitation in the global political economy, I use the term global South in the global North or global South/North.

Finally, the emerging literature on disability and the global South is increasingly addressing the experiences of girls and boys with disabilities (Curran and Runswick-Cole, 2013; Ngo et al. 2013; Singh and Ghai, 2009; Philpott and Sait, 2001). Much of the academic literature looks at access to education, situations of conflict or disasters, poverty, and experiences of violence (Miles, 2013; Trani et al. 2012; Jones et al. 2012; Singal, 2011; Trani et al. 2011; Peek and Stough, 2010; Pinnock and Hodgkin, 2010). One gap is the experiences of children in the global South in the global North and a second gap is literature that addresses the gendered nature of children's experiences of disability in the global South. Without an attention to gendered analysis, girls with disabilities are often made invisible (Stienstra, 2015).

With this understanding of the global South in the global North, we illustrate how Indigenous children and their relationships with their care providers have been rendered invisible by jurisdictional disputes between levels of government, an ongoing drive to institutionalize children with disabilities and longstanding colonial and capitalist values and systems. By looking at Jordan's principle, as well as Indigenous approaches to children, community and disability, we can see some key aspects of an Indigenous response to this constructed invisibility.

Jordan's Principle

Indigenous peoples in Canada live with the long-term effects of colonization including forced removal of children to residential schools away from their families and communities over the last century (Truth and Reconciliation Commission, 2012) and the intergenerational trauma that remains. The effects of colonization are also seen in the created structures of relationships between settlers and Indigenous nations through treaties and Aboriginal rights (Asch, 2014). Indigenous children have often been affected by colonial power including through their over-involvement and maltreatment in the child welfare system (Sinha et al. 2011; Blackstock, 2009). Many of these experiences are similar in other settler nations like Australia (Hollinsworth, 2012).

Indigenous children with disabilities who require health or education services outside their home communities are often left in a jurisdictional desert as a result of the Canadian federal state and distribution of powers. First Nations and Inuit education and health services are the responsibility of the federal government with Indigenous governments often delivering these services. A significant proportion of the budget for these services is spent on transporting

people to large urban centres outside First Nations and Inuit communities to obtain services (Shackel, 2008). However, when First Nations people have to leave their home communities, they usually go to an urban centre and access health services through the public health system, under provincial jurisdiction. In some cases, parents must give up their custody for their children with disabilities to receive services (Notice of Application, 2011). In others, government representatives argue that the choice for parents is to put their children with disabilities in institutional settings or accept limited support from the federal government for required services (PLBC v Canada 2013: 8).

Jordan River Anderson's short life has come to symbolize one significant situation of Indigenous children with disabilities in Canada. He was from Norway House Cree Nation in northern Manitoba, born in October 1999 with multiple impairments. He was ready to go home from the hospital, but had to remain in hospital an additional two years because the federal and provincial governments could not agree on which level of government would pay for his at-home care costs. He died at age 5 on February 2nd 2005 before he could go home. The First Nations Child and Family Caring Society (FNCFCFS) led by Cindy Blackstock, launched Jordan's Principle (<http://www.fncaringsociety.com/jordans-principle>).

Jordan's Principle calls on the government of first contact to pay for the services required by an Indigenous child and seek reimbursement later so the child does not get caught in the bureaucratic quagmire rather than receiving the service they require. Blackstock (2012: 368) describes Jordan's Principle as a child-first initiative 'intended to resolve jurisdictional disputes within, and between, provincial/territorial and federal governments concerning payment for services to First Nations children when the service is available to all other children.' In 2007, the federal Parliament passed a motion to support Jordan's Principle. Since then the provinces of British Columbia, Manitoba and Saskatchewan have entered bilateral agreements with the federal government on Jordan's Principle and the Nova Scotia and New Brunswick governments have tripartite agreements, including First Nations and federal governments (Sinha and Blumenthal, 2014).

The FNCFCFS has used its Jordan's Principle campaign effectively to raise issues around equitable access to services for Indigenous children who live on First Nations communities. An editorial in the Canadian Medical Association Journal (MacDonald, 2012) argues that governments are dragging their feet, leaving Indigenous children to suffer. In its 2012 review of the implementation of Jordan's Principle, the Canadian Paediatric Association argued that only one province, Nova Scotia, was making good progress in implementing the principle and called for further action (29). In addition, the FNCFCFS has encouraged organizations and individuals to support the implementation of Jordan's Principle. As of August 2014, over 8400 supporters have joined the campaign.

A critical part of the implementation of Jordan's Principle has been the Federal Court challenge by the Pictou Landing Band Council and Maurina Beadle. On July 11, 2014, the

federal government withdrew its appeal to the Federal Court decision in support of Jordan's Principle (PLBC v Canada 2013). The Court's decision is a major victory for implementing Jordan's Principle, and by withdrawing its appeal, the federal government is signalling that it will abide by this ruling on Jordan's Principle.

Jeremy Meawasige is a teenager with disabilities who lives on Pictou Landing First Nations in the province of Nova Scotia. He has complex needs for care and support and many barriers to his life and inclusion. His mother, Maurina Beadle, is his primary caregiver and ensures that he remains connected to his culture and community:

She takes him on the pow-wow trail, travelling to communities where pow-wows are held. She says Jeremy is happiest when he is dancing with other First Nations people and singing to traditional music (PLBC v Canada 2013).

In 2010 she experienced a stroke and was unable to provide the same level of care and support to him. The Pictou Landing First Nations began to provide 24-hour care to support both of them. The costs were significant for the First Nations, roughly 80% of the total monthly health care budget for the entire First Nations (PLBC v Canada 2013). The Health Centre Director was aware of Jordan's Principle and contacted the relevant federal government administrator. After several meetings, the administrator ruled in May 2011 that there was no jurisdictional dispute and this was not a case in which Jordan's Principle could be applied. She argued that the provision of 24-hour care was outside the 'normative standard of care off-reserve' and therefore could not be funded by the federal government. The administrator noted that Jeremy could be placed in an institutional setting, and in that case, the federal government would cover the costs of his care. But the administrator also noted that it was not the wishes of Maurina Beadle to place her son in a long-term care setting.

In his decision on the case, Federal Court Justice Mandamin noted there is a legislatively mandated provincial assistance policy that provides home care services for people with disabilities off reserves above the maximum in exceptional cases and applied in the case of a person with disabilities who lived off reserve. But he argued that:

a severely handicapped teenager on a First Nation reserve is not eligible, under express provincial policy, to be considered despite being in similar dire straits. This, in my view, engages Jordan's Principle which exists precisely to address situations such as Jeremy's (PLBC v Canada 2013).

The Justice noted further that the only other option for Jeremy was institutionalization and separation from his mother, his community and his culture. This decision is the first of its kind in Canada and will provide support for the implementation of Jordan's Principle in coming years. But Jordan's principle is only an initial step in an Indigenous response to the situations of children with disabilities and needs to be understood within the context of Indigenous worldviews as well as colonization.

Indigenous ways of knowing and decolonization

So much of what we know in the literature about the experiences of Indigenous children in Canada comes through the eyes of non-Indigenous people. This disparity reflects the history of colonization, with settlers writing their accounts. It also may reflect that many Indigenous traditions rely on oral, rather than written accounts. I hesitate to contribute to this set of inequalities as a settler Canadian². But I recognize that part of the important work of decolonization is to place Indigenous stories and knowledge in the forefront and use my status to increase the attention given to Indigenous ways of knowing and the experiences of children.

This work comes, for me, in the context of a five-year community-university research project with women in communities in the north of Canada called Feminist Northern Network or FemNorthNet (<http://criaw-icref.ca/femnorthnet>). Together, as Indigenous and settler women, we have struggled to understand each other and to work for change in response to resource extraction in northern communities. We have intentionally focused on intersectionality and the perspectives of those women often marginalized including Indigenous women, women with disabilities, recent immigrant women and young women. While this work has often been difficult, we have learned much from each other, including how subtle colonialism can be in our relations with each other.

Over the course of five years, one of the most significant areas of tension has been in addressing disability. Despite allocating significant funds to ensure that women with disabilities can receive the accommodations they require to participate; including representatives of the national organization of women with disabilities (DAWN-RAFH Canada) as a full partner in all of the five years; having several disability studies scholars as part of the network; and actively encouraging the inclusion of disability in community discussions and research, the voices of disabled women and girls in Canada's north have remained remarkably invisible in FemNorthNet. Together with a small group of women, I began to explore how disability was addressed in Indigenous cultures and languages relevant to the north of Canada including Dene, Cree, Ojibway, Innu, Inuit and Metis. What we learned reflected a growing understanding of Indigenous worldviews and the place of children, community and disability in those worldviews.

Children and Community

It is not possible to speak of one Indigenous worldview or way of understanding childhood. Different Indigenous nations and traditions have different ways of understanding. Kim Anderson suggests that while her book of life stages of Indigenous women comes from her people – the northern Algonquin – ‘the teachings and stories will be both familiar and applicable to Indigenous people across Turtle Island (North America)’ (2011:4). In that spirit,

I share the following stories and perspectives around children told by different Indigenous peoples.

Anderson (2011) suggests that from the very beginning each child in Indigenous communities is valued and considered part of the community. As well as contributing to the community as they grow, children brought the community together and were the responsibility of the community. The health and well-being of the community relied on the health of its children:

Every stage of childhood was a celebration because children needed to develop a sense of belonging; that sense that ‘You are important to the people.’ [If] a child doesn’t have a sense of belonging and responsibility as part of the whole, that’s a weakness that will tear up a community (Anderson, 2011: 65).

Other Indigenous women have described how the history of colonization and especially residential schools were an attack on the children, and therefore on Indigenous communities and ways of life:

Today I see our young people have lost faith in a higher state of life (spiritual, cultural knowledge, language). They don’t seem to believe in miracles. Or perhaps they were never given the opportunity to learn those things because of our residential school relatives...Those young people did not receive the value of the Anishinaabek. Instead, they inherited the feeling of loss and doom carried by our parents and grandparents due to the genocidal tactics they had to live through...the direct attack on the strength of the Anishinaabek: our children. The major weapon the government used was the residential school system (Da Silva, 2011: 89).

The legacy of residential schools is evident not only in the lack of hope in young people, but in family and individual breakdown including ‘joblessness, poverty, family violence, drug and alcohol abuse, family breakdown, sexual abuse, prostitution, homelessness, high rates of imprisonment, and early death’ (Truth and Reconciliation Commission, 2012: 77-78).

Another key legacy of colonization is the over-representation and maltreatment of Indigenous children within the child welfare system. The FNCFCS has identified the high and disproportionate rate of Indigenous children who enter the child welfare system as well as the extent of abuse they face once in the system (FNCFCS, 2005). As the report suggests, recognizing the current situation also offers the opportunity to re-establish Indigenous values related to child welfare. Blackstock (2009:12) argues that an Indigenous approach to child welfare is integrally linked with an Indigenous worldview and ontology:

First Nations believe that well-being is achieved when there is balance among spiritual, physical, emotional, and cognitive dimensions of experience at the individual, community, and natural world levels across time...For First Nations

children, learning about living in balance begins when children first learn about the oral history of their ancestors through teachings, ceremony, role modeling, and observation

From this basis, an Indigenous approach to child welfare would ask about the effects of interventions to the subsequent seven generations, recognizing the importance of culture and community through time.

Disability

Indigenous approaches to disability also vary widely from those who include people with disabilities as another valued community member to those who see disability as a gift from the Creator or as an affliction from an ancestor or spiritual powers (UN, 2013). Indigenous languages often have no word for disability or someone who is disabled:

In Cree the word *kakanatisichek* means ‘the gifted ones, the special people.’ According to a traditional Cree woman disability is understood in a unique way within her culture: ‘There is no word in our language for disability, impairment or abnormality, but again this is only what I know for my community. The Creator put these people here for a purpose so that we will learn from them; they are our teachers. No one is considered abnormal in our culture’ (Shackel, 2008:37).

In Labrador Inuit, the phrases used refer to disabled people as unconditionally accepted as who they are (*pigialaviKangituk*), and as a gift from the Great Spirit (*Aninnik Ajunginimmut Kaijausimajuk*) (Baikie, 2012). This use of language reflects deeper values around disability – inclusion, acceptance and value. One parent of a child with disabilities called her child a gift and teacher for her:

Mary sees her children as gifts whose lives have purpose. That she respects them, and understands in a very deep way that her own growth is connected to her care of them... it’s really an honour to be with him, to have him come live with me. He’s taught me a lot (Clouson, 2007: 114).

Others suggest that disability reflects a special relationship with the spirit world:

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 hareshorn 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 (Durst and Bluehardt, 2004).

Disability in Canada's North

In our work in FemNorthNet, we heard of communities like Thompson Manitoba with its Juniper Lodge – a home for people with disabilities in the community. We also learned of communities where it was difficult to move through the town because of a lack of infrastructure including ramps and sidewalks (Hutchison, 2012). We recognized how difficult it was for deaf people in Canada's north to access sign language interpretation; often requiring interpreters to come from a large urban centre in the south, 8 hours drive away. We heard of communities where people with mental health disabilities were an integral part of the community until the 'experts' from the south came in, labeled the person with an illness and sent them south to an institution. We learned of families unable to find home care for their disabled children because of the low wages of care work and the booming economy as a result of resource extractive industries, bringing in care providers from the global South through a temporary foreign workers program (Dunham, 2014).

Contact with settlers and colonization introduced perspectives of disability linked to the Western (global Northern) views of individual self and the medical model of disability with its 'label and fix' focus (UN, 2013; Stienstra and Ashcroft, 2010). Capitalist and colonial systems of governance and economy impoverished Indigenous communities and introduced a centre/periphery model of resource allocation that forced services to be delivered in the south rather than in the north or in hub centres as opposed to smaller communities. Together with the medical model of disability, these forced many Indigenous families and communities to make choices that set access to services against remaining in families, cultures and communities. For some, that meant putting their disabled child in an institution (Martens, 2000). For others, it meant moving their entire family to an urban centre where there were services (Shackel, 2008). In both cases, it resulted in displacement and loss of access to community and culture. These choices were often forced on families by systems that did not recognize the Indigenous values and relationships that were part of a family's life.

Indigenous children with disabilities are over-represented in institutional settings in Canada (Martens, 2000). Governments continue to offer institutionalization as a response for Indigenous peoples when the existing system is not able to meet their needs, as the case of Jeremy Meawasige illustrates. But we need to recognize that these are not neutral situations, or even simple cases of resource allocations.

The drive to institutionalize children with disabilities and Indigenous children with disabilities in particular, reflects and perpetuates deeply-held colonial, capitalist and ableist values. The first is to label – to create negative meaning based on differences. This is clearly linked to Western views of disability and the medical model which labels bodies that don't function within what has been defined as the norm as deficient or disabled (Davis, 2006). This practice of labeling was also used in establishing residential schools in Canada, although the differences were clearly identified as cultural related to being 'Indian' and seeing the goal

‘to civilize and Christianize’ (Truth and Reconciliation Commission, 2012).

A second value in the response to Indigenous children with disabilities was (and is) to remove and separate the children from their families and communities and into urban centres and institutions. This practice of displacement has been a consistent colonial practice in Canada’s north, justified around accessing services and education. Indigenous people in Labrador were relocated to live in communities by both governments and missionaries who refused to give access to services without a move (Stienstra, forthcoming). In the residential schools, separation from family and communities was done to break from culture and parental influences in order to meet the goals of civilizing and Christianizing the children. Currently, capitalist (and neo-liberal) models of economic rationality or efficiency of services justify this practice of collecting those who have been labelled as different into segregated settings for treatment and care.

A third value is to rely on expert treatment of impairments and conditions. Treatment has come to be linked to services from health professionals including physicians, occupational and physical therapists, audiologists etc. A shift to self-government of services for some Indigenous communities has been unable to address the existing needs and reflects inequalities that were built into the self-government agreements. These inequalities include the additional costs of providing services on a smaller scale, the limited number of professionals willing to work in remote or small communities, the low number of Indigenous professionals and the population growth in many remote communities (Fricke, 1998). Many small communities cannot afford these services and those needing treatment must go to larger centres. In addition, in many northern communities, the presence of resource extractive industries has placed significant stress on existing resources and services without sufficient recognition of these demands on the communities themselves (Stienstra, forthcoming).

Linked with the reliance on experts for treatment, is the professionalization of care both by providing pay for caring services as well as delivery of these services by strangers. This shift to understanding care as a commodity to be bought and sold has resulted in a devaluing of community-based and family care, increasing costs for small communities, with the possibilities of displacement to institutions and ruptures with families and communities. In the case of Jeremy Meawasige of Pictou Landing First Nations, his mother provided his care. When she was unable to provide it, the community provided care, but their care used up 80% of the total budget for the community. The federal government refused to cover these costs and offered to cover the costs of institutionalization. Grech (2012) argues that networks of families, relatives, friends and neighbours are essential to the lives of poor people especially in the global South. The work of those family members and others who provide care and support for disabled people is rendered invisible in many of the global discussions despite its impact on the families’ income and well-being. This is often gendered work, with women providing much of the care. Care by families and communities is critical also in the global South as in the global North.

Disability and children in the global South/North

There are similarities and differences in the situations of girls and boys with disabilities in Canada's north and the global South. For both, there remain significant barriers in their access to services including health and education and the resulting exclusion and invisibility. The UNICEF's state of the world's children report on children with disabilities (2013) suggests that girls and boys with disabilities face different forms of exclusion based on their location, class, gender and type of disability:

At the heart of these differing forms and degrees of exclusion, however, lies the shared experience of being defined and judged by what one lacks rather than by what one has. Children with disabilities are often regarded as inferior, and this exposes them to increased vulnerability: Discrimination based on disability has manifested itself in marginalization from resources and decision-making and even in infanticide. Exclusion is often the consequence of invisibility (UNICEF, 2013:2).

This exclusion and invisibility are a result of and compounded by the legacies of colonization that shape the systems of governance in both the global South and Canada's north and Indigenous communities. As Loeb (2009) argues, in times of state disintegration as a result of conflict, natural disasters or other crisis, people with disabilities may experience greater vulnerability and marginalization and their access to services becomes even more tenuous. Children with disabilities have particular vulnerabilities in times of crisis (Peek and Stough, 2010). With a lack of access to supports can also come displacement from home or community.

Displacement for children with disabilities in countries of the global South experiencing conflict or natural disasters may be to refugee camps, or through abandonment along the way (Miles, 2013; Pinnock and Hodgkin, 2010). For disabled children living in Canada's north and Indigenous communities the lack of access to supports and the colonial systems of government, regardless of the presence of a crisis, may result in their displacement from their families and communities to institutions in urban centres.

Invisibility is a key part of the experiences of being a girl or boy with disabilities in the global North and the global South. Indigenous children with disabilities and children with disabilities in northern or remote communities face greater likelihood of being or becoming invisible. Yet many Indigenous worldviews and values reject that invisibility of children with disabilities. They encourage inclusion and acceptance of all children for who they are and recognition of the important role each child plays in the community.

Jordan's Principle and the work of Pictou Landing Band Council in support of Jeremy Meawasige and his mother Maurina Beadle clearly come from those Indigenous values

around both childhood and disability. But they work in a system built around fundamentally different values and worldviews that do not value children with disabilities, care and communities in the same way. As a result, Jordan's Principle is a small first step towards reclaiming Indigenous values. It asserts the importance of putting children first, before arguments about who pays what.

Jordan's Principle will not necessarily help to ensure community-based supports for children with disabilities who live in Indigenous or northern communities. Nor will it help to redress the lack of funding to Indigenous and northern communities to enable girls and boys with disabilities to live with their families and communities. Jordan's principle does not challenge the medical model of disability nor the colonial system of governance in Indigenous and northern communities.

But the work around Jordan's Principle is important because it illustrates Indigenous people effectively using the tools of non-discrimination, courts and existing governments to support the inclusion of girls and boys with disabilities in Indigenous and northern communities in Canada. Other tools developed through Disability Rights Promotion International (Demas and Shackel, 2012) also support this work. For my friend, Michael Charlie, Jordan's Principle and using Indigenous ways of knowing around disability, come too late. But perhaps it will not be too late for other displaced Indigenous and northern children with disabilities.

Notes

1. I use Indigenous, Aboriginal, and First Nations interchangeably.
2. While I am first generation settler in Canada, my people are indigenous to the area of Friesland in what is now the Netherlands. In saying this, I recognize, as Gray (2006) suggests, that the work for settlers is to acknowledge that we too come from a place and that by doing so we can disrupt the myth of whiteness.

References

- Anderson, K. (2011). *Life Stages and Native Women*. Winnipeg: University of Manitoba Press.
- Asch, M. (2014). *On being here to stay: Treaties and Aboriginal rights in Canada*. Toronto: University of Toronto Press.
- Baikie, G. (2012). Personal communications. (July 3).
- Berghs, Ma. (2010). Coming to Terms with Inequality and Exploitation in an African State: Researching Disability in Sierra Leone. *Disability & Society*, 25 (7), 861–65.
- Berghs, M. and Dos Santos-Zingale, M. (2011). A Comparative Analysis: Everyday

- Experiences of Disability in Sierra Leone. *Africa Toda*, 58 (2), 18–40.
- Blackstock, C. (2009). When Everything Matters: Comparing the Experiences of First Nations and Non-Aboriginal Children Removed from Their Families in Nova Scotia from 2003 to 2005. Unpublished Ph.D. dissertation. University of Toronto. [Online] Available at: <https://tspace.library.utoronto.ca/handle/1807/19024> [Accessed 8 August 2014].
- Blackstock, C. (2012). Jordan's Principle: Canada's Broken Promise to First Nations Children? *Paediatric Child Health*, 17 (7), 368–70.
- Canadian Paediatric Society (2012). *Are We Doing Enough? A Status Report on Canadian Public Policy and Child and Youth Health*. Ottawa: Canadian Paediatric Society.[Online] Available at: <http://www.cps.ca/advocacy/StatusReport2012.pdf> [Accessed 22 August 2014].
- Connell, R. (2011). Southern Bodies and Disability: Re-Thinking Concepts. *Third World Quarterly*, 32 (8), 1369–81.
- Curran, T. Runswick-Cole, K. (Eds.) (2013). *Disabled Children's Childhood Studies: Critical Approaches in a Global Context*. Palgrave-Macmillan.
- Da Silva, J. (2011). Our young people have lost faith. In P. Settee (ed.). *The Strength of Women: Ahkameyimowak* (pp. 89-90). Regina: Coteau Books.
- Davis, L. (2006). Constructing normalcy: The bell curve, the novel and the invention of the disabled body in the nineteenth century. In L.J. Davis (ed.) *The Disability Studies Reader* (pp. 3-16) 2nd edition. New York: Routledge.
- Demas, D. and Shackel, D. (2012). *Giinawind Bigo Ji Wijii'iweyang (Nothing about Us without Us): Understanding Our Rights. First Nations People with Disabilities Engage in Human Rights Education*. Toronto: Disability Rights Promotion International.
- Dunham, T. (2014). Labrador City women speaks in support of foreign workers. *The Telegram*. (6 May).
- Durst, D. Bluehardt, M. (2004). Aboriginal People with Disabilities: A Vacuum in Public Policy. *SIPP Briefing Note*. 6 (January).
- Erevelles, N. (2011). *Disability and difference in global contexts: Enabling a transformative body politic*. New York: Palgrave Macmillan.
- First Nations Child and Family Caring Society (FNCFCFS) (2005). *Wen De: We Are Coming to the Light of Day*. Ottawa: FNCFCFS.
- Fricke, M. (1998). First Nations People with Disabilities: An Analysis of Service Delivery in Manitoba. Unpublished Master of Science thesis, University of Manitoba.
- Gray, L. (2006). The whole planet is holy land. In Jerry Mander and Victoria Tauli-Corpuz (eds.) *Paradigm Wars: Indigenous Peoples' Resistance to Globalization* (pp. 28-29). San Francisco: Sierra Club Books.
- Grech, S. (2012) Disability, communities of poverty and the global South. In A. Azzopardi and S. Grech (eds.) *Inclusive Communities: A Critical Reader* (pp. 69-84). Rotterdam: Sense Publishers.

- Grech, S. (2011). Recolonising Debates or Perpetuated Coloniality? Decentring the Spaces of Disability, Development and Community in the Global South. *International Journal of Inclusive Education*, 15 (1), 87–100.
- Grech, S. and Soldatic, K. (2014). Introducing Disability and the Global South (DGS): We Are Critical, We Are Open Access! *Disability and the Global South*, 1 (1), 1–4.
- Hollinsworth, D. (2013). Decolonizing Indigenous Disability in Australia. *Disability & Society*, 28 (5), 601–15.
- Hutchison, C. (2012). Interview with CBC Labrador. [Online] Available at: <http://www.criaw-icref.ca/carmela-hutchisons-interview-cbc-july-12-2012> [Accessed August 29, 2014].
- Jones, L., Bellis, M.A. et al. (2012). Prevalence and Risk of Violence against Children with Disabilities: a Systematic Review and Meta-Analysis of Observational Studies. *The Lancet*, 6736 (12).
- Loeb, M. (2009). The Effects of Failed States on the Well-Being and Lives of People with Disabilities. In M. Maclachlan and L. Swartz (eds.) *Disability & International Development: Towards Inclusive Global Health* (pp. 13-30). New York, NY: Springer US.
- MacDonald, N. E. (2012). Aboriginal Children Suffer While Governments Ignore Jordan's Principle. *Canadian Medical Association Journal*, 184 (8), 853–853.
- Martens, C.E. (2000). Intellectual Disability and Aboriginal People: An Overview of Current Practise and Process in Institutionalization. Unpublished Master of Education thesis. University of Manitoba.
- Meekosha, H. (2011). Decolonising Disability: Thinking and Acting Globally. *Disability & Society*, 26 (6), 667–82.
- Miles, S. (2013). Education in Times of Conflict and the Invisibility of Disability: A Focus on Iraq? *Disability & Society*, 28 (6), 798–811.
- Ngo, A.D, Brolan, C. et al. (2013). Voices from Vietnam: experiences of children and youth with disabilities, and their families, from an Agent Orange affected rural region. *Disability and Society*, 28 (7), 955-969.
- Notice of Application: Pictou Landing Band Council and Maurina Beadle v Attorney General, Canada. (2011, 24 June). Federal Court of Canada.
- Peek, L. and Stough, L.M. (2010). Children with Disabilities in the Context of Disaster: A Social Vulnerability Perspective. *Child Development*, 81 (4), 1260–70.
- Philpott, S. and Sait, W. (2001). Disabled Children: an emergency submerged. In Mark Priestley (ed.). *Disability and the Life Course: Global Perspectives* (pp. 151- 166). Cambridge: Cambridge University Press.
- Pictou Landing Band Council (PLBC) and Maurina Beadle v Attorney General, Canada. 2013 FC 342.
- Pinnock, H, and Hodgkin, M. (2010). Education Access for All. *Forced Migration Review*, 35, 34–35.
- Rohwerder, B. (2013). Intellectual Disabilities, Violent Conflict and Humanitarian Assistance: Advocacy of the Forgotten. *Disability & Society*, 28 (6), 770–83.

- Shackel, D.W. (2008). 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. Unpublished M.A. thesis. University of Manitoba.
- Singal, N. (2009). Disability, Poverty and Education: Implications for Policies and Practices. *International Journal of Inclusive Education*, 15 (10), 1047–52.
- Singh, V. and Ghai, A. (2009). Notions of self: lived realities of children with disabilities. *Disability and Society*, 24 (2), 129-145.
- Sinha, V. and Blumenthal, A. (2014). From the House of Commons Resolution to Pictou Landing Band Council v. Canada: An Update on the Implementation of Jordan's Principle. *First Peoples Child & Family Review*, 9 (1), 80–91.
- Sinha, V. Trocmé, N. et al. (2011). *Kiskisik Awasisak: Remember the Children. Understanding the Overrepresentation of First Nations Children in the Child Welfare System*. Ontario: Assembly of First Nations. [Online] Available at: <http://fnwitness.ca/sites/default/files/docs/FNCIS-2008-report.pdf> [Accessed 20 August 2014].
- Stienstra, D. (forthcoming). Northern crises: women's relationships and resistances to resource extractions. *International Feminist Journal of Politics*, 17 (4).
- Stienstra, D. (2015). 'Trumping' All? Disability and Girlhood Studies. *Girlhood Studies*, 8 (2).
- Stienstra, D. and Ashcroft, T. (2010). Voyaging on the Seas of Spirit: An Ongoing Journey towards Understanding Disability and Humanity. *Disability & Society*, 25 (2), 191–203.
- Stienstra, D. and Kellerman, P. (1999). Taking Action on the United Nations Standard Rules on Disability. Winnipeg, University of Winnipeg.
- Trani, J., Bakhshi, P. and Nandipati, A. (2012). 'Delivering' Education; Maintaining Inequality. The Case of Children with Disabilities in Afghanistan. *Cambridge Journal of Education*, 42 (3), 345–65.
- Trani, J., Kett, M. et al. (2011). Disability, Vulnerability and Citizenship: To What Extent Is Education a Protective Mechanism for Children with Disabilities in Countries Affected by Conflict? *International Journal of Inclusive Education*, 15(10), 1187–1203.
- Truth and Reconciliation Commission of Canada. (2012). *They Came for the Children: Canada, Aboriginal Peoples and Residential Schools*. Winnipeg. [Online] Available at: http://www.myrobust.com/websites/trcinstitution/File/2039_T&R_eng_web%5B1%5D.pdf [Accessed 20 August 2014]
- UNICEF. (2013). *State of the World's Children 2013*. New York: UN.
- UNICEF. (2012). *The Right of Children with Disabilities to Education: A Rights-Based Approach to Inclusive Education*. New York: UN.
- United Nations. (2013). *Study on the Situation of Indigenous Persons with Disabilities, with a Particular Focus on Challenges Faced with Respect to the Full Enjoyment of*

Human Rights and Inclusion in Development. New York: UN.
<http://www.un.org/disabilities/documents/ecosoc/e.c.19.2013.6.pdf>.
WHO and World Bank (2011). *World Report on Disability.* New York: United Nations.
