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## Disability as a process and social construct in the Canadian Indigenous experience

### Niepelnosprawność jako proces i konstrukt społeczny w doświadczeniu kanadyjskiej ludności rdzennej

#### Abstract

**Introduction.** The article discusses disability as a social construct and a process of re-constructing identity in reference to Indigenous experiences within the Canadian surroundings.

**Aim.** The aim of this paper is to explore critical understandings of the intersectional identities of Indigenous and disability.

**Materials and method.** The article uses the method of critical analyses related to a construct of disability in Indigenous experiences as well as the analyses of the reference literature.

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**Conclusion.** It shows that for Indigenous people the notion of *disability* is entangled in the world of senses and meanings, and thus the label of disability could be seen as a colonial construct that conflicts with Indigenous perspectives of life. It examines the role of Jordan's Principle in understanding the challenges of culturally appropriate services and supports for Indigenous children with disabilities and their families.

**Keywords:** disability, Indigenous people, Jordan's Principle, decolonization, Canada.

### Abstrakt

**Wprowadzenie.** Artykuł omawia założenia niepełnosprawności jako konstruktu społecznego oraz procesu rekonstrukcji tożsamości w odniesieniu do doświadczenia ludności rdzennej w ich kanadyjskim otoczeniu.

**Cel.** Celem artykułu jest poznanie interpretacji krytycznych, towarzyszących krzyżowaniu się identyfikacji tożsamościowych, odnoszących się do pochodzenia rdzennego i niepełnosprawności.

**Metoda.** W artykule zastosowano krytyczną analizę konstruktu niepełnosprawności w odniesieniu do doświadczenia ludności rdzennej oraz przegląd literatury przedmiotu.

**Wnioski.** Autorzy wskazują, że dla ludności rdzennej pojęcie *niepełnosprawność* jest uwikłane w świat znaczeń i sensów, i właśnie dlatego etykieta bycia niepełnosprawnym może być postrzegana przez nich jako kolonialny konstrukt, który stoi w sprzeczności z przyjętymi przez ludność rdzenną sposobami patrzenia na życie. Badacze analizują rolę Reguły Jordana pod kątem zrozumienia wyzwań stojących przed zapewnieniem kulturowo dostosowanych usług i zapewnienia wsparcia dzieciom rdzennym z niepełnosprawnościami i ich rodzinom.

**Słowa kluczowe:** niepełnosprawność, ludność rdzenna, Reguła Jordana, dekolonizacja, Kanada

## Introduction

Indigenous people with disabilities are exposed to various forms of discrimination due to the complicated nature of the disability phenomenon, arising under the influence of various factors and overlapping with ethnic identification (First Nations Information Governance Centre, 2018). Barriers relating to the phenomenon of disability among Indigenous peoples include the following:

- difficult access to care services, justified by the place of residence and the infrastructure available there;
- in social perceptions of disability and ethnicity mediated by the opinions and feelings of Indigenous people and other people (Waldram et al., 1995).

Understanding the concept of *disability* in the situation of people of Indigenous origin is sometimes inscribed with assessments, implicit demands and camouflaged labels, which refer directly to the medical model, which considers Indigenous communities as risk groups due to elevated rates of chronic disease, suicide and death relative to the ge-

neral population, and to social welfare reports of social maladjustment, substance abuse and structural unemployment (Durst, Bluehardt, 2001; Ineese-Nash, 2020). In other words, disability is firmly embedded in social and cultural contexts, creating discursive boundaries entangled in a world of intrinsically fluid and changing meanings depending on circumstances, time, and adopted perspective.

One of these is precisely the understanding of disability — in biomedical terms — as a defect that, when intersected with ethnic identifications, can create a stigma that impairs people who are physically or intellectually disabled in social opinion (Rivas Velarde, 2018). The very inscription of disability in ethnic identity, while helpful in interpreting social barriers and exclusion of Indigenous people with disabilities, can be problematic for the people concerned themselves due to their portrayal as “victims” of the system, disadvantages, lack of understanding and tolerance. Finally, how disability is understood among Indigenous people does not necessarily coincide with those that are typical or valid for the rest of society (Ineese-Nash, 2020). Thus, looking at disability as a socially constructed phenomenon based on the example of Indigenous peoples can be valuable for cross-cultural education, as it enables discussion of social inclusion and activation in terms of intersectionality and identity reconstruction.

### **(Re)defining disability**

The portrayal of disability as a socially constructed phenomenon is reflected in the social model, which focuses attention on the existence of barriers external to and beyond the control of the person in the social organization that limit his or her full participation in society (Goodley, 2011; Kowalski, Falcman, 2011). Adopting a social perspective is tantamount to rejecting the perception of disability in individual terms, as a dysfunction attributed to the person. Transferring the burden of responsibility for the inclusion of people with disabilities to society is a consequence of changing the understanding of the principles of inclusion and activation of people with disabilities towards their increased participation, positive social perception, and support in the process of becoming independent. This is because it is believed that people with disabilities adapt perceptions of themselves and their place in the group that are typical and dominant in their social environment, and thus the socially shared image of people with disabilities determines the extent of their participation in society.

In the interpretivism paradigm, one of the key categories for describing everyday life, integration and affirmation of disability is identity (Darling, 2003). It is usually used in disability studies to capture the mediating effect between self-image and the demands of social life represented by cultural patterns, social roles, and norms, with consequences in the creation of a positive or negative identity. *Identity* is also a con-

cept that is firmly embedded in the discursive framework of the perception of difference and the struggle for social recognition of individuals and groups. A manifestation of this understanding of identity is the assumption that only individuals or groups that can gain power over the meaning, sense, and representation of their identity gain the privilege of being able to subordinate narratives about themselves. In the case of groups that have been socially marginalized and their representatives excluded, their identity is the key to the struggle for their social recognition and inclusion in society on an equal basis (Putnam, 2005).

The social model of disability assumes that by changing the identity identification of people with disabilities from negative to positive, there will be a redefinition of their position in society and a turn toward a transformation of social organization that values and includes diversity (Swain, French, 2000). In other words, a feedback loop is assumed between the dynamics in the construction of the identity of people with disabilities and the transformations in the perception of disability in society resulting from how it is defined.

### **Disability in the cultural experience of Indigenous peoples**

Adopting the perspective of Indigenous peoples' view of disability can be a challenge for researchers, as there are no words in the Indigenous languages of peoples such as the Chippewa (Ojibwa), Kri (Cree), or Haida (Haida)<sup>1</sup> that could be identical to describe typical depictions of disability and its conceptualization in the social sciences (Ineese-Nash, 2020). The different understanding and interpretation of disability in the cultural traditions of Indigenous peoples is the result of the peculiarities of the languages, which are highly contextual on the one hand, and, on the other - the different attitude towards the body, which is a manifestation of its holistic vision as a link between individual identity, community, the material world, and the spiritual world (Lovern, 2008). It is therefore assumed that even the bodies of people who deviate from the accepted social norms in these cultures are justified in a higher order than the sphere of human relationships, i.e., there is a belief that people with disabilities are no different from other people in their search and discovery of their talents, which are a gift to their community. It should not be assumed, however, that representatives of Indigenous people are completely neutral toward disability, because its social perception may be manifested at least

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<sup>1</sup> The choice of these populations is not coincidental, as during research visits to Canada one of the authors had the opportunity to meet and talk to their representatives. At the same time, the groups mentioned represent one of the most numerous Indian peoples in Canada.

in the names given. Nevertheless, in contrast to typical perceptions of disability in society, disability perceived in this way is defined by the spiritual sphere and individual characteristics, thus giving a double meaning to disability, as a feature of the person, but also as an affirmation of his or her rightful place in the community and the lived world.

In Indigenous communities assimilated to the standards of Canadian society, perceptions of disability characteristic of the majority prevail, in which the social image of disability is changing toward the affirmation of diversity, but this, of course, is not the same as the realization of all the demands of the disability community and their full social participation in public spaces (Durst, Bluehardt, 2001). As mentioned at the beginning of the paper in the case of Indigenous peoples, ethno-racial identification plays an important role in the discussion of the health status of the Indigenous population and the social services and benefits available to its members. For years, there has been a dispute in Canada over the overrepresentation of Indigenous people as recipients of various public health assistance measures (Waldram et al., 1995). One of the arguments that is raised by representatives of Indigenous peoples is the charge of depreciating community resources in favour of institutionalized ways of addressing health and social problems in Indigenous groups (First Nations Information Governance Centre, 2018). This argument also arises in the discussion of disability, especially in the context of the very shift in defining and interpreting disability, which involves moving the focus from treating disability solely in terms of a person's mental and physical development with their frame of reference in the form of cultural patterns, norms, and social and occupational roles prevailing in society, to understanding disability as a peculiar social experience rooted in the cultural specificity of the environment of people with disabilities. As a result of such a change in the way of defining disability, it has been possible to integrate the cultural experience of Indigenous peoples with bodily intercourse into the treatment of people with disabilities and to transform the organization of care for people with disabilities toward a positive affirmation of their ethnic identity (Nadeau, Young, 2006). Appreciating the ethnic identity of people with disabilities has an essential political dimension for Indigenous peoples, as it allows them to move away from the historical past, according to which Indigenous people with disabilities were expected to accept their exclusion from society not only to the extent of their physical or mental impairment but primarily by stigmatizing their ethnic identification as being culturally inferior (Grech, 2015).

For some researchers of disability from Indigenous backgrounds, the concept of disability is marked by trauma in collective memory, a consequence of the painful experiences of Indigenous representatives with the ruthless policies of cultural uprooting and forced sterilization as part of the eugenics program in Canada

(Ineese-Nash, 2020). It should be remembered here that decisions on incapacitation, sterilization, deprivation of parental rights and child removal were accompanied by alleged arguments about the cognitive and social deficits of representatives of Indigenous peoples (Sinclair, 2016). According to some researchers, part of the negative stereotypes that have served in the past to label representatives of Indigenous people as mentally challenged or socially maladjusted have been officially replaced by meanings hidden in professional jargon, ways of measurement, and diagnoses that contain prejudice against Indigenous peoples, because — in their opinion — they have not undergone the necessary cultural adaptation to the living conditions of Indigenous communities (Ineese-Nash, 2020; Norris, 2014).

Because of the above objections, one of the most frequently repeated demands is a call for decolonization of ways of thinking and practice towards representatives of Indigenous peoples in Canada, as well as the most inclusive approach possible in the application of Indigenous knowledge and solutions developed in the local communities concerned to support people with disabilities (Ineese-Nash, 2020). While in an activation approach aimed at empowering people with disabilities through community integration, such solutions are accepted or even suggested, demands to grant equal status to traditional Indigenous medical knowledge to specialized knowledge and to include the role of healers and shamans in the revision process cause consternation among experts and officials.

### **Jordan's Principle vs. Indigenous children with disabilities**

A point of reference in the debate on disability in Indigenous children is Jordan's Principle, which gained support in the House of Commons of Canada in 2007 and committed federal and provincial authorities to ensure that Indigenous children and their families living on reserves have the same access to care and services and forms of support as other children and their families living in Canada (Johnson, 2015). The rule was named in honour of Jordan Rivera Anderson, a native of the Kri people, who was born with a widespread genetic disorder in 1999. Jordan never returned with his parents to the family home, despite the intervention of the Indigenous communities and the child's formal discharge from the hospital at age 2. Ultimately, Jordan died at age 5 in a Winnipeg hospital. A procedural dispute between Manitoba's federal and provincial authorities over who was legally and financially responsible in line with the child's best interests stood in the way. The case appalled Canadian public opinion, while at the same time providing an opportunity to highlight the dramatic situation of Indigenous children with disabilities in institutions, although they had relatives and their local communities had expressed a desire to care for them.

The aftermath of these tragic circumstances was not only an audit that revealed legal and administrative barriers that prevented parents of Indigenous children from receiving the support guaranteed to them by law but also the establishment of the Jordan Principle as a rule requiring authorities at various levels to ensure that they respect the equal access of Indigenous children with disabilities to the care, services, and benefits available to other children in Canada (Johnson, 2015). This also means that said equal access has to take into account the specifics of Indigenous communities in a substantive way, regardless of the solutions adopted in the province or territory (Blackstock, 2012). However, the Jordan Principle does not only include the Métis and Inuit due to its association with so-called *Canada's Indian Act*, which established the autonomy of Indian peoples (First Nations) on their territories (reserves). Critics of this arrangement have noted that limiting the Jordan Principle to the Act, which was enacted in 1876 and was subsequently modified in 1951 and 1985 to remove provisions discriminating against Indigenous peoples, limited its reach, creating deliberate confusion in determining - who does and does not belong to Indigenous people and providing grounds for narrow interpretation to identify its potential beneficiaries (Blackstock, 2012; Johnson, 2015). Faced with the exclusion of Inuit children from the Jordan Principle, the Inuit negotiated with Canadian authorities the *Inuit Child First Initiative* (ICFI) program, which provides access and care for their children to services, and benefits on the same basis as for Indian peoples.

Nevertheless, research reports indicate that the level of services for Indigenous people with disabilities on reserves is significantly lower than in other places due to the infrastructure that exists there (Chambers, Burnett, 2017; Vives, Sinha, 2019). Some researchers raise the alarm that young children living with their families in conditions conducive to their isolation and exclusion (disabling environments) are particularly vulnerable, as they are somehow invisible to those around them, and the lack of disability-friendly infrastructure makes it difficult for them to move around (Chambers, Burnett, 2017). Another limitation of the reserves is the difficulty of organizing therapy and corrective-compensatory classes for children. When classes do take place they are implemented primarily as part of school education. Parents of children are offered support and assistance off the reservation, but this usually requires them to move to the city. This type of decision is difficult to make due to a range of obstacles - from material costs to fear of social isolation. At the same time, parents' low awareness of a young child's developmental needs makes them less inclined to take advantage of the offer of off-reserve support, explaining to themselves that a young child develops "naturally" without the coercion of adult intervention. At the same time, the urban environment is sometimes perceived by representatives of Indigenous peoples as

culturally alien and hostile to them (Durst, Bluechardt, 2001). The few parents with children with disabilities who chose to receive services in the city mentioned difficulties in cultural adaptation, as they were often the only Indigenous people among the participating families. They were also not always able to connect with therapists and social workers (Vives, Sinha, 2019).

One of the proposed solutions is to increase the number of assistants for people with disabilities in the reserves, who would be culturally sensitive and trained in this area. This type of support is important for families, especially mothers, who are usually responsible for caring for a disabled child. The presence of assistants and social workers in the reserves, who have gained the community's trust, is, with the chronic lack of funds, also the most effective way to support people with disabilities and their families. This is because the assistants on the ground are best placed to know how to utilize the resources that exist in the community, as well as to enlist its support for people with disabilities in, for example, changing the physical environment to one that is more wheelchair-friendly. Better recognition of the needs of people with disabilities in the reserves has also contributed to the development of a special range of assistive and rehabilitation equipment adapted to the prevailing conditions (Vives, Sinha, 2019). Nevertheless, with the aforementioned benefits, it is essential to once again emphasize the role of trust that is placed in social workers and assistants, since it is the relational nature of their work that has shifted the most significant benefits and effects in the form of cooperation with the child's family and its local environment.

## **Conclusion**

The changes that have taken place in the understanding and construction of the concept of disability have highlighted the need for directions for the formation of identifications about social relations and roles in the group. Accordingly, people began to focus attention on the dominant ways of defining disability in the group and the places that people with disabilities themselves assign to disability in the hierarchy of roles. This meant that they began to look at the identity of people with disabilities from an intersectional perspective, noticing the dense network of meanings around them, relating to social classifications and categorizations.

In connection with the situation of Indigenous people with disabilities analysed, an interesting aspect of intercultural communication and education is the attempt to understand and clarify the re(definition) of disability about beliefs, traditional ways of giving meaning to it and rooting it in the painful experiences of Canadian Indigenous peoples with the legacy of colonialism and negative eugenics. For representa-

tives of Indigenous communities in Canada, the struggle for cultural recognition of people with disabilities is not only a move away from seeing disability as a stigma or a disorder but more importantly, an attempt to rediscover and strengthen the existing ties in traditional teachings regarding a holistic worldview, in which people with disabilities were treated like messengers to remember the diversity and complexity of this world (e.g., in Kri's case). Therefore, for some researchers of disability from Indigenous peoples, understanding disability in line with their culture and identity is first and foremost about looking at the body through the lens of self-determination, thus establishing a bond between memory (strength of relationship with ancestors, tradition), regeneration (spiritual and material interaction), and community support (integration and activation in the community).

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