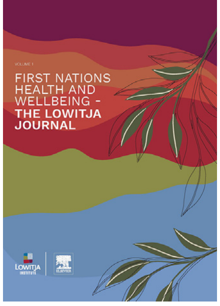

Commentary

Researching Indigenous people living with a disability: The urgent need for an intersectional and decolonising approach (BlakAbility)

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Abstract

According to available data, significant numbers of Indigenous people live with a disability and encounter both racism and disability-related discrimination. Yet, research about the impact of these intersecting sites of discrimination remains vastly under-researched. This commentary argues that research using intersectionality embedded with decolonising knowledges and practices and Indigenous Standpoints on disability, that is informed and led by those with lived experience, is urgently needed.

Keywords: Indigeneity; Disability; Intersectionality; Standpoint

Highlights

- Indigenous people living with disability battle with issues related to racism, ableism and colonisation, impacting on well-being and life outcomes throughout the life course.
- The intersection of Aboriginality and disability remains vastly under-researched.
- Research using intersectionality embedded with decolonising knowledges and practices and Indigenous standpoints on disability that is informed and led by those with lived experience (BlakAbility) is urgently needed.
- Failing to do so serves only to perpetuate inequity and oppression borne out of two centuries of colonisation and will allow disability researchers to continue theorising about Indigenous people without recognising and embedding their understandings and lived experiences that are shaped by their personal, cultural and historical contexts.

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Introduction

Based on data from the 2018 Survey on Disability, Ageing and Carers, 24% of Indigenous Australians live with disability and there is a higher rate of disability across the life course for Indigenous Australians (Australian Bureau of Statistics, 2021). Indigenous people with disability encounter the negative impacts of both racism and disability-related discrimination. Yet, *Closing the Gap*, a policy that aspires to be evidence-based, remains disengaged from data that demonstrate the acute disadvantage experienced by Indigenous people with disability; the National Disability Insurance Scheme is heading down the same path (Hindman, 2019). This commentary contributes to the discourse on disability from an Indigenous perspective, which is a vastly under-researched area (Avery, 2018; Gilroy and Donnelly, 2016; Meekosha, 2011). It is argued that research using intersectionality embedded with decolonising knowledges and practices and Indigenous standpoints on disability, which is informed and led by those with lived experience, is urgently needed. The overarching term for this complex body of work is referred to here as BlakAbility.

Indigenous peoples from around the world worked with the United Nations to establish the Expert Meeting on Indigenous Persons with Disability in 2016. A key recommendation was the urgent need for Indigenous community-controlled disability research using culturally inclusive methodologies (United Nations, 2016). Within the Australian context, Gilroy and Donnelly (2016: 558) state:

> *After two centuries of colonisation in Australia, western science in the area of disability research has not proven effective in understanding and addressing the health and well-being of Indigenous people with disability.*

Contributing to this troubling situation is the reality that there are very few Australian Indigenous people with disability who are also researchers in this field. Moreover, Meekosha (2011) notes that writings on disability have mainly come from ‘northern’ countries, whose relevance to the global south is questionable. As an Indigenous person with a physical disability, Uncle Lester Bostock asserts ‘when we look at access and equity to service agencies and access to the workforce, Aborigines [sic] are at the lowest rung of the servicing ladder’ (Bostock and Griffis, 2005: 3). Therefore, Indigenous people with disability are in urgent need of being represented in research as participants, researchers and co-designers. As an Indigenous woman academic living with the disability of vision impairment, I am uniquely positioned to drive this change, with this commentary giving voice to lived experience of both myself and those who remain largely absent in the dialogues.

Understandings of ‘disability’

Several conceptual models have been devised to assist people to understand the idea of disability. These models of disability include the *moral/religious and charitable models*, where disability is viewed as a personal tragedy or punishment for sin (Henderson and Bryan, 2004). Here, disability is seen as a condition to be feared or pitied, a result of sins from a previous life or in need of philanthropic intervention. The *medical model* views disability as an individual pathology to be overcome by medical intervention and technology, and sees disabled people as not contributing to society (Hogan, 2019). Decades of disability activism and the adoption of the United Nations Convention on the Rights of Persons with Disabilities (2006) has seen the emergence of new models, including the *social model, individual/affirmative model and human rights model*. These more recent understandings recognise individual rights to self-determination and autonomy, as well as full inclusion in society, where disability is understood as a condition not solely existing within an individual but as a phenomenon that occurs at the intersection between a person and their physical, social and/or systemic contexts. However, Indigenous understandings of ‘disability’ are absent in these dominant models.

Research confirms that conventional constructions of disability – as a barrier to individual capacity and participation in society – do not resonate with Indigenous peoples (Avery, 2018; Hollinsworth, 2013). No equivalent term or concept corresponding to ‘disability’ has been found in Australian Indigenous languages (Avery, 2018). Rather, words and phrases exist in Australian First Nations languages that describe specific conditions such as blindness, deafness, mobility difficulties and back pain; these descriptors are not used in a negative or pejorative manner (Avery, 2018: 5). Instead, First Nations people often see conditions to be unremarkable and simply represent the normal range of human diversity, particularly in the case of physical conditions. Applying dominant models of disability to First Nations people is therefore culturally fraught (Avery, 2018; Hollinsworth, 2013) and regarded by many as culturally insensitive (Gilroy et al., 2016). An Indigenous standpoint on disability is shaped by their personal, cultural and historical contexts (Avery, 2018: 368). Research undertaken by Rivas Velarde (2018) found that Indigenous people with disability often noted that ‘their Indigenous values were a way of coping and battling against what they perceived as the oppressive labels associated with the term “disabled”’ (p. 1439). Such conflicting understandings of ‘disability’ illustrate the ongoing processes of colonisation that requires research giving voice to those who remain disengaged and silenced.

Theoretical frameworks

To address the complex landscape of intersecting sites of inequity of Indigeneity and disability, a theoretical framework is needed to guide investigations. Intersectionality refers to the ways in which different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation (Crenshaw, 1989). It is an approach that emphasises that to fully understand the unique experiences of Indigenous people with disability, research must recognise that they are a discrete group at an intersection of two marginalised populations (Crenshaw, 1991). That is: racism and ableism in broader society intersect to exclude many Indigenous peoples with disabilities from, for example, public spaces and labour markets (Puszka, et al., 2022). The eugenics movement of the 19th and 20th centuries deleteriously defined Indigenous and/or disabled people as biologically inferior; a colonising discourse used to justify a range of authoritarian and discriminatory measures whose impact continues into the present (Kelm, 2004). Scholars of Indigenous peoples’ historic and contemporary experiences of disability argue that there is an urgent need to decolonise understandings of disability to change institutional and societal discriminatory practices (Connell, 2011; Hollinsworth, 2013).

Decolonisation is more than a legal domain of treaties and other political agreements between states and Indigenous peoples. Decolonisation also encompasses the reconfiguration of health and social services for Indigenous peoples by changing power relations within these (and other) institutions and transforming their conceptual underpinnings and practices (Strakosch, 2019). Critical to this decolonising transformation is the embedding of Indigenous knowledges, cultural understandings of disability and social practices into societal institutions. Indigenous standpoint theory advocates that the unique experiences of the marginalised have been neglected and oppressed by mainstream knowledge production (Nakata, 2007) and colonisation persists in policy, political and institutional domains (Strakosch, 2019). This is evident for Indigenous people with disability whose lived experiences are both under-researched and available research is mostly conducted by non-Indigenous people with or without a disability. This paper therefore proposes a theoretical framework of BlakAbility that centres the lived experience of Indigenous people with disability and is research undertaken and/or led by Indigenous people with disability. BlakAbility intersects both culture and ability, and is mindful of the intersection with other equity categories of gender, socioeconomic status, age or geography.

Conclusion

Indigenous people living with disability battle with issues related to racism, ableism and colonisation, impacting well-being and life outcomes throughout the life course. Yet, the intersection of Aboriginality and disability remains vastly under-researched. Research using intersectionality embedded with decolonising knowledges and practices and Indigenous standpoints on disability, which is informed and led by those with lived experience (BlakAbility), is urgently needed. Failing to do so serves only to perpetuate inequity and oppression borne out of two centuries of colonisation and will allow disability researchers to continue theorising about Indigenous people without recognising and embedding their understandings and lived experiences that are shaped by their personal, cultural and historical contexts.

Declaration of interests

The author declares that there are no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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