WHĀNAU HAUĀ

Reframing disability from an Indigenous perspective

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Abstract

Māori directly or indirectly experience disability at a higher rate than any other population group in Aotearoa New Zealand. Despite one in three Māori having some form of disability, Māori have less access to support and health and disability services. Currently, gaps exist in knowledge related to Māori and disability, and this is not helped by disabled Māori being excluded from health and disability policy and service planning forums. With regard to disability frameworks, the medical model and the social model are the predominant northern hemisphere approaches to working with disabled persons. These models view disability in an individualised manner that is not relevant for many Indigenous disabled persons whose worldview is holistic, relational and collective in nature. In this paper, we critically examine current approaches to working with disabled Māori and their experiences as Indigenous disabled persons before presenting Whānau Hauā as an alternative Indigenous approach to disability.

Keywords

disability, health, Indigenous, Māori, whānau hauā, health and disability service access

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Introduction

Indigenous disabled persons, similarly to all people with disabilities, have a range of enduring physical, mental, intellectual or sensory impairments. In general, disabled persons have a range of barriers and impairments restricting their full and equal participation in society. Disabled persons' experiences are central to how they interpret their place in the world, and are influenced by societal and political power relations and identity politics. For instance, the labels "disabled persons" and "persons with disabilities" highlight the polarised way in which this group of people are referred to depending upon the disability approach adopted. The social model of disability emphasises that impairments occur because of societal barriers; therefore, from this viewpoint, those with disabilities are referred to as "disabled persons". In contrast, the traditional medical model overlooks personal experiences and instead focuses on a person's disability and the deficits arising from impairments that are to be "fixed"—from this perspective, those with disabilities are referred to as "person with disabilities" (Shakespeare, 2013).

These dominant northern hemisphere cultural perspectives inform the prevailing approaches to disability, focusing attention predominantly on individuals and their experiences of disability. Such approaches do not account for Indigenous worldviews that are holistic in nature and based on the importance of consequent relationships and collective responsibilities and obligations to others (Durie, 1998). In Aotearoa New Zealand, Māori experience a higher prevalence of disability (33%) than other ethnic groups (24%) (Statistics New Zealand, 2014). In this paper, we explore the prevailing approaches to disability and introduce Whānau Hauā as an alternative Indigenous Māori framework. An exploration of Indigenous experiences of disability precedes the presentation of Whānau Hauā, an Indigenous approach that contributes to existing knowledge about disability and Indigenous perspectives of disability.

Background

Disability studies emerged from the activist agendas and the global mobilisation of disabled persons in the 1970s which involved both academics and activists from multiple disciplines and perspectives (Corker & Shakespeare, 2002; Oliver, 1996; Shakespeare, 2014). The World Health Organization (WHO) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) define disability in three ways: first, as an impairment; then, as having limitations in activity; and finally, as experiencing restrictions on participation (Office of the High Commissioner for Human Rights [OHCHR], 2017b). Impairment signifies a problem with body function or structure, while activity limitation occurs when a person finds performing a task or function difficult. On the other hand, participation restriction refers to a person having problems with involvement in a variety of life situations, be they physical or social (WHO, 2017). Disability is a complex phenomenon, particularly when it interferes with the interactions between persons with impairments and the society they live in, which leaves them marginalised in some form. Overcoming these difficulties and enabling full participation in society requires the removal of environmental and societal barriers (Shakespeare, 2013).

In the past, the traditional Western medical model used for understanding disability saw it simply as a physical disease or illness. This perspective ignored the broader holistic dimensions influencing those living with a disability, especially the impact of societal influences on their lives. The advent of the social model of disability offered an alternative viewpoint to the medical model and its prevailing emphasis on pathology. However, the social model of disability, driven by a political agenda, refocused

the approach taken to disabled persons onto addressing barriers preventing their full inclusion in society (Shakespeare, 2013). Instead of concentrating on a person's impairments, the social model of disability determines the obstructions that arise from social oppression and exclusion, and highlights society's moral responsibility to address these. By removing barriers that prevent disabled persons' full participation in society, the social model of disability also aims to improve their psychological wellbeing and self-esteem (Shakespeare, 2013).

Shakespeare and Watson (2001), however, claimed the social model of disability has established a disability-impairment dichotomy in the process of shining the light on how society denies individuals' experiences of impairment. They argued that in reality the line between impairment and disability can be unclear, especially as impairment may cause disability and, conversely, disability can exacerbate an impairment. Similarly, Garland-Thomson (2005) argued that disability is a socially constructed notion about the interaction between people's bodies and their environments. Impairment, on the other hand, creates restrictions on a person's ability to fully participate in physical and social activities.

Yet physical, social and material environments are interacting entities of equal importance. Shakespeare (2014) proposed an ontology of embodiment whereby everyone has some sort of impairment and therefore little qualitative difference between able-bodied and disabled persons exists. While to some extent this may be right, in reality many people with impairments experience barriers that others do not. Meekosha (2011) claimed the distinction between disability and impairment is a gap in disability research.

The International Classification of Functioning, Health and Disability (ICF) (endorsed by WHO) influences the way in which disabled persons are diagnosed and treated (Westby, 2013). The ICF focuses on positive influences and the impact disability has on a person's functioning rather than the cause of their disability. Furthermore, the ICF adopts a holistic approach and accounts for the interplay between a range of multifaceted influences and contexts impacting a person's functioning, disability and quality of life (Alford, Remedios, Webb, & Ewen, 2013).

While potentially person-centred and participatory, the ICF is marred by inappropriate cultural processes and a lack of interventions based on Indigenous people's understanding of disability and their needs (Hollinsworth, 2013). The ICF's utility is less relevant in a Māori cultural context (e.g., it does not recognise the importance of ancestral connectivity and community collectivity). To avoid incongruence with Indigenous needs, users of the ICF need to possess culturally specific knowledge for interpretation against its standardised classifications (Bell, Lindeman, & Reid, 2015; Wright-St Clair et al., 2012). Given the diverse Indigenous contexts and understandings of disability, the ICF is considered unreliable (Harwood, 2010; Hollinsworth, 2013). Harwood (2010) makes it clear that universal approaches do not work. Still, little is known about mutual understandings and assessment decisions using the ICF in relationship to the type and quality of care available. Alford et al.'s (2013) systematic review found the ICF has the potential to help understand the complexity of Indigenous people's health and functioning, but limited literature exists about the experiences and the efficacy of the ICF as an appropriate tool (Hollinsworth, 2013; Wright-St Clair et al., 2012). Further research is needed to understand Indigenous people's experiences of the ICF.

The *World Report on Disability* (WHO/ World Bank, 2011) makes clear disability services are designed to serve dominant populations, and have to more specifically address the needs of disabled people to offer inclusive, equitable and culturally appropriate services. Currently, disabled persons are subject to inadequacies across policies and standards, service provision and delivery, funding, accessibility,

and negative attitudes. Moreover, they are likely to be neither involved in nor consulted about decisions affecting them. Ensuring inclusive and appropriate services requires the reduction of discrimination and, importantly, the involvement of disabled persons to guide service improvement and the cultural competence of providers (Wright-St Clair et al., 2012). In fact, the disability community advocates for equity in all aspects of people's lives along with the need to accommodate a person's disability or impairment (Shakespeare, 2014).

Indigenous disabled persons have experiences and challenges that non-Indigenous persons do not, related to the impacts of ongoing colonisation and the contemporary influences of multiple intersecting forms of oppression, including discrimination arising from racism (King, Brough, & Knox, 2014; Stienstra & Nyerere, 2016). King et al. (2014) maintain that colonising experiences created Indigenous people's disablement, something perpetuated by the dominant culture. For King et al. (2014) and Hollinsworth (2013), at the time of colonisation "disability" did not exist. The medical and social models of disability fall short in explaining Indigenous experiences of disability. Indigenous people have additional and diverse historical and contemporary impacts of disablement arising from colonisation, societal discourses about racism, subjugation and dysfunction that are in themselves disabling (Hollinsworth, 2013). Whānau Hauā offers a uniquely Indigenous Māori perspective on disability that is holistic and based on spiritual, collective and relational values (Hickey, 2015).

Māori and disability

Disability is a significant phenomenon for Māori and one that is not always acknowledged. The main impairments Māori live with are psychological/psychiatric, learning, speech, and intellectual in origin. The age-adjusted disability rate for Māori is 32% compared to 24%

for non-Māori (Statistics New Zealand, 2014). Māori with disabilities are mostly a young population, with more than one third (37.8%) aged under 15 years and half (49%) aged under 25 years (Ministry of Health [MOH], 2012). Half (50.9%) of Māori with disabilities have intellectual disabilities while a third (32.2%) have physical impairments. Almost one in four (23%) Māori with a disability have very high support needs (MOH, 2012). Unsurprisingly, Māori generally acquire disabilities at a younger median age (40 years) than non-Māori (57 years) (Statistics New Zealand, 2014), with just over a third (38%) being under 15 years and half (49%) under 25 years (MOH, 2012). Disability rates for Māori increase with age, rising from 15% for those under 15 to 63% for those over 65. Disease and illness (40%) followed by accidents and injury (28%) are the main causes of disability for Māori (Statistics New Zealand, 2015). Derrett et al. (2013) noted that 19% of Māori, both hospitalised and non-hospitalised, experience disability 24 months following an injury. These researchers also found Māori experienced disability at a significantly higher rate than non-Māori who are hospitalised.

Despite having higher rates of disability, Māori are more likely to have unmet needs relating to special equipment and consultations with a health professional (MOH, 2015). One in four disabled Māori also report having insufficient income to meet their daily needs (Statistics New Zealand, 2015) and experience inequities in accessing funding for equipment and care. The New Zealand Health Survey (MOH, 2016) found that 39% of Māori generally reported an unmet health need (1.4 times the rate of non-Māori) and 21% reported being unable to get an appointment at their usual medical centre. While 23% of disabled Māori have a very high level of support needs, only 16% accessed MOH-funded disability support (MOH, 2012). Kingi and Bray (2000) reported that Māori "go the extra mile" (p. 10) in terms of whanaungatanga and manaaki, which could account in part for their low uptake of disability

support, particularly when funding and services are complex and hard to access. But this does not totally explain the low uptake of disability support. Māori in general are thwarted by a number of issues when trying to access quality health services, which will be discussed later. When whānau hauā are able to access needed equipment, the literature indicates this may decrease the need for caregiver support and increase a sense of independence (Bray, Noyes, Edwards, & Harris, 2014). More research is needed to explore further the cause of these inequities, and to investigate whānau hauā insights into the reasons Māori have a relatively low uptake of disability support services.

Whānau Hauā

Informed by te ao Māori, Whānau Hauā provides a Māori perspective on disability. Indigenous worldviews encompass spiritual, holistic, relational and environmental dimensions—all important aspects of an Indigenous Māori worldview. Donny Rangiahau (Tuhoe) gifted the term whānau hauā and its description to Te Roopu Waiora, a Māori disability agency based in South Auckland. He described whānau hauā as an umbrella term suitable for disabled Māori. The term whānau hauā is now incorporated into Te Roopu Waiora's policies and procedures when working with Māori with disabilities (T. Kingi [Kaiwhakahaere of Te Roopu Waiora], personal communication, 2016).

Metaphorically, whānau hauā signifies the wind that propels whānau with member(s) who have a disability. The term whānau means to be born or to give birth and refers to the extended family network who may live within or outside of a home. Whānau differs from the commonly understood construction of the nuclear family, and can be made up of either whakapapa whānau or kaupapa whānau (Metge, 1995). Whakapapa whānau comprises members who are genealogically connected by common ancestors. Whānau may also be made up by those with a common purpose or experience, such as those with similar disabilities like kapo or turi. These whānau are referred to as kaupapa whānau, whose members provide caring, support and nurturing roles that traditional whānau provide. The collective orientation of the Māori whānau means its members also have associated responsibilities and obligations to manaaki other members and the whānau as a whole. The word "hau" means "wind", "gale" or "breeze" while "ā" refers to the drive or urge that propels this wind. Depending upon the mood of Tāwhiri-mātea, the wind can quickly change the environment, making it unstable.

Embedded in the Māori identity of disabled persons and their whānau, Whānau Hauā also sits within local historical and contemporary contexts. These contexts affect whānau and their ability to access crucial determinants of health as well as needed disability and health services. Whānau hauā often struggle to achieve balance in their lives when navigating seemingly unstable and unfriendly environments. Obtaining a sense of balance is therefore dependent on the efforts of the collective whānau members, not just the individual alone (Hickey, 2015).

Whānau Hauā is grounded in the collective whānau and individual members' experiences of someone with a disability. In addition to a collective orientation, the key aspect that makes Whānau Hauā distinct from common understandings of disability is that from this perspective a disability does not define a person. In other words, disability is positioned within a person's background, coming to the forefront in times of need and compromised ability to achieve or undertake necessary activities. Whānau hauā manage disability as part of their daily life rather than it being central to an individual's identity or everyday life.

The concept of Whānau Hauā is similar to the Western social model of disability, which holds that barriers to daily life do not originate from the disabled person, but are those perpetuated by society. Higgins, Philips, Cowan, Wakefield, and Tikao (2010) argued that "society disables

people by taking no account of their identity, their culture, or the meanings they give to disability" (p. 14). What makes Whānau Hauā distinct from the social model of disability, however, is the added cultural dimension of whānau working together to restore balance in their lives (Hickey, 2015). Therefore, Whānau Hauā sees disability as a collective endeavour of both the individual and the whānau as a whole. Whānau hauā are driven by a collective effort and the cultural obligations and responsibilities that whānau members have to each other and the whānau as a whole, while they strive to achieve balance within an environment of change and institutional barriers.

Access to quality health and disability services

"Whāia Te Ao Mārama: The Māori Disability Action Plan" (MOH, 2012), which was developed with more than 200 disabled Māori, whānau and service providers, identifies priority areas to reduce barriers faced by whānau hauā and to realise their aspirations of Objective 11 of the New Zealand Disability Strategy (NZDS) specifically states it will "promote the participation" of the disabled (Office for Disability Issues, 2001). Consulting fully with whānau hauā helps ensure appropriate benefits or changes are included in health and disability services planning (WHO/World Bank, 2011).

Māori generally lack access to quality care because of discrimination as well as struggling with the associated costs and transport, and navigating the complexity of the health and disability system (Harris et al., 2012; Rumball-Smith, Sarfati, Hider, & Blakely, 2013; Wilson & Barton, 2012). Prohibitive costs are one issue challenging whānau hauā access to services because many lack the disposable income for costs associated with access, reliable transport and appropriate carer support (The Centre, 2014). Moreover, we suggest that quality care for whānau hauā would be a

whānau-focused service that responds not just to the disabled person's needs but also to the broader cultural and whānau needs. Such a service would be consistent with Māori concepts of hauora.

Wiley's (2009) evaluation of Objective 11 in the NZDS found not only a conflict of paradigms (i.e., Indigenous versus mainstream providers), but also a systemic failure to hear whānau hauā, which in turn risked their refusal to access and use services. Wiley recommended collaboration, the establishment of accountability structures and effective evaluation of services. Harwood (2010) confirmed universal approaches do not work, and indicated Māori needed Māori-specific assessment criteria, access to a cultural experience and involvement in the assessment process. This requires skilled, knowledgeable and culturally competent professionals. To help achieve this, Ratima et al. (2007) provided a framework for culturally appropriate services for whānau hauā.

Rights

The honouring of Indigenous disabled persons' rights is questionable: they possess rights under the UNCRPD (ratified by New Zealand in 2007), the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and, in Aotearoa, Te Tiriti o Waitangi ("the Treaty"). The UNCRPD guarantees all disabled persons basic human rights, along with the respecting of their dignity and their right to autonomy (OHCHR, 2017a). Although the UNCRPD acknowledges that Indigenous persons with disabilities are a specific vulnerable group within the disability community, further elaboration about Indigenous people is absent from its articles. Preamble P does, however, briefly mention Indigenous people as one group of several subjected to multiple forms of discrimination (OHCHR, 2017a).

The implementation of the UNCRPD requires a paradigm shift to start recognising

the diversity existing within the disability community. This paradigm shift would entail representation of the diverse groups of disabled peoples, including whānau hauā, so that they can fully participate as stakeholders with the relevant government agencies (Mittler, 2015). The New Zealand Government's Office for Disability Issues' vision is for Aotearoa to become a "non-disabling society". To this end, they partner with Disabled People's Organisations (DPOs), which is a collective of disability-led non-government organisations, for their input into the implementation of and monitoring system for the UNCRPD. It is unclear exactly what involvement whānau hauā have in this relationship.

The UNDRIP aims to address the ongoing widespread violations against Indigenous people worldwide (Joffe, 2010). Articles 21 and 22 specifically attend to the marginalisation of Indigenous disabled persons and outline their rights to health, education, cultural and social life choices. The New Zealand Government did not sign the UNDRIP until 2010. Seven years later, policy linking the UNDRIP and UNCRPD together does not exist, and no policies have been developed that provide equal access to the rights of whānau hauā, rights that are set out in the Universal Declaration of Human Rights (1947).

In Aotearoa, the Treaty sets out the relationship between Māori and the Crown as well as the rights afforded to Māori. Whānau hauā (like all Māori) also have rights under the Treaty to equity. However, the differing views of Māori and Pākehā about the meaning of the Treaty make it difficult for whānau hauā to have their rights fully realised. This is not helped by the government and courts struggling to attain a common understanding of the Treaty. The Royal Commission on Social Policy (1988) proposed a unified approach to implementing the Treaty through a set of principles: partnership (relationship with Māori for service delivery), participation (involvement of Māori in activities and decision-making affecting them at all levels) and protection (equity and safeguarding of cultural values, beliefs and practices and promotion of their wellbeing) (Statistics New Zealand, 2015). These Treaty principles have become the primary means for government and its agencies to understand and express their commitment to the Treaty. Nevertheless, Māori continue to promote the Treaty articles of kawanatanga, tino rangatiratanga, oritetanga and wairuatanga to advance their equitable access to health and disability services and supports. Despite possessing these rights, whānau hauā continue to experience difficulties in accessing the support services that would assist them in their daily lives.

Importance of an Indigenous disability perspective

Not only do Indigenous disabled persons have to contend with the issues of race, identity and colonisation, but they also must grapple with the marginalisation of disability within their own cultural community as well as society generally (Higgins et al., 2010). One example of marginalisation made worse is the area of abuse. Disabled women, in particular those of colour, have higher rates of abuse than their counterparts and those without disabilities (Dowse, Frohmander, & Didi, 2016). This is often compounded by their abusers being professional support people whose role should be to protect and assist them (Cramer & Plummer, 2009). Bevan-Brown (2013) found that both Māori and non-Māori have exclusionary attitudes and practices that are embedded in their cultural practices, which can cause tensions for whānau hauā. For instance, some whānau hauā may experience access restrictions to marae if their guide or mobility dogs are prohibited.

The concept of intersectionality can help explain the compounding nature of how multiple identities and inequities intersect and compound over time (Cramer & Plummer, 2009; Stienstra & Nyerere, 2016).Identities

associated with race, class, gender, indigeneity and disability intersect as multiple forms of oppression (Gillborn, 2015). Gillborn argued that to gain a critical understanding of intersectionality, it is important to appreciate how race interacts with other forms of oppression at different times and in different circumstances. Consequently, being Indigenous, having experiences of colonisation and institutionalisation, experiences of racism and discrimination, and living with disabilities gives rise to multiple identities that go unseen by people with or without experiences of disability. Historically, these identities have been used to define, segregate and oppress Indigenous peoples with disabilities, and therefore there is a need to adopt a critical perspective when examining these identities because those socially constructed identities exacerbate oppression and inequality.

There has long been a denial of the scholarly colonisation of Indigenous peoples with disabilities (Meekosha, 2011). Policies and procedures around disability deny whānau hauā identity at every level. Given the over-representation of Māori regarding disability and the frequent absence of Indigenous identity in disability policy, it seems that Indigenous disabled persons and whānau hauā will continue to have difficulties accessing health and disability services until systemic issues are addressed. King et al. (2014) describe the incongruity between service and organisation expectations and culturally appropriate care, and highlight the need for disability services to be decolonised so that they include Indigenous cultural constructions of health and disability. As long as disability policies and services providers do not recognise unique aspects of Indigenous identity such as whānau hauā, policies and procedures governing Māori disability needs are prone to fail.

The current disability worldview is informed by a universal northern hemisphere colonial framework and has little compatibility with New Zealand and other Indigenous contexts. Such a worldview leaves little or no room for an Indigenous perspective of disability such

as Whānau Hauā. As Hollinsworth (2013) explains:

> Many Indigenous people regard only gross or highly visible conditions such as strokes, severe motor impairment, spinal cord injury, and amputation as disability (Gething 1995; Maher 1999). Conversely, in some communities, alcohol and drug dependence is seen as a disability as are some psychotic disorders. Definitions of disability vary widely across the highly diverse Indigenous communities. Standardized assessment tools (including the International Classification of Functioning and Disability [ICIDH-2]) and techniques are unreliable for many Indigenous people. (p. 609)

Competing worldviews of disability have promoted a dichotomy between the Western concept of individualism and the Indigenous concept of collectivism. Individualism's discourse about rights in terms of individuals is opposed to collectivism's focus on individuals' responsibilities and obligations to their collective group, such as whānau.

Ghai (2003) has argued that the Western construct of disability ignores Indian-specific issues and therefore cannot be applied to Indian disability issues. Meekosha (2011) likewise identified that disability discourses originating from the northern hemisphere do little to address Indigenous disabled persons residing in the southern hemisphere because their historical and contemporary experiences and needs differ. King et al. (2014) claim little has been done within the Australian context to comprehend the disablement of Indigenous persons due to colonisation and the invisibility of their disability experiences. Policies that are underpinned by the social model of disability and are individual focused have led to no reduction in the inequities experienced by whānau hauā. Indigenous meanings and experiences of disability are diverse, and are located within the histories of colonialism and the disablement resulting

from colonisation (Hollinsworth, 2013; King et al., 2014).

Whānau hauā and policy and service delivery and planning

Seemingly "tokenistic" consultation and decision-making approaches have been taken with respect to Māori by the MOH and the Ministry of Social Development, in which individuals are appointed by a minister rather than the disability community. Such appointments appear to be based on race rather than on disability experience, knowledge or skill. These appointments ignore the importance of individuals identifying with or having a background of whānau hauā. While two groups of Māori with impairments, kapo and turi, have national recognition in the disability sector, there is minimal representation of other whānau hauā within the disability organisations at any level. Despite the high level of Māori with learning and intellectual impairments, there is no Māori organisation for this group of disabled persons. However, People First NZ, a DPO that advocates for those with learning and or intellectual impairments, has a large Māori membership. This mainstream organisation, while not specifically focusing on Māori, enables its members to be leaders and decision-makers. This is somewhat unusual because most disability networks have predominantly Pākehā memberships, with little to no Māori involvement or participation.

Nevertheless, most whānau hauā remain unrepresented on any government disability entities dealing with disability, and the two existing representative groups lack the mandate and knowledge to speak for the diverse whānau hauā that exist. It is not uncommon for there to be no Māori representative, meaning no whānau hauā perspective is provided. The literature highlights the need to understand Indigenous disability experiences within the context of Indigenous identities (Hollinsworth, 2013; King et al., 2014). The original draft of the NZDS (Office for Disability Issues, 2001) lacked substantive consultation with Māori, and the Māori, and those Māori who were appointed by the Crown inevitably overlooked whānau hauā. The NZDS does have as an objective the promotion of participation of "disabled Māori" in the community, and equitable access to resources in a culturally appropriate manner. However, the 2015 progress report notes that 44% of Māori (compared with 29% non-Māori) with long-term impairments continue to have unmet service or assistance needs (Office for Disability Issues, 2015).

Despite the prevalence of Māori experiencing disabilities, generally there is minimal whānau hauā representation in hapū and iwi planning and decision-making. Oftentimes it appears no clear process exists for ensuring their inclusion. Nonetheless, there are positive examples where inclusion of whānau hauā has been made. In Northland, the Ngati Hine Hauora Trust has a whānau hauā leadership group who encourage participation and inclusion of their members within the hapū. The involvement of whānau hauā has enabled those with disabilities to achieve leadership positions within their local area. A similar outcome has occurred with the above-mentioned Te Roopu Waiora. These are positive examples of how representation could promote the inclusion and needs of whānau hauā at a national level. Such representation could also assist marae to become accessible and enable sign language to become more visible. Such actions also promote disabled individuals' inclusion within their community, rather than exclusion because of their disability and others' attitudes and actions.

Conclusion

Little research into the wellbeing of whānau hauā exists, yet evidence shows a disproportionately high rate of disability in Indigenous communities compared with their non-Indigenous peers. Furthermore, Indigenous disabled persons have

a low uptake of access to disability supports within a context of high levels of unmet needs. This is despite whānau hauā having international and national rights to equitable access to quality support and services. The lack of formal recognition of Indigenous disability identities occurs within a context of a prevailing dominant northern hemisphere Western ideology. Policies for determining the rights of disabled persons need to include a Māori worldview of wellbeing and disability to better meet the needs of whānau hauā. Continuance of a universal approach will perpetuate inequities for whānau hauā. Whānau Hauā offers a uniquely Indigenous approach for disabled Māori.

Acknowledgement

Glossary

Aotearoa	Māori name for New Zealand; lit., "land of the long white
hapū	group of whānau with a common ancestor, commonly referred to as a sub-tribe
hauora	health, wellbeing
iwi	people or tribe
kapo	Māori who are blind or have a visual impairment
kaupapa whānau	family comprising members with a common purpose
kawanatanga	governorship
manaaki	support, take care of, protect
Māori	Indigenous people of Aotearoa New Zealand
marae	tribal meeting grounds
oritetanga	equality, equal opportunities
Tāwhiri-mātea	god of the wind
te ao Māori	Indigenous Māori world
Te Tiriti o Waitangi	Māori-language version of the Treaty of Waitangi (1840)
tino rangatiratanga	self-determination, autonomy
turi	Māori who are deaf or have a hearing impairment
wairuatanga	spiritual wellbeing
whakapapa whānau	extended family whose members are connected genealogically by a common ancestor
whānau	extended family that includes multiple generations
whānau hauā	Māori families who are living with disability
whanaungatanga	the interrelationship of Māori with their ancestors; relationship, kinship, sense of family connection

References

Alford, V. M., Remedios, L. J., Webb, G. R., & Ewen, S. (2013). The use of the international classification of functioning, disability and health (ICF) in Indigenous healthcare: A systematic literature review. *International Journal for Equity in Health*, *12*, 32–32. http://doi.org/b8bq

Bell, D., Lindeman, M. A., & Reid, J. B. (2015). The (mis)matching of resources and assessed need in remote Aboriginal community aged care. *Australasian Journal on Ageing*, *34*(3), 171–176. http://doi.org/b8bs

Bevan-Brown, J. (2013). Including people with disabilities: An indigenous perspective. *International Journal of Inclusive Education*, *17*(6), 571–583.

Bray, N., Noyes, J., Edwards, R. T., & Harris, N. (2014). Wheelchair interventions, services and provision for disabled children: A mixed-method systematic review and conceptual framework. *BMC Health Services Research*, *14*(1), 309. http://doi.org/f596p6

Corker, M., & Shakespeare, T. (Eds.). (2002). *Disability/postmodernity: Embodying disability theory*. London, UK: Continuum.

Cramer, E. P., & Plummer, S.-B. (2009). People of color with disabilities: Intersectionality as a framework for analyzing intimate partner violence in social, historical, and political contexts. *Journal of Aggression, Maltreatment & Trauma*, *18*(2), 162–181. http://doi.org/cs9rwh

Derrett, S., Wilson, S., Samaranayaka, A., Langley, J., Wyeth, E., Ameratunga, S., . . . Mauiliu, M. (2013). Prevalence and predictors of disability 24-months after injury for hospitalised and non-hospitalised participants: Results from a longitudinal cohort study in New Zealand. *PLoS ONE*, *8*(11), e80194. http://doi.org/b8bt

Dowse, L., Frohmander, C., & Didi, A. (2016). Violence against disabled women in the global South: Working locally, acting globally. In S. Grech & K. Soldatic (Eds.), *Disability in the global South: The critical handbook* (pp. 323–336). Cham, Switzerland: Springer. http://doi.org/b8bk

Durie, M. (1998). *Whaiora: Māori health development* (2nd ed.). Auckland, New Zealand: Oxford University Press.

Garland-Thomson, R. (2005). Feminist disability studies. *Signs*, *30*(2), 1557–1587. http://doi.org/b8r5pt

Ghai, A. (2003). *(Dis)Embodied form: Issues of disabled women*. New Delhi, India: Har-Anand.

Gillborn, D. (2015). Intersectionality, critical race theory, and the primacy of racism: Race, class, gender and disability in education. *Qualitative Inquiry*, *21*(3), 277–287. http://doi.org/b8bv

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012). The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine*, *74*(3), 408–415. http://doi.org/dwm2hs

Harwood, M. (2010). Rehabilitation and indigenous peoples: The Māori experience. *Disability & Rehabilitation*, *32*(12), 972–977. http://doi.org/c75sn7

Hickey, H. (2015). Tātau tātau: Engaging with whānau hauā from within a cultural framework. In J. Bevan-Brown (Ed.), *Working with Māori children with special education needs: He mihi whakahirahira* (pp. 70–84). Wellington, New Zealand: NZCER.

Higgins, N., Philips, H., Cowan, C., Wakefield, B., & Tikao, K. (2010). *Growing up kāpo Māori: Whānau, identity, cultural well-being and health/E tipu kāpo Māori nei: Whānaungatanga, māramatanga, Māoritanga, hauoratanga*. Retrieved from http://www.donaldbeasley.org.nz/assets/Uploads/publications/Growing-up-kapo-Maori.pdf

Hollinsworth, D. (2013). Decolonizing Indigenous disability in Australia. *Disability & Society*, *28*(5), 601–615. http://doi.org/b8bw

Joffe, P. (2010). UN Declaration on the Rights of Indigenous Peoples: Canadian Government positions incompatible with genuine reconciliation. *National Journal of Constitutional Law*, *26*. Retrieved from http://quakerservice.ca/wp-content/uploads/2011/05/NJCLPJArticleUNDeclaration2010.pdf

King, J. A., Brough, M., & Knox, M. (2014). Negotiating disability and colonisation: The lived experience of Indigenous Australians with a disability. *Disability & Society*, *29*(5), 738–750. http://doi.org/b8bx

Kingi, J., & Bray, A. (2000). *Māori concepts of disability*. Dunedin, New Zealand: Donald Beasley Institute.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667–682. http://doi.org/bwbqbp

Metge, J. (1995). *New growth from old: The whānau in the modern world*. Wellington, New Zealand: Victoria University Press.

Ministry of Health. (2012). *Whaīa Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017*. Retrieved from http://www.health.govt.nz/system/files/documents/publications/whaia-te-ao-marama-maori-disability-action-plan.pdf

Ministry of Health. (2015). *Tatau kahukura: Māori health chart book 2015* (3rd ed.). Wellington, New Zealand: Author.

Ministry of Health. (2016). *Annual update of key results 2015/16: New Zealand Health Survey*. Retrieved from http://www.health.govt.nz/system/files/documents/publications/annual-update-key-results-2015-16-nzhs-dec16-v2.pdf

Mittler, P. (2015). The UN Convention on the Rights of Persons with Disabilities: Implementing a paradigm shift. *Journal of Policy and Practice in Intellectual Disabilities*, 12(2), 79–89. http://doi.org/f7d3nb

Office for Disability Issues. (2001). *New Zealand Disability Strategy 2001*. Retrieved from https://www.odi.govt.nz/nz-disability-strategy/about-the-strategy/new-zealand-disability-strategy-2001/2001-strategy-read-online

Office for Disability Issues. (2015). *Towards an inclusive and enabling New Zealand: The annual report from the Minister for Disability Issues to the House of Representatives on implementation of the New Zealand Disability Strategy*. Retrieved from https://www.odi.govt.nz/nz-disability-strategy/about-the-strategy/new-zealand-disability-strategy-2001/progress-reports/towards-an-inclusive-and-enabling-new-zealand-2015

Office of the High Commissioner for Human Rights. (2017a). Convention on the Rights of Persons with Disabilities. Retrieved from http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#1

Office of the Commissioner for Human Rights. (2017b). Human rights of persons with disabilities. Retrieved from http://www.ohchr.org/EN/Issues/Disability/Pages/DisabilityIndex.aspx

Oliver, M. (1996). *Understanding disability: From theory to practice*. New York, NY: St. Martin's Press. http://doi.org/b8bm

Ratima, M. M., Brown, R. M., Garrett, N. K. G., Wikaire, E. I., Ngawati, R. M., Aspin, C. S., & Potaka, U. K. (2007). Strengthening Māori participation in the New Zealand health and disability workforce. *Medical Journal of Australia*, 186, 541–543.

Royal Commission on Social Policy. (1988). *Future directions* (Vol. 2, pt. 2). Wellington, New Zealand: Author.

Rumball-Smith, J., Sarfati, D., Hider, P., & Blakely, T. (2013). Ethnic disparities in the quality of hospital care in New Zealand, as measured by 30-day rate of unplanned readmission/death. *International Journal of Quality in Health Care*, 25(3), 248–254. http://doi.org/f42wpw

Shakespeare, T. (2013). The social model of disability. In L. L. Davis (Ed.), *The disability studies reader* (4th ed., pp. 214–221). New York, NY: Routledge.

Shakespeare, T. (2014). *Disability rights and wrongs revisited*. London, UK: Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9–28. http://doi.org/d3df59

Statistics New Zealand. (2014). Disability Survey: 2013. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

Statistics New Zealand. (2015). He hauā Māori: Findings from the 2013 Disability Survey. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey.aspx

Stienstra, D., & Nyerere, L. (2016). Race, ethnicity and disability: Charting complex and intersectional terrains. In S. Grech & K. Soldatic (Eds.), *Disability in the global South: The critical handbook* (pp. 255–268). Cham, Switzerland: Springer. http://doi.org/b8bp

The Centre. (2014). *Hauā Mana Māori – Living unique and enriched lives: A report for the Health Research Council and the Ministry of Health*. Retrieved from http://www.donaldbeasley.org.nz/assets/Uploads/publications/Haua-Mana-Maori-Living-unique-and-enriched-lives.pdf

Westby, C. (2013). Implementing recommendations of the *World Report on Disability* for indigenous populations. *International Journal of Speech-Language Pathology*, 15(1), 96–100. http://doi.org/b8bz

Wiley, A. (2009). At a cultural crossroads: Lessons on culture and policy from the New Zealand Disability Strategy. *Disability & Rehabilitation*, 31(14), 1205–1214. http://doi.org/bv2n5d

Wilson, D., & Barton, P. (2012). Indigenous hospital experiences: A New Zealand case study. *Journal*

of Clinical Nursing, 21(15–16), 2316–2326. http://doi.org/f35b5b

World Health Organization. (2017). Disabilities. Retrieved from http://www.who.int/topics/disabilities/en

World Health Organization & World Bank. (2011). *World Report on Disability: Summary.* Retrieved from http://apps.who.int/iris/bitstream/10665/70670/1/WHO_NMH_VIP_11.01_eng.pdf

Wright-St Clair, V. A., Kepa, M., Hoenle, S., Hayman, K., Keeling, S., Connolly, M., . . . Kerse, N. (2012). Doing what's important: Valued activities for older New Zealand Māori and non-Māori. *Australasian Journal on Ageing, 31*(4), 241–246. http://doi.org/b8b2