

Yuin, Kamilaroi, Sámi, and Maori people's reflections on experiences as 'Indigenous scholars' in 'Disability Studies' and 'Decolonisation'

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Disability research in Indigenous communities operates within a culture of academic neo-imperialism. There is a need to decolonise disability research on a global level. Limited knowledge exists on Indigenous disability researchers' experiences in the disability research academy and on Indigenous disability research methodologies. In part, this is due to the limited writings produced by Indigenous peoples on disability research and research methodologies. Four indigenous disability researchers, one from the Nordic Region and two from Australia, and one from New Zealand met during and after the 2017 Nordic Network on Disability Research conference and reflected on and discussed each other's experiences as Indigenous disability researchers. This paper reports on these scholars' reflections on comparing the research methodologies and experiences of their disability research. Findings highlight how although Indigenous peoples are from different tribes/nations and countries, there are similarities and differences between each of the Indigenous disability researcher's approach to decolonisation in disability research. The paper concludes that Sami, Australian Aboriginal people, and Maori people can learn from each other to advance the decolonisation of disability research, service and policy, at local, national and international levels.

Keywords: Indigenous; Decolonizing research; Nordic countries; Australia; New Zealand

Introduction and background

This paper forms part of our ambitions as Indigenous peoples¹ to decolonise disability research. The World Health Organization (WHO) (Alderete, 1999) and the United Nations (2009) have identified how European colonisation and colonialism have had a dramatic global impact on the health and welfare of millions of Indigenous peoples. Schofield and Gilroy (2015) define colonisation as a process by which one cultural/ethnic group occupies by force the lands once foreign to them primarily for the benefit of the invading group. There are many examples of colonisation in global history, such as the Roman, Spanish and British

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Empires. Colonialism, however, are those ideologies, values, and desires that falsely underpin the process of colonisation as justified. Colonialism, in effect, serves the interests of the colonial elite classes.

Multiple reports suggest that the rates of disability and chronic health conditions amongst Indigenous communities in colonised nations that collected population statistics are higher when compared with non-Indigenous communities (Alderete, 1999; UN, 2009; Schofield and Gilroy, 2015). European colonisation attempted to destroy Indigenous cultural identity through Euro-centric assimilationist policies and practices (Alerete, 1999). These assaults on Indigenous cultural and social solidarity are considered root causes of Indigenous communities around the world reporting alarming life situations for those living with disability, and/or higher rates of disability and chronic disease when compared to their non-Indigenous counterparts (Alderete, 1999; Biddle et al., 2013; Statistics New Zealand, 2014; Uttjek, 2016).

Universities and colleges see themselves as the leading institutions for research and knowledge production. These institutions compete for elite status using a small number of 'global ranking' systems. Ranking systems prioritise research production, teaching outcomes, and public reputation as the main factors for prestige (QS World University Rankings, 2017; Times Higher Education, 2017; Academic Ranking of World Universities, 2017). These institutions often prioritise Western capitalist ideologies (research outputs, industry partners, tertiary graduate employment) above the values and principles of Indigenous communities.

In this paper, we report on how we, the authors, four Indigenous disability scholars from three countries (Australia, Sweden, and New Zealand), came together in an effort to have our voices heard on the global stage. This paper compares and contrasts our individual stories as Indigenous peoples working as researchers, with a focus on disability. Firstly, we provide a background to the aim of decolonisation methodology. Second, we highlight our individual stories about our work, including how we tailored and implemented decolonisation in our research methodology and practices more broadly. We then compare the similarities and differences between our experiences.

Indigenous research and decolonisation

This paper is the first attempt where a number of Indigenous scholars have come together to write an article on Indigenous-disability research. In Sweden, this is the first time that Sámi informants have their views of current issues relating to disability research illustrated without, what other scholars refer to as 'being interpreted or misinterpreted through imperialists' eyes (Tuhiwai Smith, 2012; Uttjek, 2016). For centuries, disability research has thrived and achieved domination through the roots of academic neo-imperialism at a global level. Academic neo-imperialism is the process that allows non-Indigenous researchers to impose their values and desires on Indigenous peoples even though these desires and values

too often conflict with and negate the interests of Indigenous peoples (Gilroy et al., 2013; Gilroy, 2012). Many of these imposed values and desires feed into evidence-based policy, practice and praxis.

Recently, critical disability research scholars, Indigenous disability scholars and advocates have called to decolonise disability research at a global level (see Grech, 2015). Decolonisation centres on privileging the voices of Indigenous people and analysing, as well as dismantling the power balances that exist between Indigenous and non-Indigenous peoples, knowledge, practice and leadership. Chilisa (2012) defines decolonisation as a process that honours Indigenous people by sharing their voices in a way that promotes Indigenous people's worldviews, values and beliefs. Chilisa (2012) describes the central aim of decolonisation as that of restoring, developing and maintaining cultural practices that were lost or interrupted by colonisation. Decolonisation does not aim to 'remove' non-Indigenous peoples from the lands of which their forefathers have invaded. Rather it is a metaphysical process whereby Indigenous and non-Indigenous peoples revisit and critique the process of colonisation and shift the power imbalances in a bid to achieve equality and equity between Indigenous and non-Indigenous peoples (Dudgeon and Fielder, 2006). Dudgeon and Fielder (2006) emphasise that respecting social and cultural diversity remains at the heart of decolonisation, in particular exploring the power relationships that exist between the coloniser and colonised.

Coloniser and Indigenous people can come together in what Dudgeon and Fielder (2006) refer to as a *third space* where cross-cultural communication occurs, and where the process and operations of colonialism and colonisation can be deconstructed. The term *coloniality of power* conceptualises the overpowering force of the elite classes of the coloniser's values, world views and beliefs had, and continue to have, on Indigenous peoples' knowledges, roles and responsibilities (Dudgeon and Walker, 2015). We, Indigenous scholars, work within research institutions that apply colonised governance structures, processes, and regulations of research. As such, our positions within these institutions mean that we must advocate for culturally responsive and decolonising approaches that do not perpetuate colonial values and practices in any research process.

Although decolonising processes highlight the critical differences in the way Indigenous research is carried out, we also acknowledge that Indigenous researchers around the world uptake approaches that are unique to their family, community, culture, experience, and objectives as Indigenous people. Dudgeon (2008) contends that there are similarities between the position of self as a researcher in an anti-colonial and a feminist standpoint, such as oppression and talking back to the oppressors. Moreton-Robinson (2014) argues that feminism, though providing an avenue for Indigenous research methodologies within the Australian academy, has two fundamental differences from an Indigenous Standpoint Theory. The first is that Australian Indigenous methodologies are founded on connections with countries, communities and ancestors (Moreton-Robinson, 2014) and reflect cultural

protocols (Tuhiwai Smith, 2012). The second is that Indigenous Women's Standpoint addresses the privileged relationships of Australian non-Indigenous women to the nation's sovereignty, underpinning their social situation and considering the process of a colonised history of Australia (Moreton-Robinson, 2014). These differences alongside privileged positions are essential to understand, since they provide important cultural protocols for Indigenous researchers and Indigenous research methodologies.

Method

To further explore these issues in our own practice, we now provide a narrative about our own practices as Indigenous researchers expanding the realms of decolonising methodologies as we work with our own kin, cultures and communities, and explore the experience of disability. Each of our journeys are unique to our traditional lands and kin and cultures. We chose this narrative style, as it reflected, in some way, our individual cultural and/or communication protocols. It also provided an avenue for us to develop and grow relationships with each other. Most importantly, this narrative methodology, promoted Indigenous voices, both the diversity within our voices and also the similarities that unite us as Indigenous peoples. Each of the authors answered three questions:

- What inspired me to be an Indigenous researcher?
- How did I implement a decolonisation methodology in my practice?
- Why did this decolonisation methodology work best for this research?

After responding to these questions, we discuss both similarities and differences, as well as the implications for practice, policy, and praxis.

Findings

In the following section we present our narratives.

Chontel Gibson

What inspired me to be a researcher?

Many factors inspired me to become a researcher and I will share some with you now; truth-telling being the first factor. Stories, experiences and knowledges that our Elders and older people share with family and kin remain central to community lives and to my research. Until recent times, the research sector mostly excluded or misappropriated Aboriginal and Torres Strait Islander people's narratives, pedagogies and methodologies (Smith, 2012). Culturally

responsive research has the potential to open respectful avenues to share stories, experiences and knowledge. This involves research processes that reflect and respect our ways of sharing knowledge. In my research role, I am able to work closely with communities, so that I can share community voices in research processes. I include communities in important decision-making processes such as deciding how to conduct research, which questions to ask and how to represent communities' voices.

Over time, I have and continue to witness how non-Indigenous people and sometimes Aboriginal and Torres Strait Islander people devalue or exclude cultural knowledge, including my Kamilaroi knowledge. An important part of my ongoing life lessons and advocacy role is to highlight how Western knowledge, systems and processes, disempower Indigenous knowledge systems and practices. Colonial knowledge systems and their institutions enforce a Western way of knowing, being and doing (Yalmambirra, 2000; Tuhiwai Smith, 2012). In high school, I recall holding different opinions to my peers about the perceived 'benefits' of globalisation. I questioned the propaganda, such as the omission of Aboriginal cultures and histories. In my undergraduate occupational therapy degree, I recall the lack of Indigenous knowledge, leadership and practice included in the curricula. I recall not fitting into the occupational therapy profession. Previously and still to a large extent today, my peers express strong emotions, some of which are negative, when I suggest that occupational therapy is not universally accepted or applicable. In this context and many others, I draw on the strength of my cultural connections and take my place within the occupational therapy profession and the research sector in a way described by Tuhiwai Smith (2010: 170):

Cultures are created and reshaped; people who are often seen by the mainstream as dangerous, unruly, disrespectful of the status quo and distrustful of established institutions are also innovative in such conditions; they are able to design their own solutions, they challenge research and society to find the right solutions.

Together with Aboriginal and Torres Strait Islander people and others, I now advocate for the inclusion of their knowledges, practice and leadership in allied health curricula. I do this with the aim of dismantling power imbalances of knowledges and transforming the way we practice as researchers, teachers and health professionals. For example, we developed a set of critical reflective questions which may help occupational therapists unpack the power imbalance of knowledge and practice that exists within the social context of Australia and in our profession (see Gibson et al., 2015). As co-founder and co-chair of the National Aboriginal and Torres Strait Islander Occupational Therapy Network, I work with my peers and other organisations to facilitate the decolonisation process in the profession. In 2013, we also successfully advocated for the inclusion of standards that relate to Aboriginal and Torres Strait Islander partnerships, content and pedagogies in the compulsory accreditation process for undergraduate occupational therapy degrees. In 2018, we advocated with success for an

Aboriginal and Torres Strait Islander Occupational Therapist to be included in a reference group which is now reviewing the before mentioned accreditation process.

The second inspirational factor for being a researcher relates to both justice and equality. The injustices and inequalities experienced by Aboriginal and Torres Strait Islander people as a result of colonisation, along with the ongoing oppressive policies, pervades the daily life of many, if not all Aboriginal and Torres Strait Islander people in Australia (Dudgeon, 2017). Dudgeon (2017:107-108) succinctly describes some experiences and expressions of colonisation, when she explains the context of her chapter,

...Aboriginal women have resisted colonisation and oppression, the ways they fought back to protect themselves and their children – whether it was playing the game and playing humble or whether it was standing up and fighting the system.

In spite of colonisation, Aboriginal and Torres Strait Islander people understand how to maintain, restore and/or develop cultural knowledge. This understanding, along with my cultural obligation to address injustices and inequalities drives me to implement research practices that promote survival of our cultures and therefore of our identities. Thus, for me it is paramount that my research does not mimic colonisation and the colonising process.

The third and final inspiration factor for being a researcher, are my cultural obligations, which drive many kinship roles and responsibilities. Many Aboriginal and Torres Strait Islander people enact roles and responsibilities through a set of activities that one must undertake for, with, or in proxy of other family or community members. I am a Kamilaroi person who previously lived and worked on Wiradjuri country, and this means that I respected Wiradjuri Country, including all Elders and older people living on Wiradjuri Country. Like many other Aboriginal women such as Martin and Miraboopa (2003), my lived experiences, along with my cultural connections, influence how I interact and interconnect with my world, including research. In my family, I have a special caring responsibility for older and younger people, particularly as it relates to health and wellbeing. I have the privilege of embedding my cultural obligations in the workplace, such as working with older and younger people, with a focus on health and wellbeing. As I become older, my roles and responsibilities expand to include sharing and maintaining cultural knowledges relating to familial, historical, social and cultural contexts. These contexts not only influence my roles and responsibilities, but also how I undertake them.

How did I implement my decolonisation methodology in research?

A decolonisation methodology is not only a philosophical approach used in research but instead a practice implemented in every aspect of research, teaching and health practice. For me, a key method to implement a decolonising methodology is through developing and

maintaining relationships. Relationship-building is a journey. This journey helps partners, including me, to develop an understanding of how communities define themselves, along with aspirations and needs relating to the research. The journey provides opportunities for partners to learn and implement preferences and protocols, including communication strategies for the research. Many scholars, including Martin and Maraboopa (2003), recognise that communities' needs, requirements and priorities are central to the research journey. One example of how I practice this community-centred approach is by allowing time for decision-making processes and being flexible so that communities can fulfil family and community obligations. I use yarning to support this community-centred approach. Yarning is an Aboriginal communication tool that is now commonly used as a research method. It involves breaking down the power relations between the 'researcher' and the 'researched' (Dean, 2010). In yarning, the researcher is accountable to the yarning members, and is directed by the connections between yarning members, including if, how, and when information is shared (Dean, 2010; Bessarab and Ng'andu, 2010). Yarning privileges its members' voices as the culturally appropriate nature allows them to explore and elevate their own experiences, knowledge and stories (Nakata, 2007; Rigney, 1999; Fredericks, 2008). Importantly, yarning is a place where yarning members can discuss the impact of colonisation, work through the conflict resulting from the ongoing impact of colonisation and work collaboratively to heal the wounds of colonisation.

Why did this methodology work best for the research findings?

Many reasons exist as to why a decolonising approach works best for research findings. For example, a decolonising approach facilitates sharing knowledge in a manner that can withstand research integrity in both the Indigenous and non-Indigenous research spheres. A decolonising approach allows researchers to develop principles and values relevant to the research and community. It requires the researcher and research partners to consider the impact of historical, political, cultural and social factors. A decolonising approach provides an opportunity for research partners to discuss which community members participated in the research and therefore, how the research, unintentionally, privileges some voices and not others in research findings. My research never speaks the truth of all community members or speaks on behalf of other communities, as some community members may perceive this 'expertise' or 'leadership' as a form of oppression. However, my research still provides an opportunity for community members to share their truth, to build on the shoulders of our ancestors and to provide a platform for the inclusion of all truths.

Margaretha Uttjek

What inspired me to be a researcher?

Sámi language was prohibited when I grew up, and I went to Swedish schools. The Sámi land has been colonised for several centuries and Christianity was forced on my people, which included the prohibition of our language and culture for a long time (Ruong, 1982). Despite that, my people have maintained several of our languages and our culture (ibid, 1982). My academic education was at a Swedish university, based on Eurocentric epistemologies. I always had with me my traditional indigenous upbringing, which included reindeer herding in my family (but in previous generations), and I have strived to maintain my language, which has helped me in understanding and learning how to live in these two worlds. In addition, my upbringing also included a basic understanding of human equality, regardless of gender or where in the world you come from.

Research on issues regarding Sámi with disabilities was an emerging issue for Sámis in Northern Europe. Sámis advocate that Sámi researchers undertake research to ensure that disability research maintains its importance. Sámi leaders prefer research to be undertaken from an etic position, that is from an indigenous lens (Cajete, 2000; Tuhiwai Smith, 2012), in order to have a fair point of departure in this knowledge. This issue was emerging since authorities, striving for a developed welfare service, asked for knowledge about living conditions among Sámis with disabilities, and also regarding the fact that statistics on this issue was limited (Uttjek, 2016). In Sweden, authorities are not allowed to register persons based on disability or ethnicity.

Being a Sámi and a researcher at the Department of Social Work where the Centre for disability research is located, and with research experiences from the area of Public Health, as well as long experiences from working as a social worker, through a research network, I was asked to participate in a Nordic study on living conditions among Sámis with disabilities (Uttjek, 2016). Indigenous and human rights have been parts of both my private and professional life for so many years, and that also inspired my engagement in these research issues.

Consequently, I started from the very beginning. I found limited literature on decolonizing research methodologies in disability research from a Sámi context, and from an indigenous perspective, that could be applied on Sámis land (see also Cajete, 2000; Tuhiwai Smith, 2012). In addition, I found no literature on the experiences of indigenous scholars in disability research from a Sámi context. There was also limited literature on Indigenous conceptual and theoretical frameworks. Therefore, I developed my own methodology to present the informants' stories with a perspective from within with my Sámi eye, mind, and soul (Cajete, 2000; Tuhiwai Smith, 2012).

My research area is about disability issues among Sámis, and violence targeted at Sámi women and children, and previously I worked on research addressing the consequences of having psoriasis in everyday life (Uttjek, 2005, 2006, 2007, 2008, 2013, 2015, 2016; Uttjek et al., 2004, 2005).

How did I implement my decolonisation methodology in research?

The aim of the research was garner knowledge about living conditions among Sámis with disabilities in Sweden, if they wanted any changes regarding this, and if there were any gender differences in this regard (Uttjek, 2016). My experience in disability research in the Public Health area about living with consequences of psoriasis, and gender differences regarding this, facilitated my research work. So did my work with research on Indigenous issues regarding violence addressed at Sámi women and children (Uttjek, 2013, 2015; Uttjek et al., 2007, 2008).

My cultural heritage informed the decolonizing methodology I developed during the research process. The first part of the process was to establish a reference group with Sámis for the project in order to engage Sámi society, and to shift who owns Sámi research issues. One of the original meetings was to ascertain if any Sámi had concerns about the research. Since the research issue was considered to be important and I knew I had support from my community, I started with the research. The original methodology proposed for this study was not suitable for Sámi. The Norwegian Directorate for Children, Youth and Family Affairs based in Norway, together with the Nordic Welfare Centre in Stockholm, propose an interview guide with 17 questions developed from the worldview of mainstream *society* as it was done by non-indigenous researchers, and thus from ‘imperial eyes’ (Smith, 2012:44). The advisory group’s view was that these many questions developed from a Eurocentric worldview and might have been a risk for dominating the informant’s choice of what they would tell regarding the issues (Tuhiwai Smith, 2012; Uttjek, 2016; Battiste, 2013). This risk evaluation is similar to what Linda Tuhiwai Smith (2012) writes about as the research through imperialist eyes, and also Battiste’s (2013) work on eurocentric epistemologies, which also are used in dominating Nordic universities. As Battiste (2013) writes on Canada, the Eurocentric worldview is also dominating the current education system in Sweden.

We changed the methodology to suit the interests of Sami with disabilities. I adopted the traditional practice of story-telling, and I asked them to tell about their everyday life, how they lived their life. I also asked about their views on disability in their lives, inspired by my own Sámi worldview and living experiences as well as Bongo’s (2012) writings, who showed in her study from northern Norway how Sámis preferred not to talk about various diseases. Instead they talked about their lives and life situations (ibid, 2012). I encouraged informants to tell with their own words about their everyday life with their disabilities. Furthermore, I used a modified interview guide as a checklist in order to cover the areas of interest for the

whole Nordic project, including to facilitate comparisons (Uttjek, 2016). This approach favoured the traditional practice of the informants telling me, the researcher, their lived experiences and various situations. This approach is contrary to the original proposed methodology, which situated the process in the asking of prescribed questions. In doing so, there may be a risk of dominating the informant's perspectives and replies. Instead, I wanted to give space for the informant to choose her/his own way of telling me whatever she/he wanted to tell me. In order not to dominate the informants' stories, I asked them to tell about their everyday life. Furthermore, in order to have the interview guide fit into my work and the Sámi context, I used this guide only to check if similar areas of interest were covered, which was a part of the agreement in the larger Nordic project, aiming at making comparisons between Nordic countries (Uttjek, 2016).

I wanted to encourage their own stories with their experiences and their own worldview. Importantly, I did not want the informants to be dominated by the questions in the interview guide, since it was developed through imperialist eyes (Tuhiwai Smith, 2012).

The project's analytical framework was designed to accommodate the Sámi perspective, focused on 'who I am' and 'what I am doing', inherited from my parents and ancestors, and learning in living experiences (Cajete, 2000). Cajete (2000) describes this process as 'learning relationships in context', and not from a Eurocentric one based on the categories and diagnoses that define disabilities. The support and help offered to persons with disabilities by the Swedish welfare state are based on such categories and diagnoses (Uttjek, 2016). Such help and support are determined by the individual's diagnosis and how much help and support the individual needs. Furthermore, since I found similarities in being indigenous and a researcher and how to work in the research process, I was also inspired by the work of other indigenous researchers (see for example Bongo, 2012; Tuhiwai Smith, 2012; Smith, 2015; Battiste, 2013; Cajete, 2000).

Why did this methodology work best for the research findings?

My point of departure was to present the results from the informants' views, in order to offer them an opportunity to tell what was on their mind and what they wanted to put forward. I was striving for me as a researcher and the informants as knowledge-holders to work together and develop a message to authorities about how to improve the welfare state measures and services provided to Sámis with various abilities. Our approach was similar to Cajete's (2000) recommendation emphasising the need to support and respect indigenous knowledge, which includes that the informant's thoughts and knowledge are important and have their own merits. Thus, they should be put forward on their own terms, without being validated by any eurocentric system (Cajete, 2000). What we did may also be considered to be one way to take proactive actions and make space for our own way to put 'out there' the informants' knowledge about views on disability and living with various abilities. This bears some

similarities to Graham H. Smith's (2015) writings about the importance of working proactively rather than in a reactive manner to colonial structures and systems. Working with my indigenous 'eye', facilitated the analysis and presentation of the results, staying close to the informants' own words (Cajete, 2000; Smith, 2015; Tuhiwai Smith, 2012).

John Gilroy

What inspired me to be a researcher?

I was born with a profound speech impairment and mild hearing impairment related to a respiratory condition called rhinitis. Growing up as a child I often was teased and bullied by my school peers because of my disability and my Aboriginality. There was a time during primary school where I was called a 'stuttering white nigga' by non-Indigenous children. This event led to a fight between my relatives and the non-Aboriginal students in the school. Since high-school (secondary school) I became a committed advocate for the human rights of people with a disability, which I continue to this very day.

It was not until I was at university that I overcame my stuttering using public speaking and talking with no shame. During university I became one of the first Aboriginal cadets for the then NSW Government Department of Ageing, Disability and Home Care as a policy officer assistant. I then worked for a not-for-profit non-governmental agency called National Disability Services. It was working in this agency that I realised that there were no leading Aboriginal disability researchers, and at which point I decided to move into research.

My scholarly career commenced with a large study called the *Factors that Can Influence the Participation of Aboriginal People in Disability Services*, undertaken between 2009 and 2012. The research aimed to identify the factors that influence the participation of Aboriginal people in disability services and supports. Participants for this study were recruited from one Aboriginal community controlled organisation and one generic disability service provider in a metropolitan region of New South Wales. Workers varied in their service background, training, experience, expertise and engagement in Aboriginal communities. Two reports were made about the findings of this study (Gilroy, 2012; Gilroy et al., 2016).

How did I implement my decolonisation methodology in research?

I struggled to find an appropriate theoretical framework for this research project that took into account the needs and experiences of Aboriginal peoples and the needs of people with a disability. Even critical disability studies theories could not help. Despite the growth of Indigenous research methodologies being used in Aboriginal health research, none took into

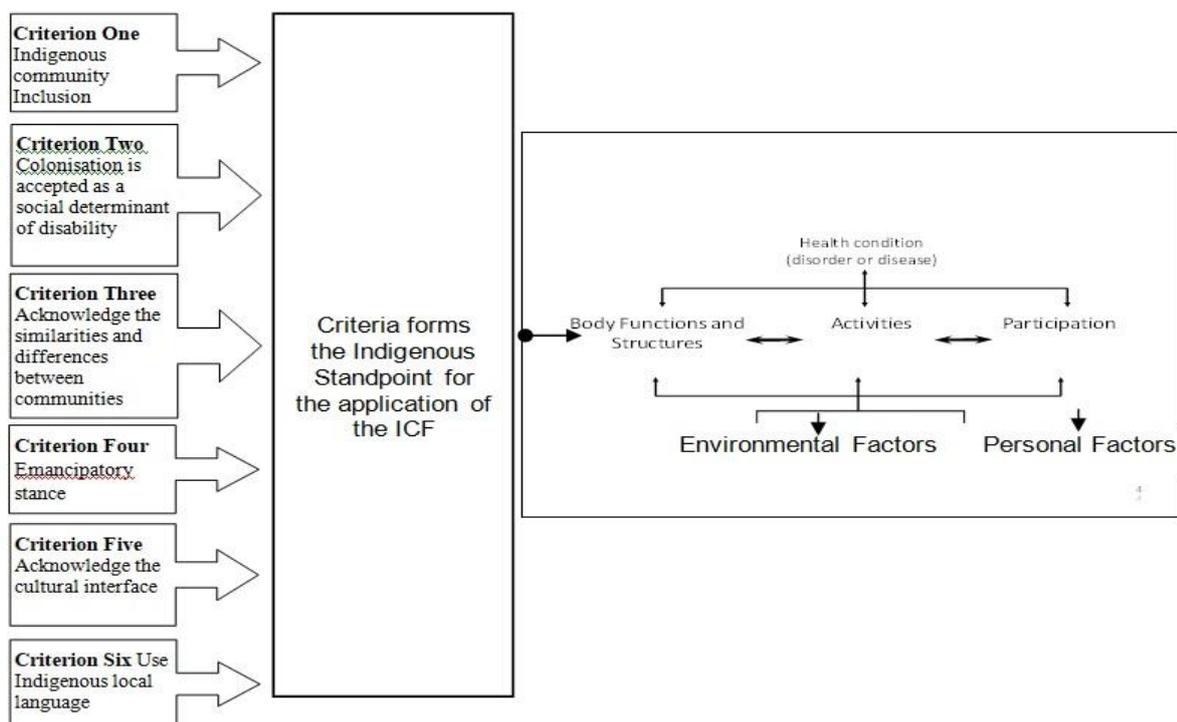
account the social experiences of living with a disability.

As such, I developed my own social constructivist framework for this research that is closely aligned with Indigenous Standpoint Theory, as discussed by many Australian Indigenous scholars (Nakata, 1997; Foley, 2006; Moreton-Robinson, 2000). Although I was inspired by the Australian Indigenous scholars, I was also inspired by Tuhiwai-Smith's (2012) decolonising publications.

The focus of this enquiry was on the cultural interface as defined by Nakata (1997), a complex web of experiences of local Aboriginal and non-Aboriginal service workers and managers of generic and Aboriginal community managed disability service providers (Gilroy, 2010). The cultural interface is a metaphysical space where we Indigenous peoples are expected to transition and operate in the socio-cultural realms of Indigenous and non-Indigenous cultures. I incorporated this with the relatively recent International Classification of Functioning of Health and Disability (ICF) to ensure that the multitude of factors that influence disability were considered (see Gilroy et al., 2013; Gilroy and Donnelly, 2016).

This framework includes criteria that bridge the cultural interface between Aboriginal and non-Aboriginal communities, whilst helping to emancipate Aboriginal people with a disability in the research and policy development process in Australian disability and Aboriginal affairs. The six criteria in the figure below are suggested as a starting point to help researchers develop a localised IST for Indigenous disability research that acknowledges the cultural diversity within Indigenous and non-Indigenous populations.

Figure 1: Conceptual Framework for research on disability with Indigenous communities



Gilroy et al. (2013) suggested that ‘utilizing IST with the ICF could help ameliorate the current weaknesses of the global contextual framework in disability research and policy development’. The listed criteria could help increase the likelihood that the researchers (or team) consider the structural factors within Indigenous communities together with the experiences of living with disability. This framework acknowledges that both individual and social approaches to disability and Indigeneity need to be adopted in research.

This framework helped frame and structure my research questions and data collection. I established a support and governance network of Indigenous community-controlled organisations and disability organisations to support the development and operations of the project. The executives of these organisations helped formulate the series of trigger questions derived from the literature and our collective experiences working as advocates for Indigenous people with disability.

I opted to facilitate focus groups and yarn ups (culturally appropriate interviewing) with staff from these two agencies. All focus group participants were offered the opportunity to participate in an individual interview. Interestingly, this was only taken up by Aboriginal workers who wanted to talk in confidence as Aboriginal persons to discuss personal matters such as racism in the disability services workforce.

The data were analysed using situational analysis within this framework as I wanted to explore the actual situations that lead to Aboriginal peoples’ engagement in disability services. In particular, I wanted to explore the enablers and barriers to individual participation. This approach also enabled me to explore the participants’ experiences using their own narratives, which is fundamental to Aboriginal people’s cultural practice of talking about issues using their own stories.

Why did this methodology work best for the research findings?

This methodology worked as it reflected my own personal experiences of being an Aboriginal man living with a disability and also my experience as an advocate for Aboriginal people with disability. I was able to incorporate my own historical and cultural knowledge and experience of being a ‘client’ of disability services into the research process without undermining Aboriginal human rights or disability human rights.

I also had an Aboriginal community control structure to govern the research process. This ensured that Aboriginal people who are disability advocates guided and mentored the whole research process. Furthermore, the disability services sector incorporated the research findings into disability service policy and practice.

Kirsten Smiler

What inspired me to be a researcher?

‘Becoming’ a disability researcher was, and is not a profession, category or even a calling which I have and will ever aspire to. In fact, the words ‘disability’, ‘researcher’ and ‘profession’ are not words, concepts or activities which even resonate with my experiences or worldview. Rather, I would prefer to say that this is a ‘space’ that recently others have informed me that I occupy; ‘disability research’ is a place which has been mapped out and described by a multitude of people, and it seems that the markers on the map seem to be ever evolving and now include me. My inroad to this space was through my professional experiences of undertaking graduate, doctoral and post-doctoral research with regards to Deaf people, and most specifically with Deaf people who are also Māori. Naturally, the association was made – that I am indeed a Māori disability researcher/academic. I however very rarely describe myself in this way. This raises questions (eyebrows) around: ‘Where do I think I am?’ and ‘What it is that I think that I am doing here?’ There is no question however about how I found myself here.

As a Māori hearing child of a non-Indigenous culturally Deaf woman (Child of a Deaf Adult or CODA in short form) and a hearing Indigenous (Māori) father in Aotearoa/New Zealand, my socialisation during childhood into sign language and Deaf culture set a compass for what ‘being and becoming Deaf’ as a socio-cultural identity means. Sign language and Deaf culture is the embodiment of Deaf as a socio-cultural experience. My mother’s open practice of language and culture in spite of societal messages (and formidable daily-pressure) categorising her as sub-human, taught and role modelled the transformative praxis of practicing language and culture as resistance to cultural and linguistic colonisation. Paradoxically, my ability to practice language and culture as a Māori child was inhibited since my grandparents (the last native-speaking language models) died too early to witness my childhood. To add to this complexity, both communities (Deaf and Māori) actively exercised wider societal prejudices regarding the others’ culture and language in their respective communities despite having similar experiences of marginalisation. Consequently acquiring te reo Māori as a third language required educational-based interventions which still continue into my adulthood. These were experiences which influenced my research journey. My ‘work’ was to unpick threads of early social experience – to understand them within a wider context and body of knowledge surrounding colonisation and decolonisation. It was through this process that I was first introduced to disability research and at times found myself referred to by others as a ‘disability researcher’. Given my childhood socialisation in Deaf and Māori cultures, and emphasis on the interconnectedness between kin within the intergenerational familial unit of whānau, operating under this disability framework has often felt like wearing ill-fitted clothing.

As an undergraduate student I examined methodology literature as if I would find a ‘formulaic recipe’ to reproduce in my own work. And initially I tried to ‘duplicate’ these recipes (methodologies) to address my research questions (Smiler, 2014). Upon implementation, I found the discomfort of ill-fitted methodologies quickly wore away at me. Undergraduate study prepares you to understand the world how others have seen it; the experience does however have the potential to drown out your inner voice and ability to set that knowledge in juxtaposition to Indigenous knowledge. In response, I gave myself permission to revisit the knowledge (expressed in academia as well as oral histories) of my communities. My childhood experiences taught me that while literacy is one way of exchanging knowledge, knowledge can also be embedded in art, embodied through performance – in other ‘active’ ways of knowing and being. In my last piece of work, I ventured off the beaten ‘academic’ track and framed my work in the traditional knowledge base surrounding rāranga (Māori weaving).

How did I implement my decolonisation methodology in research?

My doctoral research methodology was inspired by an art form – rāranga (or Māori weaving) (Puketapu-Hetet, 1989). A serendipitous journey occurred at the outset of my research journey, and I began to practice research and rāranga parallel to one another. Within Māori society, rāranga is an intellectual as well as artistic tradition which (like research) values the process as well as the output; through the process you embody the creative, intellectual and spiritual lessons that present before you. Practicing rāranga provided me with the transformative praxis for how I would re-conceive or de-colonise my experience of research (Smiler, 2014).

Rāranga is a tradition which has offered Māori society theorising and knowledge of human behaviour, of whānau connectivity, healthy human relationships, human (with a focus on child development) development, and, interconnectedness between people and environment (Puketapu-Hetet, 1989; Metge, 1995). Since whānau (specifically whānau raising Māori deaf children) was a central focus of my research, it made sense to employ a Māori methodology which drew from the knowledge embedded in the tradition of rāranga. In this approach, whakawhanaungatanga (developing a research community which operates in accordance to Māori value and social norms) was a central part to process and outcome. The journey was a collaborative one between myself and a small number of whānau. Māori methods such as korero-a-waha/ringa/tinana, (shared narratives in spoken, signed, social performance) and wānanga (collective theorising) were co-constructed to form ‘whenu’ (threads/themes ready to analyse or constructively weave). The whenu (themes) were collectively ‘woven’ to produce kete mātauranga (baskets of knowledge – case studies in a Western context). A series of kete mātauranga (each representing the case of a single whānau raising a Māori Deaf child) were made available (in the form of words) for others to review within the doctoral

thesis. Weavers often examine other kete (baskets) for their form, function and ‘story’ – either embedded in a succinct code conveyed through form, pattern, function, colour and tension. The kete mātauranga in this research offered both a description of context and an analysis answering the question; in their ‘form’ they offer opportunities for understanding context, post-reflection and theorising.

Why did this methodology work best for the research findings?

Whānau is the microcosm of where and how colonisation affects us most deeply – including how we perceive and live with disabilities. My masters, doctoral and post-doctoral research (Smiler, 2014; Smiler, 2004) all focus on whānau ‘living with disability’ and critique why family-centredness is a key tenant on which they base their programme philosophies. Revisiting rārangā as a foundation for methodology I also revisited the traditional knowledge surrounding the form, function and operation of whānau as a social entity and what this means for contemporary contexts of ‘disability-related’ services and supports.

Discussion

Despite the diversity of approaches to research between the four of us, our personal journeys were driven by the values of human rights relating to our ancestral lands, culture, and kin. Our academic career is a vehicle for our human rights advocacy. We were aware that much of the research that was being produced by non-Indigenous peoples about disability in our communities was not being undertaken with our families and ancestors, either as collaborators, partners or co-producers of our own knowledges and lived experiences. Much of non-Indigenous peoples’ research was serving the needs, wants, and desires of the colonial elite due to our exclusion from the research process.

In effect, our own methodologies were influenced by our traditional knowledges handed down from our ancestors and our own experiences of being Indigenous persons. Our methodologies were a blend of our Indigeneity (heritage, culture, ancestry and history) and our academic disciplines’ protocols. In effect, our roles as scholars extended the ‘typical’ academic definition and we are first and foremost advocates for Indigenous peoples’ leadership, sovereignty, and scholarship. Our indigeneity and families are the priority! This was obvious and interesting, not least considering differences in geography, climate, and political contexts in our countries.

What really stood out from writing this paper is that all of us were inspired in some way by the decolonisation movement in New Zealand, such as the works of Tuhiwai Smith (2012) and Smith (2015). The decolonizing work in Canada was also an inspiration for the Sámis (see Cajete, 2000; Battiste, 2013). In spite of the many works in postcolonial theory, anti-

colonial theory, or even Southern theory (Connell, 2011), we were mostly inspired by New Zealand and Canada. In addition, this inspiration was revealed after our paper was completed. That is, we had similarities in our research work without all of us being fully aware of the others and their working processes. Furthermore, we had the direction of Indigenous rights, including the right to speak for oneself. It was both interesting and inspiring to recognize and learn from our similarities, and also from our differences. Furthermore, Indigenous rights, including the right to speak for oneself, may be considered to be self-evident in democratic countries such as Australia, New Zealand and Sweden. However, in practice, this has not always been the case for indigenous people in research.

The research governance mechanisms were inclusive of local Indigenous community law and practice. These systems were formulated with Indigenous peoples to reflect the needs of the research and research outcomes for local communities. These systems were not ‘advisory’; they were a formal research governance approach. These governance systems ensured that the research process was reflective of cultural protocols.

Implications for practice

Decolonising disability research holds important implications for practice, including service provision, research, tertiary teaching, and public policy. Decolonising practices rely on all individuals recognising the importance of dissolving the privileged position of colonial power and control. It is only when this power and control is shared that people living with a disability can direct policy, practice, and praxis in ways that have meaning for individuals and their communities.

Decolonising practices allow the person and/or institution to critically reflect and deconstruct their own values, beliefs and world views and how this impacts on their practice. Once the process of decolonisation gains momentum, relationships and partnerships situated in equal distribution of power address social inequities and inequalities between Indigenous and non-Indigenous people.

It is important for all people working in the disability sector to understand how their language can be very excluding of Indigenous peoples. The Indigenous authors of this paper, who by their communities’ definition are Indigenous, did not use the term ‘Indigenous’ but instead identified themselves by using the terms that connected them to their communities, countries and culture. This is the same for many Indigenous peoples. Furthermore, as highlighted earlier, the word ‘disability’ is not always used in Indigenous communities. This means it is important for all people and institutions to develop a shared language with the person, who may be a consumer of a service, a research participant/informant, or a recipient of a policy. Allowing the person to share their lived experiences, including expressions of health,

wellbeing and disability can help the service provider to identify a strength-based and holistic story from the person and better understand what language the person uses to describe these experiences. This preference for language raises many issues around forms and assessments, which although allows for a shared language between service providers, excludes people who may not express their lived experiences using this same language.

There is also a need to revise how universities review the factors that are included in the world university rankings surveys and its relationship to the financing of research and community projects in our communities. Currently, universities across the world measure research impact using factors (such as research publication outputs) prescribed in the world rankings (Academic Ranking of World Universities, 2017; QS World University Rankings, 2017; Times Higher Education, 2017). These factors influence how universities obtain quality students and funding for projects and research. For us, the impact of research is measured by how the research activities and actions achieve change for our families and traditional lands. Furthermore, our accountability to the population of Indigenous people and/or local Indigenous communities who are partners in the research projects is of critical importance. There is limited evidence that these rankings have included the voices of Indigenous peoples. Academics meeting the requirements of the university world rankings, such as publishing in high impact journals, paradoxically reinforces universities as the gatekeepers of research and knowledge production.

Conclusion

This paper presents a comparison of decolonising approaches in disability research between one Sámi woman from Sweden, one Maori from New Zealand, and one a Kamilaroi woman and one Yuin man from Australia. The idea for this paper came up at a conference theme on Indigenous disability research. We have identified many similarities and differences between our respective approaches. We encourage disability researchers to learn from our experiences and work with Indigenous peoples in their countries to continue the fights for the human rights of Indigenous people with disability.

Notes

¹ Terminology relating to Indigenous peoples is highly politicised and this is a result of how governments use and/or govern terminology. Furthermore, governments often use this and other terminology relating to Indigenous peoples, as a way to control and demonise the peoples. None of the authors identified themselves as being Indigenous. However, in this paper, the authors used the term 'Indigenous' as a shared language to highlight similarities and differences within the disability sector, to advance the culturally responsiveness of the

disability sector, including its research.

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